How teachers deal with paediatric cancer survivors returning to their classrooms after remission

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This thesis is presented in partial fulfilment of the requirements for the degree of Master of Education – Thesis & Coursework of The University of Western Australia

Graduate School of Education
2016
ABSTRACT

This research has generated substantive theory about the ways Western Australian teachers deal with students in remission from cancer (head and brain tumours or Acute Lymphoblastic Leukaemia) who have endured therapies affecting their central nervous systems. The teachers’ individual perspectives of the difficulties they were coping with, including; teacher preparedness, absenteeism of the students, communication issues, learning difficulties or disability these students were experiencing and the way they were accommodated or supported by the school or other agencies, enabled generalisations to be drawn about the situation in Western Australian schools.

The survival rate of paediatric and adolescent cancer patients has risen dramatically in the last four decades because of new protocols and drugs used in treatment. Although the survivor rate steadily increases, there is a serious survivorship issue of educational equity for those left with neurocognitive disability related to central nervous system therapies used during treatment. This research sheds light on the current situation in Western Australian schools.

All of the four teacher participants were deeply concerned about issues these students were facing at school and were unsure how to proceed in assisting the students. None of the teacher participants had received any extra assistance, support or guidance apart from the relationship-based support of other teachers and all were unsure about the student’s medical history, current treatments and the impact this may be having on their day to day academic performance. All participants felt that more information about their students would be useful to them. None of the teachers were aware that the involvement of central nervous system therapies could be having an impact on the academic performance of their students. None of the students qualified for any extra support time or assistance in the classroom, even whilst one student (a brain tumour
survivor) was experiencing extreme, worsening learning disability. This research also exposed a new and rapidly growing special needs area in education.

None of the students were on an Individual Education Plan. However all of the students were experiencing fine motor integration difficulty, or Dysgraphia, manifested in problems with writing, which affected all subject areas. They were also experiencing difficulty with literacy recall such as phonics and grammar rules. Problem solving in maths was another area where teachers believed recall might be an issue. These difficulties could be attributed to working memory deficits, as described in the literature. The teachers believed these problems were related to; absenteeism, fatigue, “lost skills”, physical health and development issues or were caused by maintenance treatments.

This study highlights the need for teachers to be informed and supported in the classroom to understand the way their students’ health situation and CNS treatments may be having an impact on their performance at school. It highlights the need for teachers to be assisted to develop Individual Education Plans addressing and documenting the difficulties faced by the students, even if they appear to be minor difficulties, so that a plan of action can follow the student through remission and into long term survivorship, throughout their early schooling and into their high school education.

Teachers also require communication strategies and guidance to deal with the difficulties families of these students may be facing; issues related to ongoing medical protocols during maintenance treatment, social and emotional issues for the students, managing school life around frequent absenteeism due to sickness, fatigue, hospital visits and viral threats and balancing realistic expectations for the students’ success at school whilst they are still recovering from life-threatening illness.
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ACKNOWLEDGEMENTS

First and foremost I would like to express my gratitude to Professor Simon Clarke for agreeing to supervise this project and persevering with it for almost five years. I was not only blessed to have your supervision, leadership and guidance but also honoured, for you are an astounding researcher, professor, teacher and person. Your dedication to excellent research is inspiring. You guided me through this entire process with patience and finesse and gave me the encouragement I needed to complete this major undertaking. Without your attention, I am not sure this project would have been completed as there were considerable obstacles to hurdle. These obstacles were time-consuming, cumbersome and at times, seemed totally insurmountable.

I am also extremely appreciative for the help of my other supervisor, Professor Tom O’Donoghue. I was privileged to have you as my supervisor. You were one of my first professors on this long journey and you opened my eyes to concepts I had never imagined, teaching me the true meaning of enquiry. Your gentle inquisitive approach, demonstrated by gathering qualitative data from your students is a model I will never forget. I am grateful to the three professors who made comment on my research proposal; Winthrop Professor Anne Chapman, Associate Professor Val Faulkner, and Associate Professor Ken Glasgow. The valuable feedback you provided made me clarify my thoughts and gave me direction. I loved the encouraging and challenging comments and they gave me hope at times when I was ready to give up.

I am ever grateful to the students’ parents who bravely showed their support for the project by silently agreeing to pass on the participant information pack to their child’s school principal. This small group of kind souls made the project possible. Without the help and guidance of Barb Donnan and the Ronald McDonald Learning Program staff I could not have reached these parents and I was lucky to have been steered in Barb’s direction. Sharing the Educational Pathways research with me was
extremely helpful also. Barb’s insights, wisdom and understanding proved to be instrumental in the search for a way to find participants. I am indebted to my small group of participant teachers and their principals for their willingness to be involved with this project. These teachers generously gave their time and insights and their compassion for the cancer survivors in their classrooms was inestimable.

Associate Professor Richard Cohn generously gave me copies of unpublished work and references to extremely useful articles and Claire McKenzie gave me priceless advice about navigating ethical limitations and sensitively constructing parent letters. To both inspirational researchers I’m ever grateful. To Doctor Ruth Rechis Oelker, a long-term survivor and a pioneer of traversing difficult country, who kindly and patiently provided faith in my study, I’m thankful. Earnest thanks also go to my favourite teacher, Kerry Blom, who inspired my love of literature and passion for teaching.

I’m also grateful to my family and friends who have been supportive, encouraging and patient throughout this long journey. John, Sally, Jenny and Claire, Daysi, Jeannie, Diane, Betty, Max and Heather Dawn Kelly are all appreciated for their gentle coaxing and kind encouragement. Thanks also must go to Terry and Greg, Mus, Josh and Andre for always being there to assist with the everyday obstacles of life. Without this support crew, I couldn’t have survived the whirlpools and hazards leading up to the stage 5 rapids which appeared along the way. My daughters Julia and Marie, who are inspirational models of resilience, optimism and strength, cheered from the riverbank all the way and I thank them whole-heartedly. Finally, I am ever grateful to my wonderful parents Terry and Pam who made many sacrifices over the years for their children’s education. I hope they can feel proud of this research and share the achievement.


Declaration

In accordance with the regulations for presenting theses and other work for higher degrees I hereby declare that this thesis is entirely my own work and that it has not been submitted for a degree at this or any other University.

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CHAPTER 1

1.1 Introduction

The first chapter will describe the study’s background, its purpose and give a definition of terms used throughout this chapter and the ensuing ones. This study explores the perspectives of Western Australian teachers and examines the ways they deal with students who have endured central nervous system treatments and who are back in mainstream education in their classrooms. The teachers’ individual perspectives of the difficulties they were coping with, including, among others; teacher preparedness, absenteeism of the students, communication issues, learning difficulties or disabilities these students were experiencing and support from school or other agencies enabled generalisations to be drawn about the situation in Western Australian schools. Some background needs to be elucidated in order to explain why teachers of these students in particular were purposively sampled in order to apply grounded theory interpretivist strategies and construe meaning from the collected data.

Neurocognitive late effects have been reported in paediatric cancer survivors who have been treated with central nervous system therapies, so by purposively sampling teachers who had such a student in their class, this phenomenon could also be investigated in the study. This chapter examines the purpose of the study, explaining its usefulness to Australian Hospital schools, Outpatient Paediatric Oncology Departments and Follow-Up or Late Effects Clinics and teachers, parents, administrative staff and school psychologists in Western Australian Department of Education and independent schools.

The section Disability Discrimination Protection for Cancer Survivors explains how current policy in Western Australian schools exists to ensure that students with disabilities receive special consideration, assistance and adjustments (if required), to
enable them to fully participate in school life. This policy has significant implications for teacher practice in dealing with paediatric cancer survivors, especially those who may have neurocognitive deficits related to their central nervous system treatments. AITSL’s (Australian Institute for Teaching and School Leadership Limited, 2014)

*Professional standards for teachers* aspire to exemplary disability discrimination protection (even at Graduate level), through the stipulation that teachers have comprehensive understanding of the way students learn, knowledge about differentiating curriculum to best cater for individual needs with special learning strategies and full recognition of the legislation protecting the rights of the students, as it pertains to disability.

A section with the definition of terms follows, to assist in interpreting the terminology which will frequently appear in the subsequent chapters, most particularly in the Literature Review. The first part of the definition of terms covers terms related to cancer, such as; ALL, Brain Tumours, Central Nervous System Therapies, Relapse, Remission and Maintenance Therapy. The second part includes terms related to writing difficulties or disability, such as; Allographic Store, Dysgraphia, Graphemic Buffer and Graphemic Store. The overview of the chapter then follows, summarising the major points in Chapter 1.
1.2 Background

“Sixty years ago, cancer was nearly always a death sentence for a child. Now eight out of 10 children survive”. (Children’s Cancer Institute Australia, n.d., para 1)

According to Associate Professor Richard Cohn of the Children’s Cancer Institute Australia, 80% of children diagnosed with cancer in Australia can now hope for long-term survival and 90% of those children will be alive and free of cancer five years after diagnosis with a normal life expectancy. Most of these survivors will still be alive fifteen years post-diagnosis. Cohn reports; “Unfortunately, while more children are surviving childhood cancer than in the past, many go on to develop one or more life-altering chronic health conditions such as infertility, neurocognitive deficits, short stature, hearing or vision loss and low-grade second cancers.” (Children’s Cancer Institute Australia, n.d., para 3)

Cohn estimates that one in 900 young Australians between 16 - 45 years of age is a child cancer survivor. Cohn adds; “However up to 70 per cent of long-term survivors go on to develop one or more chronic health conditions as a result of having been treated for cancer as children.” (Children’s Cancer Institute Australia, n.d., para 1)

Wheeler, Thompson, Samers & Seymour (2009) describe the first attempts to cure leukaemia in children as follows:

When Farber first used methotrexate to treat children with leukaemia in 1948, short remissions resulted, but ultimately all patients succumbed to the disease. His initial report in the New England Journal of Medicine in 1948 was met with derision, as the prevailing view was that leukaemias were incurable and that the children should be allowed to ‘die in peace’. Indeed, in the 1960s parents were often told to take their children home and to love them, as there were no sustained remissions. (p.190)
In 1970, paediatric and adolescent oncology survivors were rare, with a 10% survival rate. Today, 80% of young people who endure oncology protocols will survive. (Children’s Cancer Institute Australia, n.d.) Wheeler et al. (2009) explain how, in the 1960s, the introduction of multi-agent chemotherapy resulted in; “the first reported, durable remissions” (p. 190) from leukaemias and lymphomas in young patients; however these treatments resulted in other tragic consequences for the children. The researchers describe the late effects as such:

Until this watershed, the only long-term survivors of childhood malignancy resulted from curative surgery or curative radiation. The numbers were small, but even then there was a recognised cost seen in these long-term survivors with growth effects, neuro-cognitive and neuroendocrine complications and the suggestion of increased second malignancies. (p.190)

Wheeler et al. (2009) also explain that children under two years of age who had endured craniospinal radiotherapy often required ongoing institutional care afterwards. The survivorship of children who have been cured of cancer brings with it many questions involving their long-term medical, socio-emotional, psychological and academic survival and progress. Medically, their progress will be monitored for life to track any late-effects of the treatments they have endured. Academically, they are on their own.

The Australian Government Cancer Australia’s (2016) new Children’s cancer website has a section on statistics which explains that; “Childhood cancer, also known as paediatric cancer, is defined as cancers that occur between birth and 15 years of age.” (para 2)

In 2016, it is estimated that 650 children aged 0-14 years will be newly diagnosed with cancer in Australia (365 boys and 285 girls). The number of new
diagnoses is estimated to be higher in the 0–4 year age group (315 children) than in 5–9 year olds (160 children) and 10–14 year olds (175 children). (para 3)

The statistics for the annual number of child cancer diagnoses vary among agencies in Australia, with The Children’s Hospital at Westmead Research Institute (n.d.) estimating 600 - 700 children under the age of 15 being diagnosed, Fight Cancer Foundation (2016) estimating 800 paediatric cancer diagnoses and Children’s Cancer Foundation (n.d.) stating that 810 children are diagnosed each year. According to the Children’s Cancer Institute website in 2009, more than 625 Australian children were diagnosed with cancer each year. This figure has increased and now the website states; “every year 950 Australian children and adolescents will be diagnosed with cancer. Every week nearly three Australian children and adolescents will die of cancer”. (Children’s Cancer Institute Australia, n.d., para 1)

The most common childhood cancers are acute lymphoblastic leukaemia, brain cancer and neuroblastoma. (Children’s Cancer Institute Australia, n.d.) Many of these children or adolescents who survive their cancer treatments will require special help for learning difficulties which may appear when they are in treatment, during remission or much later in their lives. Teachers of these students may mistake a learning disability for a socio-emotional difficulty, for health issues related to a student’s medical treatment, or for simply missing work because of absenteeism related to maintenance therapy appointments. This study’s purpose was to shed light on all of the factors this group of teachers believed to be important in dealing with their students’ re-entry into a mainstream classroom. The late effect of central nervous system therapies causing neurocognitive deficits in survivors was one of the factors to be considered.
1.3 Purpose

This research focused on the teachers educating students in remission from cancer after surviving chemotherapy or radiotherapy protocols involving the central nervous system; leukaemia survivors or students who have received radiotherapy to the head. These survivors are at most risk of demonstrating learning difficulties at any stage post-remission. Although leukaemia and malignant brain tumours are very different types of cancer, the therapies used in their eradication involve the central nervous system. Butler & Mulhern (2005) conducted research on brain injury rehabilitation and describe the way different cancer treatments can result in the same outcomes for young cancer survivors. They explain as follows:

Despite the differences between ALL and malignant brain tumors, there are significant similarities among the symptoms comprising neurocognitive deficits, particularly with regard to the treatments of brain irradiation and intrathecal chemotherapy. (p.66)

The Central Research Question: How do teachers deal with paediatric cancer survivors returning to their classrooms after remission? was answered by gathering data related to teachers’ beliefs, feelings, ideas and observations about teaching students who were in remission and returning to their classrooms. The sample group included teachers of primary students. The teachers in government and independent primary schools were located in metropolitan and rural Western Australia. Using internal comparative data from different teachers within the Western Australian education environment provided generalisations. From these generalisations, conceptual categories were generated and the data could then be accurately sorted and analysed. The data reflects individual teacher attitudes, understandings and beliefs about a range of factors which affected them and their students when they returned to mainstream education after cancer treatment. The interpretation and analysis of the data provides
substantive theory about the ways in which teachers deal with, cope with and assist students in remission from cancer who have special needs and who may also be demonstrating learning difficulties or disability in their classroom environments.

An enriched understanding for educational professionals of the ways teachers cope with the special needs of paediatric cancer survivors in their classrooms; “and involving them in the development of effective intervention models is critical to success in helping children who survive a terrible disease, only to face a difficult and overwhelming academic world.” (Armstrong & Horn, 1995, p.302) Australian Hospital schools, Outpatient Paediatric Oncology Departments and Follow-Up or Late Effects Clinics, school psychologists and Western Australian Department of Education and independent school teachers and their leaders may also be seeking information and understandings about the needs of these students and the needs of their teachers. Parents of paediatric cancer survivors may also benefit from increasing awareness of the issue.

1.4 Disability discrimination protection for cancer survivors

In the United States, child and paediatric cancer survivorship and the educational concerns related to late effects are widely researched, discussed and addressed phenomena. Children’s hospitals offer assistance and links to many supportive agencies to assist parents and teachers in addressing the learning problems children and young people may experience. Hospitals promote advocacy agencies to address equity within learning environments and transitions to higher study. Oncology nurses are trained in this field and social agencies are equipped to provide support - personal and online - to teachers, schools and families when students return to their regular classrooms. The Leukaemia and Lymphoma Society (n.d.) offers a free educational programme for school staff; The Trish Greene Back to School Program for Children with Cancer. This national curriculum and model for school re-entry was created by the Leukaemia and Lymphoma Society and is being implemented across the USA and Canada. The goal of
the program Welcome back: Facilitating the return to school for children with cancer is; “To educate school personnel, parents, and healthcare professionals, on the cognitive and late effects of childhood cancer treatment and to improve the transition of childhood cancer survivors from the hospital or clinic to the classroom.” (Leukemia and Lymphoma Society, n.d.) Learning and living with cancer: Advocating for your child’s educational needs (Leukemia and Lymphoma Society, n.d.) is another resource to help parents advocate for their child returning to school after cancer.

Other school resources provided by The Trish Greene Back to School Program for Children with Cancer include colouring and activity books for young cancer patients and their classmates; Pictures of my journey and The stem cell transplant. Why, Charlie Brown, why? is a DVD which uses Charles Shultz’s Peanuts characters to help children understand what leukaemia is, how it is treated and how the patient feels. The Leukemia and Lymphoma Society (n.d.) also provides the resource guide; Back to school resources, which identifies organizations, web sites, books and videos that help with the educational needs of childhood cancer survivors. Such information and advocacy systems do not exist widely in Australia, despite good support for other learning disabilities and a clear foundation in social policy evident in legislative documents such as The Disability Discrimination Act of 1992 (now under review) which is primarily aimed at eliminating discrimination against people with disabilities as well as ensuring equality before the law and promoting acceptance within the community of the fundamental rights of people with disabilities.

The 1994 Commonwealth Disability Strategy, The Disability Discrimination Act Standards and the Commonwealth/State/Territory Disability Agreement also protect those with disabilities. Through the C/S/TD Agreement, the Australian, State and Territory Governments strive to enhance the quality of life experienced by people with disabilities through assisting them to live as valued and participating members of the
community. (Commonwealth/State/Territory Disability Agreement, 1994). The Australian Human Rights Commission (n.d.) relies on the Disability Discrimination Act of 1992 for its policy. The over-arching human rights policy, as it relates to educational institutions in Australia is described as follows:

A person with a disability has a right to study at any educational institution in the same way as any other student. The DDA makes it against the law for an educational authority to discriminate against someone because that person has a disability. This includes all public and private educational institutions, primary and secondary schools, and tertiary institutions such as TAFE, private colleges and universities. (para 1)

On the Australian Human Rights Commission’s (n.d.) website, in the section D.D.A. guide: Getting an education, adjustments are explained as follows: “If a person with a disability meets the essential entry requirements, then educators must make changes or ‘reasonable adjustments’ if that person needs them to perform essential course-work”. (para 6) The Australian Human Rights Commission (n.d.) lists some of the types of adjustments educators may need to make for students with a disability as follows:

- Modifying educational premises. For example, making ramps, modifying toilets and ensuring that classes are in rooms accessible to the person with a disability.
- Modifying or providing equipment. For example, lowering lab benches, enlarging computer screens, providing specific computer software or an audio loop system.
- Changing assessment procedures. For example, allowing for alternative examination methods such as oral exams, or allowing additional time for someone else to write an exam for a person with a disability.
- Changing course delivery. For example, providing study notes or research materials in different formats or providing a sign language interpreter for a deaf person.

(para 7)
The Commonwealth Disability Strategy of 1994 was meant to be a ten year programme and is now the foundation for the current development of a National Disability Act, still under review. In *Disability Access and Inclusion Plan 2012–2017*, (The Government of Western Australia Department of Education, 2016) the state government agency committed to the six prescribed Disability Access and Inclusion Plan (DAIP) outcomes and chose to include two additional outcomes to reflect its position as a large employer and education provider. Outcome 8 was particularly relevant to this study:

Improved learning outcomes for students with disability, promote, and provide support and advice for, evidence-based practice that promotes successful learning outcomes for all students, continue to build capacity for inclusive schools that meet the learning needs of all students, ensure that students with disability continue to access and participate in all aspects of school life, continue to build capacity for teachers, principals, school staff to support the educational needs of students with disability. (pp. 10-11)

This document has now been superseded by the Government of Western Australia School Curriculum and Standards Authority’s *Disability and Access Inclusion Plan 2011–2016* (2016), which cites the WA Equal Opportunity Act 1984, the Commonwealth Disability Discrimination Act 1993 and the United Nations Convention on the Rights of Persons with Disabilities as the legislative authorities underpinning access and inclusion policy. The plan states:

It is a requirement of the Disability Services Act 1993 (amended 2004) (the Act) that public authorities develop and implement a Disability Access and Inclusion Plan (DAIP) so that people with disability have the same opportunities as others to access services, facilities and information. (p.2)
As the result of an amended act of parliament in 2004, the Government of Western Australia now requires every government agency to follow the *Disability Access and Inclusion Plan (DAIP)* (2016). This plan is described on The Government of Western Australia Department of Education (2016) website in *Disability Access and Inclusion Plans*, as follows:

The Disability Services Act 1993, amended in 2004, requires all local government and selected State Government agencies to develop a Disability Access and Inclusion Plan (DAIP). DAIPs assist public authorities to plan and implement improvements to access and inclusion across seven outcome areas, in regards to services and events, buildings and facilities, information, quality of service, complaints, consultation processes and employment. These plans benefit people with disability, the elderly, young parents and people from culturally and linguistically diverse backgrounds. (para 1)

The Australian Government Department of Education commenced the Nationally Consistent Collection of Data on School Students with Disability in selected schools in 2013 and 2014, with full national implementation in all schools in 2015 to address the lack of nationally consistent data collected on students with disability.

The government and all states and territories agreed to the annual August census, based on the definition of disability in the Disability Discrimination Act 1992 and the responsibility of schools under the Disability Standards for Education 2005, to provide students with disability the opportunity to participate in school activities and access education with the same equity as students without a disability. Gathering information from the census will create a national database. The reasons for establishing such a database are described on The Australian Government Department of Education’s (2016) website, as follows:

Until now there has been a lack of comprehensive and nationally comparable
data about school students with disability. The national data collection will give governments, education authorities and schools nationally consistent information about: how many students with disability are enrolled in Australian schools, where these students are located, the broad level of reasonable educational adjustment provided to assist them participate in schooling on the same basis as other students. (para 2)

The Australian Government Department of Education’s (2016) Education Council, in Nationally Consistent Collection of Data School Students with Disability: Notice for schools and school principals, explains the rationale for creating the database as follows:

The implementation of a Nationally Consistent Collection of Data on School Students with Disability means that information about students with disability across Australia will be available in a consistent, reliable and systematic way. This collection will strengthen existing approaches to supporting students with disability. (p.1)

According to The Australian Government Department of Education (2016), the goals of the census are to enable schools to; better understand their student population, formally record support and adjustments already provided to students with a disability, utilize the professional judgment of school teams to reflect upon and make decisions about their provision of support for students with disability and make improvements to their systems in dealing with student need.

The Australian Government Department of Social Services (2014) has published a guide to the revised list of recognised disabilities; “based on determinations approved in 2005, 2006, 2010, 2011 and 2014 by the Secretary of the Department.” (para 1) The Disability and carers guide: List of recognised disabilities is the reference for the provision of social services to families and carers with a person who has a disability. In
Part 2, the list of medical disabilities includes children undergoing cancer treatment, namely: “The following Haematological/Oncological conditions: Leukaemia, Haemophagocytic Lymphohistiocytosis and other childhood malignancies where the child is undergoing chemotherapy, radiotherapy or palliative care.” (para 18)

In part 1, of Disability and carers guide: List of recognised disabilities (The Australian Government Department of Social Services, 2014) some neurodegenerative and severe or profound intellectual disabilities are described, but neurocognitive late effects attributed to childhood cancer treatments are not included. The eight categories of disability listed are; Autism Spectrum Disorder, Deaf and Hard of Hearing, Global Development Delay, Intellectual Disability, Physical Disability, Severe Medical Health Condition, Severe Mental Disorder, and Vision Impairment. Each category has its own eligibility criteria which may require specific assessment or diagnosis by a specialist.

In Western Australia, eligibility for the classification of Intellectual Disability is based on IQ criterion. In the Disability Services and Support Directorate Statewide Services document, Intellectual disability (The Government of Western Australia Department of Education, 2016) the eligibility requirements are described as follows: “significant sub-average intellectual functioning- an IQ of 69 or below on an individually administered appropriate IQ test.” (para 3) A student’s eligibility for this classification entitles the student’s school to a Disability Allocation, comprising an Individual Disability Allowance and an Educational Adjustment Allowance, for the provision of staff training and support, equipment, resources or modifications to the school site if required. Review of resources is undertaken at the end of Kindergarten, Year three and Year eight. (The Government of Western Australia Department of Education, 2016)

Many students, who are cancer survivors with neurocognitive late-effects following treatment would not meet this criterion, yet do require extra assistance or resources for
their school to cater to their needs. It seems these students would not be supported by these legislative protections or systemic department policies and so the responsibility for their support would fall to their teachers and schools. An Individual Education Plan addressing learning difficulties or disabilities they are experiencing would document their progress throughout their school life. For educators, awareness of neurocognitive late effects in paediatric or adolescent cancer survivors who have endured central nervous system therapies is fundamentally important for the students’ optimum progress and assistance. Therefore, as explained in the previous section, consistent disability discrimination protection policy is entrenched in wider educational, human rights and social policy in Western Australia.

The following section is the Definition of Terms, in which important and pertinent terminology is explained. This will provide useful information to assist in reading the description of the various sections of the literature review. These terms appear frequently throughout the literature review.

1.5 DEFINITION OF TERMS

In order to access the body of literature which is mostly drawn from the disciplines of medicine and psychology, it is necessary here to provide a definition of terms. This ensures clarity about the terminology used throughout the thesis and relevant literature. The terms ALL, Brain Tumour, Central Nervous System Therapies, Maintenance Therapy, Relapse, Remission, Allographic Store, Dysgraphia, Graphemic Buffer and Graphemic Store are defined.

1.5.1 ALL

The Leukaemia Foundation Australia (2016) defines acute lymphoblastic leukaemia as follows:
ALL is characterised by an overproduction of immature white blood cells, called lymphoblasts or leukaemic blasts. These cells crowd the bone marrow, preventing it from making normal blood cells. They can also spill out into the blood stream and circulate around the body. Due to their immaturity, these cells are unable to function properly to prevent or fight infection. Inadequate numbers of red cells and platelets being made by the marrow cause anaemia, and easy bleeding and bruising. (para 1)

The American Cancer Society (2016) in *Childhood leukemia* describes how leukaemia begins as such:

Leukemia is a cancer that starts in early blood-forming cells found in the bone marrow, the soft inner part of certain bones. Most often, leukemia is a cancer of the white blood cells, but some leukaemias start in other blood cell types.

(para 2)

The causes of childhood leukaemia are unknown. The American Cancer Society (2016) explains that there are three types of childhood leukaemia which are; acute lymphocytic (lymphoblastic) leukemia (ALL), acute myelogenous leukemia (AML) and hybrid or mixed lineage leukemia. The American Cancer Society (2016) reports that ALL is most common in early childhood, peaking between 2 and 4 years of age. Hispanic and white children are more likely to be diagnosed with ALL than African-American or Asian-American children and it is more common in boys than girls.

Butler & Mulhern (2005) describe acute lymphoblastic leukaemia, or ALL, as; “a malignant disorder of lymphoid cells found in the bone marrow that migrates to virtually every organ system, including the central nervous system (CNS), via the circulatory system.” (p.65)

The Leukaemia Foundation Australia (2016) explains how leukaemia cells migrate to other organ systems thus:
Any of the blood-forming cells from the bone marrow can turn into a leukemia cell. Once this change takes place, the leukemia cells no longer mature in a normal way. Leukemia cells might reproduce quickly, and not die when they should. These cells build up in the bone marrow, crowding out normal cells. In most cases, the leukemia cells spill into the bloodstream fairly quickly. From there they can go to other parts of the body such as the lymph nodes, spleen, liver, central nervous system (the brain and spinal cord), testicles, or other organs, where they can keep other cells in the body from doing their jobs.

(para 3)

The Leukaemia Foundation Australia (2016) in *Leukaemias* describes the effect of rapidly reproducing leukaemia cells on the rest of the body as such: “Left untreated, these leukaemia cells crowd out the healthy cells, leaving the body starved of oxygen, with little immunity to disease or infection and unable to “plug” wounds in the skin and blood vessels.” (para 4)

Butler & Mulhern, (2005) state that ALL is the most common of all childhood leukaemias as it comprises about 75% of all childhood leukaemias. The cause or causes of ALL are as yet unknown. Butler & Mulhern (2005) explain that there are many theories about the cause as follows: “Although genetic, environmental, viral, and immunodeficiency factors have been implicated in the pathogenesis of ALL, the precise causes of most cases remain largely unknown.” (p.65)

The American Cancer Society (2016), in regard to the causes of ALL, states: “Most adults and children with leukemia have no known risk factors, so there is no sure way to prevent leukemias from developing.” (para 8) The American Cancer Society (2016) also explains that; “There are very few known lifestyle-related or environmental causes of childhood leukemias, so it is important to know that in most cases there is nothing these children or their parents could have done to prevent these cancers.” (para 8)
ALL is usually treated by chemotherapy, which can take from two and a half to three years (longer for boys), explained by Butler & Mulhern (2005) as such:

The duration of treatment varies from 30 to 36 months and in the modern era is usually restricted to intervention with combination chemotherapy, reserving cranial irradiation for patients who experience a CNS relapse.

(p.65)

**1.5.2 Brain tumours**

Paediatric brain tumours can vary enormously from patient to patient. They can vary in type, location and risk. Brain tumours are the second most common form of childhood cancer and can sometimes occur in children who have survived ALL but have relapsed. The causes of paediatric brain tumours are unknown. Butler & Mulhern (2005) explain their incidence as follows:

Pediatric brain tumors are considerably more heterogeneous than ALL in that they vary by histology as well as location. Next to ALL, brain tumors are the second most frequently diagnosed malignancy of childhood and are the most common pediatric solid tumor, with an annual incidence of 3.3 per 100,000. The etiology of most pediatric brain tumors is unknown, although brain tumors can appear as a second malignancy following the treatment of ALL with CRT.

(p.66)

Wheeler et al. (2009) describe the treatment for brain tumours as such: “Brain tumours are usually treated with up-front surgery followed by up to 59 Gy of radiation.” (p.191)

**1.5.3 Central nervous system (CNS) therapies**

As part of their treatment protocols, leukaemia (ALL) survivors have endured intrathecal or intra-spinal chemotherapy, in which chemotherapy drugs are injected directly
into the spinal fluid. This treatment prevents leukaemia cells from migrating to other organs. (Leukaemia Foundation Australia, 2016) Cancer survivors who have suffered tumours in the brain or head area may have endured surgery, radiotherapy to the head and often chemotherapy too. Both of these groups of survivors are at risk of neurocognitive late effects during or after remission. (Armstrong & Horn, 1995)

1.5.4 Maintenance therapy

Maintenance therapy is generally given at home, with parents taking responsibility for administering drugs and antibiotics as well as special hygiene routines to protect against infections which could compromise recovery. Very frequent hospital visits are still required to check for side effects and to spot signs of relapse. Stevens (2011) explains the process of maintenance treatment after the first round of intensive therapy:

After intensive therapy is given over the first six months of treatment, further treatment (known as maintenance) continues in a less demanding fashion, using anti-cancer drugs taken by mouth, and administered by the patient’s parent/carer at home. In addition to this maintenance therapy, patients must also receive supportive therapy comprising antibiotics by mouth and mouth rinse to prevent infection. These are also administered outside of school hours, so it is usually not necessary for any routine therapy to be administered during school hours. The patient attends the cancer treatment clinic regularly every two weeks during maintenance for blood counts and check-ups, to monitor for side effects of the maintenance therapy and for possible relapse. (p.6)

Two and a half years or even three years is a long time in a child’s life, but the first year off treatment is the most critical because of the risk of relapse. Butler & Mulhern (2005) explain the reasons maintenance therapies are required for such a long period of time as follows:
Maintenance therapy is required for a prolonged period because of the presence of undetectable levels of leukaemia that nevertheless have the capacity to be fatal. After the completion of treatment, approximately 20% of those children who will eventually relapse will do so in the first year off therapy, with a subsequent risk of relapse in the remaining patients of 2 to 3% per year for the next 3 to 4 years. (p.66)

1.5.5 Relapse

During the maintenance therapy phase, regular check-ups and blood tests will monitor signs of relapse, indicated by a high white blood cell count or low red blood cells. Children or adolescents in this phase are immune-challenged and susceptible to infections, with extra precautions taken by using antibiotics and antibacterial rinses as part of the daily routine. Returning to school presents another immunity challenge, with simple coughs, colds, infections and chicken pox becoming serious threats to immunity, jeopardising the successful progress of maintenance therapy. Relapse at this point would mean a return to intensive chemotherapy or a bone marrow transplant for leukaemia survivors and further surgery, chemotherapy or radiotherapy treatments for a brain tumour survivor. Stevens (2011) explains the nerve-wracking waiting involved while a child is in remission as such:

As well as the concern that their child could pick up an illness from school, interfering with their maintenance therapy, between hospital visits, parents face the anxious wait for the results of the regular blood tests, assuring them their child is still in remission. Relapse is usually detected in advance of any symptoms, by finding circulating blasts in the blood film, or by a fall in the numbers of normal blood cells, or both. (p.6)
1.5.6 Remission

The term remission would seem to imply that a paediatric cancer patient was now free of their disease. This is partly true, except that with leukaemia survivors, once their bone marrow is clear of harmful cancer cells, their maintenance treatment will continue for a further two and a half years or up to three years for male survivors. During their remission phase, children or adolescents will resume their schooling whilst continuing hospital visits for maintenance therapy. Stevens (2011) explains the lengthy process:

Therapy is continued for two years after the patient achieves remission, ie for a total of 25 months, including 18 months of maintenance therapy. During this time, any residual leukaemia is usually completely eradicated. After completing 25 months of chemotherapy, provided relapse has not occurred, the patient with ALL will usually cease treatment. (p.6)

1.5.7 Allographic store

The allographic store is the part of working memory which houses letter case forms, such as upper and lower case letter and style forms, manuscript style or cursive. “Slips of the pen” (p.265), as described by Ellis (1979), reflect errors in accessing or retrieving allographs from the allograph store, a part of working memory.

1.5.8 Dysgraphia

Dysgraphia is the impaired ability to make word and letter choices. Dysgraphia is different from Acquired Motor Dysgraphia which is the inability to form letters due to motor or physical restriction. (Berninger, 2004) According to Berninger (2009), Dysgraphia can be described as; “handwriting problems despite motor function that falls within the normal range.” (p.79) Berninger explains the disability further as such: “The hallmark features of dysgraphia, a biologically based learning disability, are impaired
orthographic coding and/or graphomotor planning for sequential finger movements, which together function as the orthographic loop.” (p.79)

1.5.9 Graphemic buffer

The graphemic buffer is the process during writing, where letters are held in working memory while motor plans are formulated and executed. (Ellis, 1982) This process is easily susceptible to interference or disruption by disordered attention. Attentional deficits affect the graphemic buffer and cause difficulty with writing. (Hillis & Caramazza, 1989) Deficits in the function of the graphemic buffer may be demonstrated by the presence of unusual spelling errors, as described by Hillis & Caramazza (1989) as follows:

Because errors resulting from damage to the Graphemic Buffer must arise in the storage of an accurate series of graphemes, the errors should reflect the degradation of the spatially encoded, graphemic representation of the target word. The expected types of spelling errors are deletions, substitutions, insertions, and transposition of letters, which lead to the production of phonemically implausible nonwords (i.e., responses that do not respect phoneme-grapheme correspondence; e.g., blame + blome, lbame, and so on). (pp. 209-210)

1.5.10 Graphemic system

The Graphemic System is the cognitive system which; “distinguishes the individual feature of a grapheme” (p.8) and which guides motor planning in letter production. (Rothi & Heilman, 1981) This system plans the stroke or action required to form different letters, case and styles of script.
1.5.11 Overview of the thesis chapters

This chapter has provided an overview of the research reported in this thesis on how Western Australian teachers deal with students who have survived cancer and who have now returned to their classrooms in remission. The teachers selected by purposive sampling were teaching students who had endured central nervous system therapies; head or brain tumour or leukaemia survivors.

The remainder of the research consists of five chapters. Chapter Two describes the literature review. In the literature review, there are five areas of focus; neurocognitive late effects, the prevalence of cancer survivors’ cognitive late effects, factors responsible for cognitive difficulties, how late effects learning deficits appear in survivors and finally, how late effects neurocognitive deficits are being addressed.

Chapter Three provides a detailed description of the methodological approach taken in the research. Chapters Four and Five describe the research findings, with reference to five major themes or categories. These themes are; teacher preparedness, absenteeism of the students, communication issues, learning difficulties or disabilities and support from the school or other agencies.

Chapter Six, Conclusions and implications of the study’s findings for future research, policy and practice, presents the theory generated. This chapter describes the background of the study, summarises the work, explains the limitations of the study, and suggests implications of the findings for future research, policy and practice. These implications are grouped according to the five themes.
CHAPTER 2
LITERATURE REVIEW

2.1 Introduction

In this chapter, it will be seen that a great deal of research exists around the topic of paediatric cancer survivors, but there is very little explaining how teachers deal with them when they return to their classrooms when in remission. This chapter will disclose the reasons why it was necessary to purposively sample teacher participants teaching such a specific typology of cancer survivor, as it will be seen that there are many important, additional issues for these teachers to deal with.

This chapter will disclose the search for information about the topic in the databases at the researcher’s university and the reasons why it was necessary to search further afield for contemporary theory and evidence about the topic. The complex collection of relevant literature, mainly from medical and psychological sources, was split into five classifications. These groups of literature are introduced in turn, after describing the initial research results from the university databases in the first section.

The next section describes the literature concerned with the concept of neurocognitive late effects. These are the lasting problems with thinking, learning and brain function, which continue long after a child is considered to be cured of cancer, and is in long-term remission. This section identifies the literature which explains the neurocognitive late effects that occur. For brain or head tumour and leukaemia survivors, neurocognitive late effects often involve concentration and attentional deficits, memory and working memory problems, processing speed deficits and other problems concerning the integration of visual-motor function, such as writing.

The prevalence of cancer survivors’ cognitive late effects was the second classification of relevant literature. This literature justified the notion that only cancer survivors who had endured central nervous system therapies might have difficulties
with learning. It describes studies which compare CNS cancer survivors with survivors of other cancers, who do not have the same level of learning difficulties. CNS cancer survivors have similar learning difficulties to brain trauma victims and IQ declines have been measured in CNS survivors who have endured radiotherapy to the brain. Long-term CNS cancer survivors self-report difficulties with executive function.

The subjects of the third area of literature were; the factors responsible for cognitive difficulties. Researchers concur that cancer treatments in children involving the brain and spinal cord (brain or head tumours and leukaemia) will cause, over time, changes to the structure and function of the brain. Intrathecal chemotherapy (administered through the spinal column) and radiotherapy to the head, or both, can cause changes to the white matter in the brain, resulting in neurocognitive late effects, demonstrated by learning deficits or dysfunction.

In the fourth area, how late effects learning deficits appear in survivors, studies which involved; the identification of learning deficits, screening survivors for neurocognitive late effects and recommendations for testing are discussed. As well as regular, age-related standardized testing, other testing is required to identify the specific learning deficits in CNS cancer survivors. Some of these deficits, especially in the attention domain, can easily appear to be behavioural problems rather than learning deficits.

How late effects neurocognitive deficits are being addressed was the fifth area of focus for the literature review, illustrating the successful strategies being used to provide cognitive rehabilitation and support for young cancer survivors, who can benefit from the same type of interventions as brain trauma victims.
2.2 Neurocognitive late effects

An extensive search of The University of Western Australia databases, using OneSearch, of; “children with cancer returning to school” yielded 16,349 articles. From a sample of three hundred and fifty, sixteen were directly related to the topic. Most of these international articles deal with the socio-emotional aspects of returning to school, including support from medical and nursing practitioners to provide communication to the teacher in the classroom. Thirty eight articles discuss the psychiatric aspects of paediatric cancer diagnosis and treatment including ten which address the socio-emotional coping strategies for parents, pain management strategies, family adjustment to diagnosis and cancer care and communicating with families about bad news, social issues and cognitive psychology. Korean, Greek, Lebanese, British, American, Chinese and Turkish perspectives are represented. Three articles focus on Post-Traumatic Stress Disorder in paediatric cancer survivors, four discuss quality of life, two discuss alternative medicine and complementary therapies, thirty five address cancer screening and skin cancer prevention, eighteen discuss genetics and cancer risk, thirteen focus on bereavement and seventeen describe the socio-emotional aspects of other serious and chronic childhood illness.

The majority are involved with psychological, socio-emotional aspects related to; absence from school, quality of life, grief and bereavement issues and support agencies developing systems to provide assistance to the family of the paediatric survivor returning to schooling after treatment. Fourteen articles discuss return to school, “re-entry” programmes but only two deal with neurocognitive late effects; one discussing chemotherapy related cognitive impairment and the other the cognitive consequences of meduloblastoma brain cancer. Charlton, Pearson & Morris-Jones (1986) expose the issues for solid tumour cancer survivors returning to school, citing; absence, anxiety, teasing, psychological problems in siblings and difficulty obtaining prostheses as the
major concerns. One American journal article (Bauman, 2010) highlights the importance of the school counsellor in helping to address psychological adjustment and educational difficulties for survivors returning to school. Bauman (2010) explains the importance for school counsellors to understand that there may be the possibility of neurocognitive late effects and that the onset of these neurocognitive late effects could be delayed. A Turkish article (Lahteenmakei, Huostila, Hinkka & Salmi, 2002) reports the results of a study observing test results in brain tumour survivors at Turku University School, discovering that 30.8% required tutoring because of poor test results, especially in Maths and Languages and 31.7% reported being bullied at school because of their appearance after cancer treatments.

In a Proquest Search, the same key words generated four hundred and sixty thousand, one hundred and seven articles. Many of these are related to the school re-entry of a broad range of people in society; army personnel and military veterans, students and adults with serious medical conditions, HIV and AIDS and eating disorders, ex-offenders, Native Americans, students and adults with mental illness, those in society minority groups, dropouts and older minority adults. Twelve describe school reintegration programmes for paediatric cancer survivors (Prevatt, Heffer & Lowe, 2000), mostly discussing the socio-emotional aspects for students; absenteeism, bullying due to changed appearance during treatment, parent guides to the stages of post-remission and returning to school after treatment, school response to families, unmet psychological and social needs for students (Selwood, Hemsworth & Rigg, 2013) and methods of forging links between medical and nursing staff, parents and school in order for the students to be supported through their school re-entry. These articles treat school re-entry as a psychological, socio-emotional challenge, with some generated by agencies addressing mental health issues in paediatric survivors (Botcheva, Hill, Kane, Grites & Huffman, 2004).
A minority of articles focus on parent issues coping with paediatric survivors, including issues of over-protective parenting, social and emotional difficulties, even their cortisol levels in response to treatment and school re-entry. One article deals with the health-related quality of life for parents of children with cancer in China. One German study (Goldbeck, 2006) also focuses on quality of life for parents of paediatric cancer survivors. One Korean study (Yoo et al., 2010) presents the results of the Pediatric Functional Assessment of Cancer Therapy Questionnaire, translated and cross-culturally adapted in Korean and administered to teenage brain tumour survivors for psychological rating of anxiety and depression levels.

One journal article written by a (now adult) paediatric cancer survivor, (Rechis, 2006) delves into the emotional responses of school staff dealing with paediatric cancer survivors returning to school. Kliebenstein & Broome (2000) analyse the emotional impact of students’ (with a variety of serious illnesses, including cancer) school re-entry on school staff.

Only two discuss teacher perceptions regarding coping with the academic needs of cancer survivors, with neurocognitive disability or late effects. Only two articles on school reintegration (Joshua, 2010) and (Coughlin, 1997) discuss neurocognitive disability in student cancer survivors returning to school. A U.S.A. case study (Coughlin, 1997) of a brain tumour survivor’s school re-entry, describes the adjustments made by both school and teacher accommodating the student in the most suitable way by comparing mainstream classroom with support or language centre learning. Joshua (2010) also compares differing styles of learning environment; Hospital schooling, Homebound schooling, Virtual schooling and Community schooling. Joshua (2010) advocates careful planning of school re-entry involving parents, medical and psychological professionals, teaching, administration and support staff, evaluating health, socio-emotional and academic factors prior to the paediatric survivor re-
commencing at school. Joshua (2010) describes the purpose of the re-entry meeting thus:

The school re-entry meeting is designed to provide schools and districts with information on the patient's current health status and the effects treatment has had on academic development. These meetings might result in a formalized academic plan, such as a 504 Accommodation or Individualized Education Plan. (p.25)

This search of The University of Western Australia databases uncovered many serious and important issues surrounding paediatric cancer survivors. These universal issues (mostly psychological or socio-emotional) are related to aspects such as: quality of life, other health problems after cancer treatment and family difficulties adjusting to life with a young cancer patient. Several articles also explain the emotional issues for teachers when dealing with paediatric cancer survivors returning to school.

Only two articles delve into the learning needs of paediatric cancer survivors returning to school after remission and they address the topic of neurocognitive late effects in survivors and the adjustments required at school in dealing with the problem. These articles gave enormous insight into the research area, as they sparked the idea that teachers may have more to deal with than just the psychological and socio-emotional issues surrounding students who have been critically ill with cancer, survived gruelling treatments and have returned to school after remission. One of these articles is a guide for school counsellors, suggesting the formulation of an Individual Education Plan at the first school re-entry meeting (Joshua, 2010) and the other (Coughlin, 1997) documents the return to school of a brain tumour survivor with neurocognitive late effects. In trying to answer the central research question: How do teachers deal with paediatric cancer survivors returning to their classrooms after remission? it was
necessary to research further to discover the kind of problems teachers might be faced with, apart from psychological or socio-emotional issues.

### 2.3 Prevalence of cancer survivors’ cognitive late effects

Neurocognitivepsychological deficits in paediatric and adolescent cancer survivors (“late effects”) have been widely investigated and verified in Australian, British, Canadian and American literature but Australian teachers, school psychologists and even parents may be unaware of the learning consequences for the survivors in schools.

The aim of the research was to use the research literature by targeting only the teachers of students with the typology of survival of treatment for leukaemia (ALL) or cancer in the brain or head area. According to the literature, these students are most at risk of their past therapies interfering with their normal academic progress and their day to day success at school. In longitudinal studies, cancer survivors who have not endured central nervous system therapies do not seem to have the same level of academic difficulties. Gerhard et al. (2007) comment on this as follows:

> Most children, particularly those diagnosed with tumors not involving the central nervous system (CNS), adapt relatively well during initial diagnosis and treatment. (p.448)

However, Gerhard et al. (2007) describe the survivors who are most likely to suffer cognitive late effects thus:

> However, some subgroups of survivors may be at greater risk for difficulties than others. Previous research has found that children who were treated at a younger age, as well as those who had more severe forms of treatment (e.g., cranial radiation, intrathecal chemotherapy) or late effects may have a greater risk for educational and occupational difficulties over the long term. (p. 449)
Therefore, not every paediatric or adolescent cancer survivor will experience neurocognitive late effects so it was critical to target only teacher participants involved with teaching students who had undergone central nervous system therapies. Australian researchers, Wheeler et al. (2009) in Challenges facing survivors of childhood and adolescent cancer, describe these late effects using words such as “devastating” (p.192) and “profound” (p.192) as follows:

Often the most devastating long-term effect is the functional neurological compromise suffered by patients who have had brain tumours or cranial irradiation. Similar, but not as profound effects can be seen in patients who have had intrathecal methotrexate, especially if cranial radiotherapy is also given. (p. 192)

Stevens (2011) in Cancer in childhood, confirms the presence of neurocognitive late effects in children who have endured cranial irradiation treatments and also asserts that other survivors can experience these late effects too. Stevens (2011) explains:

Learning difficulties related to neurocognitive dysfunction may manifest in survivors of childhood cancer, particularly when earlier treatment has included radiation therapy to the brain. Cranial radiation therapy remains the major risk factor for neurocognitive dysfunction, but learning difficulties may also occur in survivors who did not receive cranial radiation therapy. (p.19)

Wilson, Cohn & Ashton (2010) state that cranial irradiation and intrathecal methotrexate have; “been previously shown to be associated with the occurrence of neurological and sensory sequelae in long term survivors of childhood cancer.” (p.1059) The researchers explain these late effects as follows:

Neurocognitive late effects are among the most prevalent neurological sequelae observed in survivors of childhood cancer and manifest as deficits in overall
global function, as measured by Intelligence Quotient (IQ) tests, or more commonly, as diminished capacity in specific areas, such as attention and concentration, memory, non-verbal abilities, visualspatial and perceptual motor skills. Accordingly, long term survivors may experience difficulties with language, reading and mathematics, as well as diminished academic performance. Declines in IQ observed among survivors of childhood cancer are most likely to result from the inability of survivors to learn at an age appropriate rate, rather than from a loss of previous knowledge. (p.1059)

Askins & Moore (2008) in Preventing neurocognitive late effects in childhood cancer survivors, explain how new treatments for childhood cancer offer medical success but result in neurocognitive deficits, as such: “Newer aggressive, more effective medical treatments directed at the child’s brain are often associated with neurocognitive morbidity.” (p.1161)

Measurable, physical changes in the brain have been observed by researchers investigating neurocognitive late effects in paediatric survivors, particularly those who have been treated with cranial radiotherapy. These changes are ongoing, with some studies measuring levels of decline over time. Askins & Moore (2008) measured IQ decline in paediatric cancer survivors and state:

Children treated for cancer are at risk for neurocognitive late effects that produce declines in IQ, academic skills, and career attainment. The use of intensive chemotherapy (eg, methotrexate) and radiation therapy are thought to cause damage to cortical and subcortical white matter, resulting in these late effects. Symptoms consistent with attention-deficit disorder and deficits in mental processing speed, working memory, executive functioning and memory combine to leave survivors intellectually and academically disadvantaged. In
some children, IQ drops by as much as 3 to 4 points per year (approximately 1 SD every 5 years). (p.1161)

The literature demonstrates that paediatric and adolescent cancer survivors who have endured CNS therapies will be at risk of learning disability and possibly academic decline over time. In many studies, these survivors have been included in research groups along with brain trauma victims and the therapies, symptoms and outcomes are strikingly similar (Sohlberg & Turkstra, 2011), (Butler & Mulhern, 2005), (Butler et al., 2008a) and (Butler et al., 2008b). Cognitive rehabilitation therapies have been demonstrated to be effective in treating both brain trauma and cancer CNS late effects and early intervention is encouraged for all conditions. Askins & Moore (2008) outline the neurocognitive problems and describe them as such:

Neurocognitive sequelae are most apparent in attention, memory, visuospatial abilities, executive functioning, and cognitive processing speed. Because of deficits in these important functional domains, survivors experience declines in IQ and academic achievement relative to same-age peers. (p.1163)

Askins & Moore (2008) describe how these neurocognitive late effects continue to have an impact on the survivors long after treatment has ended, affecting their quality of life as follows:

This does not mean that cognitive growth is arrested or declines as in dementia, but that growth rate is reduced compared with same-age peers. Therefore, as elapsed time since treatment increases, the gap in abilities between survivors and the general population increases. This presents challenges for some survivors in problem solving, academic attainment, independent living, and general quality of life. (p 1163)

Ness et al. (2008) in their nine year longitudinal study, The impact of limitations in physical, executive and emotional function on health-related quality of life among adult
survivors of childhood cancer: A report from the childhood cancer survivor study, asked participants to self-report their physical health, emotional health and executive function. They found that, of the 14,372 cohort participating, 47.9% of these survivors had endured central nervous system therapies and 14% identified executive functioning as a significant limitation in their daily lives. In Appendix A, “Questions from the Brief-A used in the second follow-up survey” by Ness, et al. (2008), (p.135) the statements used for the executive function component of the study are listed. These statements were derived from the Behavioral Rating Inventory of Executive Function–Adult Version (BRIEF-A). (Ness et al., 2008)

Ness et al. (2008), conclude that: “Executive function limitations, like poor organizational skills, difficulty initiating a new task, or persistent memory problems, interfere with educational and job opportunities.” (p.135)

The existence of neurocognitive late effects in survivors of head or brain tumours as well as leukaemia survivors is undisputed. Butler et al. (2008a) explain how this is incontrovertible rather than conjectural as follows:

In fact, there is general consensus that not only do CNS treatments for leukemias and brain tumors significantly affect neuropsychological development but that there is a consistent pattern of deficits involving vigilance attention, working memory, spatial awareness, processing speed, and self-monitoring. As a result, school performance is often adversely affected, especially for mathematics. (p.367)

Butler & Mulhern (2005) in the table (Appendix B) “Neurocognitive deficits and risk factors among children treated for Acute Lymphoblastic Leukemia (ALL) and malignant brain tumors” (p. 68) describe the core and secondary symptoms of neurocognitive deficits in ALL and brain tumour survivors and also list the risk factors
for deficits, which include female gender and younger age at diagnosis. Therefore, it is certain that children or adolescents who have endured central nervous system therapies to treat head or brain tumours and leukaemia have a very clear risk of demonstrating neurocognitive late effects because of their treatments. The reasons these types of paediatric cancer survivors suffer neurocognitive late effects requires a detailed description of the types of treatments they have endured. The next section, Factors responsible for cognitive difficulties, describes childhood cancer treatments and the resultant sequelae of late effects related to neurocognitive disability.

2.4 Factors responsible for cognitive difficulties

The literature mainly deals with the connection between the type of cancer endured and the specific treatments responsible for the late effects cognitive difficulties. Armstrong et al. (2005) in Learning and living with cancer: Advocating for your child’s educational needs, list the risk factors for late effects as such:

Not all childhood cancer survivors will develop late effects. Factors that increase the risk for learning problems in school include: cancer diagnosis at a very young age, cancer treatment involving the central nervous system (the spinal cord and brain), certain types of cancer, such as: – brain or spinal cord tumors– tumors in the eye, eye socket, head, or facial area – Acute lymphoblastic leukemia (ALL) – Non-Hodgkin lymphoma (NHL) – Hodgkin lymphoma, brain surgery, radiation to the total body or to the head, female gender - girls may be more at risk for cognitive late effects. (p.5)

The two most common forms of cancer in children are brain tumours and leukaemia, and these will account for 50% of cancers in children (Armstrong & Horn, 1995).

Although the researchers state that all children with cancer will have obstacles related to school attendance and academic performance because of absenteeism, acute effects and
infections: “For children with leukaemias or brain tumours, school problems may additionally be related to changes across time in the structure and/or function of the brain following treatment with chemotherapy administered into the cerebrospinal fluid (intrathecal chemotherapy) and/or radiation therapy to the brain.” (p.292)

Specific therapies associated with certain types of cancer treatment are thought to be responsible for learning difficulties which may appear at any stage during remission, either early on or long-term and so the time of onset of the difficulties may be hard to pinpoint. Armstrong & Horn (1995) explain how the therapies which saved the lives of the paediatric cancer patients can also contribute to cognitive changes and problems later in their lives as follows:

There is no doubt that the advancement of understanding and use of new drug protocols in the last four decades has led to a dramatic increase in survivor numbers. Unfortunately, evidence suggests that while these drugs are effective in treating the cancer, they are also associated with an increased risk for structural brain changes and long-term difficulties in learning that emerge over time. (p.302)

Palmer, Reddick & Gajjar (2007) explain how CNS radiotherapy treatment for malignant medulloblastoma tumours results in severe neurocognitive deficits. The researchers describe the risk of radiotherapy as such:

Due to the high metastatic potential of these brain tumors, RT includes targeting the entire craniospinal axis with an additional boost aimed at the primary tumor site. Long-term side effects following treatment for medulloblastoma have been consistently demonstrated. Research has indicated that, of the therapeutic modalities used in treating medulloblastoma, RT appears to be most related to the severity of neurocognitive deficits in survivors in a dose-related fashion. (p.1041)
Radiotherapy is given in “risk-adapted strategy” (p. 1041) protocols, so that only high risk tumours (with more metastatic disease and more residual tumour left after surgical resection) receive the largest doses. Average risk disease is treated with lower levels of radiotherapy. Palmer et al. (2007) explain that in 12 of 18 studies reviewed, brain tumour patients who had received cranial radiation had IQ levels 12–14 points lower than those who did not. Young children who had been treated with cranial radiation had IQ levels 14 points lower. Cognitive functioning decline also occurs, about a year after treatment, followed by a gradual decline in IQ scores. Younger children demonstrate cognitive decline soon after treatment and this decline continues over time. Older children demonstrate cognitive functioning decline after about two years, thereafter remaining stable. Functional memory deficits and verbal memory deficits, including both retrieval and recognition, are also observed in children who have been treated for medulloblastoma. Palmer et al. (2007) explain that new radiotherapy delivery techniques such as 3D technology and proton beam irradiation may help reduce radiation exposure to healthy brain tissue.

Wilson, et al. (2010) describe the variance in radiotherapy treatments and the different neurocognitive outcomes for children of different ages as such:

The incidence of neurocognitive deficits is related to the volume of brain irradiated, total dose received, and the age at which the cranial irradiation is received. While children younger than six years who receive radiation doses of between 18 and 24Gy as prophylactic cranial irradiation for leukaemia may experience difficulties learning basic skills, equivalent treatments given to older children may not result in impaired learning capacity, except for acquisition of complex skills, such as learning a new language or high-level mathematics. (pp. 1059)
Hollen, Hobbie & Finley (1997) studied fifty two survivors, who were aged 14 – 19 years. These survivors had received no treatment for two years and had not relapsed. They had all kinds of cancers except for brain tumours. The survivors were interviewed when they attended their follow up clinics. The researchers examined medical records, ran intelligence testing (Weschler IQ) and ran semi-structured interviews with the teenagers. Hollen et al. (1997) define the criteria for cognitive function being at risk as: “A history of cancer therapy threatening cognitive function (defined as ≥18 gy of radiotherapy, intrathecal or high-dose systemic methotrexate, or both). (p. 305)

Jain et al. (2009) in Sex-specific attention problems in long-term survivors of pediatric acute lymphoblastic leukemia, explain that there are major differences between boys and girls as to the rate and times at which regions of their brains grow and develop during childhood. The researchers elaborate on this as follows:

The rates of myelination of various brain regions differ between boys and girls during early development, with boys displaying a larger increase in white matter development during childhood. This rapid increase in myelination in boys may buffer them from processes that impact white matter development and enhance subsequent performance on tasks dependent on white matter integrity, as in the case of chemotherapeutic treatment for ALL. (p.4242)

Central nervous system treatments for brain or head tumours and leukaemia affect boys and girls in different ways and their neurocognitive outcomes will differ too. On this, Jain et al. (2009) comment:

Consistent with the findings of this study, it would be expected that boys would evidence difficulties on tasks mediated by gray matter, as their rate of gray matter development during childhood is slower than that for girls. The converse is true for girls, who experience a slower rate of white matter development, which subsequently would result in reduced performance on tasks related to
white matter functioning, a finding that is also consistent with the current results. (p.4242)

Askins & Moore (2008) explain how cranio-spinal irradiation, chemotherapy and surgery (or combinations of these) are the medical treatments which will bring children’s cancer into remission, however the use of these treatments then leaves children at risk for late neurocognitive sequelae. The risk of this is even higher for younger children and girls diagnosed with head or brain tumours or leukaemia. Askins & Moore (2008) comment on this as follows:

It is well established now that children with brain tumors demonstrate declines in neurocognitive functioning and academic achievement over time. Younger age at diagnosis and female gender place children at great risk for neurocognitive and academic declines. In some children, symptoms consistent with attention deficit disorder are present. (p.1163)

Researchers are united in their observations of the relationship between intrathecal (administered through the spinal cord) chemotherapy and head radiotherapy treatment and neurocognitive late effects. In the Journal of Pediatric Hematology/Oncology article Cognitive sequelae in children treated for Acute Lymphoblastic Leukemia with Dexamethasone or Prednisone, Waber et al. (2000) attribute neurocognitive late effects to Dexamethasone therapy. In subsequent studies, intrathecal doses of Methotrexate and cranial radiotherapy are linked closely with cognitive-neuropsychological late effects in survivors.

An Ontario study conducted by Mountour-Proulx et al. (2005) focussed on leukaemia survivors who had endured intrathecal (through the spinal cord) doses of Methotrexate and the research implies that this drug alone is the cause of the significant decline they observed in Weschler Performance IQ scores, although Weschler Verbal IQ and Memory results were stable. Despite the differing theory about the precise cause
of neurocognitive late effects, Askins & Moore (2008) state that whichever treatment is responsible, damage to the white matter in the brain is commonly seen by researchers as being the fundamental problem. On this, Askins & Moore (2008) comment:

Treatments for brain tumors and high-risk acute lymphoblastic leukemia frequently involve high-dose chemotherapy and radiation therapy delivered to the brain. Although different mechanisms have been postulated to explain the underlying neurological basis of neurocognitive dysfunction, damage to cortical and subcortical white matter has received the most attention. (p.1162)

Askins & Moore (2008) discuss the longitudinal study by Copeland, Moore, Francis, Jaffe & Culbert (1996) of 99 long-term survivors which found that those survivors who had experienced intrathecal chemotherapy demonstrated perceptual motor skills decline over time. However, in the sub-group of children under the age of 5 at diagnosis, 90% showed neuropsychological deficits and 70% had white matter changes. Askins & Moore (2008) list the range of late effects which might be seen in long-term survivors as: learning difficulties (from radiation or chemotherapy), hearing loss (from some types of chemotherapy), visual impairment (from brain tumours or therapies) or growth and development problems from treatment.

In the past, leukaemia patients were treated with prophylactic doses of radiotherapy in order to minimise the chance of leukaemia cells growing again after successful initial treatments. (Stevens, 2011) Very long term survivors of leukaemia who were cured of cancer in the 1970’s would remember interminable radiation treatments in adult hospitals. This type of therapy was replaced with intrathecal protocols, with radiotherapy reserved as a treatment only for the most aggressive cases which did not respond to intrathecal therapy. Cranial radiation treatment greatly increased the likelihood of neurocognitive late effects and Stevens (2011) explains here how some
groups are even more susceptible to learning difficulty late effects: “The risk of learning difficulties in this setting increases with younger age at time of original therapy (especially under three years of age), female gender, and increasing time from original treatment.” (p.19)

To summarise, Keene, Hobbie & Ruccione (2007), in Childhood cancer survivors: A practical guide to your future, encapsulate the causative factors for neurocognitive deficits seen in paediatric cancer patients who have undergone treatments for ALL and head or brain tumours as such: “Childhood cancer and its treatment can leave survivors with unique educational needs. Treatments that sometimes affect school performance are brain radiation, brain surgery, intrathecal methotrexate and high-dose systemic methotrexate.” (p. 89)

The students most at risk of demonstrating learning difficulties when they return to their classrooms are leukaemia (ALL) survivors and survivors of brain tumours or any cancer requiring radiotherapy treatment to the head. Western Australian government and independent school teachers, teaching children who have endured these therapies and are now in remission, were the focus of the research reported in this thesis.

The preceding section has outlined the research in the literature dealing with the factors responsible for neurocognitive late effects in childhood cancer survivors. Radiotherapy to the head is a high risk factor for brain tumour survivors or for leukaemia patients who relapse. (Stevens, 2011) Chemotherapy is another risk factor for learning deficits in survivors; therefore leukaemia survivors can also demonstrate neurocognitive late effects. Damage to white matter caused by central nervous system therapies is the reason for the neurocognitive late effects and this is why younger age at diagnosis and being female increase the likelihood of neurocognitive deficits. (Askins & Moore, 2008)
The following section describes the literature dealing with how late effects learning deficits appear in survivors. There is a broad range of neurocognitive late effects identified in this section, the extent of which can vary from survivor to survivor, depending on the type of cancer they have survived, the treatments they have received, their age at diagnosis and their gender.

2.5 How late effects learning deficits appear in survivors

Other research focuses on how the late effects of the therapies appear in survivors. Jain & Krull (2009) in Should long-term survivors of pediatric cancer be screened for neurocognitive impairment? estimate that 40% of long term survivors of paediatric cancer will demonstrate impairments related to memory, processing speed and attention. They discuss the recommendation of the North American Children’s Oncology Group to undertake routine monitoring of neurocognitive functioning in the groups of survivors who are most at risk and the difficulty in implementing this recommendation due to professional resources and expense.

Jain & Krull (2009) devised an economical, (in time and cost) thirty minute neurocognitive screening tool which tested attention, processing speed, memory and executive functioning in 240 survivors. Two of the case studies they outline in detail include a leukaemia and a brain tumour survivor. Both demonstrated significant cognitive difficulties. The leukaemia survivor was found to have average intellect but poor attention and working memory and was referred for a stimulant medication trial to improve her attention skills. The brain tumour survivor had impaired intelligence and multiple academic problems including memory and fine motor dexterity difficulty. He qualified for special education services and occupational therapy. Jain & Krull (2009) surmise that the acquisition of early - developing neurocognitive skills is interrupted during cancer treatment and that those higher-level neurocognitive abilities such as
executive functions, which will develop later into adolescence and young adulthood will also be affected by these neurocognitive deficits. They recommend early intervention and regular neurocognitive screening.

In Sex-specific attention problems in long-term survivors of pediatric Acute Lymphoblastic Leukemia, Jain et al. (2009) tested 103 long term survivors of ALL for attention problems. They describe the differences in survival rates and neurocognitive outcomes as follows:

Sex of the patient has been identified as a potential moderator of late effects and neurocognitive outcomes. Boys are reported to display worse event-free survival at 2 and 5 years after diagnosis, and higher rates of hematologic relapse.

Conversely, girls appear more sensitive to the purine antimetabolite mercaptopurine, requiring more frequent dosage decreases in comparison with boys. Girls also appear to be at increased risk for adverse neurocognitive outcomes after chemotherapy. (p. 4239)

Jain et al. (2009) found that, overall, there were; “attention problems” (p.4243) and “deficits in attention and processing speed”. (p.4238) Girls had difficulty with shifted attention and sustaining attention over time, while; “boys had difficulty with working memory and inhibited control over responding.” (p.4238) Jain et al. (2009) report:

“Both of these skills involve cortical control over more basic processes and, as such, are often referred to as executive functions”. (p.4242) For long-term, female ALL survivors with attention difficulties, processing speed may consequently be a problem. Jain et al. (2009) explain this as follows: “Both the shifting attention and sustained attention tasks are speed dependent, and likely rely upon the integrity of anterior white matter.” (p.4242) Askins & Moore (2008) describe the range of deficits seen in young cancer survivors who have had CNS treatments as such:
The functional neurocognitive domains that are affected the most by cancer treatments are attention, executive functioning, processing speed, working memory, and ability to learn, which in turn adversely affect the academic performance of pediatric cancer patients and childhood cancer survivors. (p. 1163)

Armstrong & Horn (1995) also flag; memory, attention, fine motor integration and processing speed deficits as learning difficulty areas to be monitored. Many researchers agree that academic measures of reading in this survivor group may yield normal results so a different battery of testing needs to be used to properly define the neurocognitive deficits. Armstrong & Horn (1995) also raise the enigmatic fact that reading and language abilities can appear to be intact despite other disabilities being experienced. They comment on this as follows:

Treatment of the CNS with radiation and/or chemotherapy seems to result primarily in deficits in processing speed, visual-motor integration, fine-motor coordination, attention and concentration (typically of a non-hyperactive nature), sequential memory, and arithmetic. While there may be temporary changes in language and verbal abilities immediately following CNS treatment, these seem to recover and few long term difficulties in the language or reading areas occur. (p.298)

Armstrong & Horn (1995) discuss the way the academic performance of children with cancer involving the central nervous system declines over time and the way the younger the child developed cancer, the greater the deficits observed because most post-natal brain development occurs under the age of five. They state that intervention studies look promising, especially with the use of stimulant medication and cognitive rehabilitation together. They advocate re-evaluation on a regular basis as brain
maturation occurs well into the third decade of life. Armstrong & Horn (1995) pinpoint
the abilities most affected by CNS treatments thus:

Data from outcome studies suggest that abilities most likely to be affected by
CRT or intrathecal chemotherapy are those involved in organizing and storing
newly acquired information (e.g., sequential memory, attention, visual-motor
integration), demonstrating what has been learned (e.g., fine-motor
coordination involved in handwriting), or acquiring and recalling information
under time constraints (e.g., processing speed, arithmetic). (p.300)

Handwriting essays and written assessment tasks under time constraint, completing
multiple choice item tests under pressure of time and speed tests, such as mental maths
or mathematical algorithms, may present enormous difficulty for students with
neurocognitive late effects. Many of these types of tasks are standard assessments used
in secondary education settings and this may be the time when the late effects emerge as
learning difficulties for the student. (Armstrong & Horn, 1995)

Armstrong & Horn (1995) advocate specific identification of the cognitive late effects
and state that:

The assessment battery should include standardized, age-normed measures of
processing speed, sequential memory, attention and concentration, and visual-
motor integration, as well as measures of functions unlikely to be impaired,
such as measures of language functioning. This will permit development of an
educational plan that both targets weaknesses and builds upon areas of
strength. (p.300)

The National Children’s Cancer Society (2015) Beyond the cure online resource
offers many informative resources for students who have survived cancer as well as for
their teachers, nurses and parents. The National Children’s Cancer Society (2015)
describes the programme as such: “Our Beyond the Cure program prepares survivors
and their families for life after cancer. We educate survivors through our extensive web-based information center, conferences and free publications so they can gain a better understanding of the late effects of their treatment.” (para 1) The programme offers free “Just in Time” (The National Children’s Cancer Society, 2015) training modules for teachers, nurses and parents of paediatric cancer survivors. Confusion identifying late effects learning difficulties is intimated in the choice of title for one of their 2008 teleconferences: Does my child need discipline or accommodations? One of the NCCS 2010 webinars is titled; Cancer treatment may impact school: How to convince your child's teacher.

Stevens (2011) in Cancer in childhood, also explains this confusing appearance of negative behaviour traits which may appear to a teacher (especially in the high school setting) as sloppy or careless behaviour and inconsistent or incomplete work. In the high school setting, organisation, reasoning and competent time management are essential ingredients for school success. Stevens (2011) describes these traits as follows:

The deterioration in academic performance is related to a diminished rate of skill acquisition rather than a loss of previously learned information. The most common difficulties are impaired concentration, processing speed, visual perceptual skills, executive function, and memory. Poor attention in this setting is frequently not accompanied by hyperactivity, and might be misinterpreted as lack of interest or inappropriate behaviour. Careless errors, incomplete assignments, and inconsistent academic performance are common. (p.19)

Hollen, et al. (1997) in Cognitive late effect factors related to decision making and risk behaviors of cancer-surviving adolescents, found that, for the fifty two teenage cancer survivor participants in their study, their medical histories of cancer therapies which threatened cognitive function (CNS involving radiotherapy or intrathecal chemotherapy) were; “a marginally significant predictor of poorer -quality decision
making in the first regression model” (Hollen et al., 1997, p.305) and; “poorer-quality decision making was a significant predictor of one or more risk behaviors in the second model”. (p.305) Difficulty with abstract and analytical thought processes was affecting their cognitive processes, in particular, decision making and risk taking. This was concerning, since the study participants were teenagers. The researchers go on to make the following observation:

Abstract and/or analytic ability may be important links for decision making and risk behaviors of teen survivors, thus warranting further examination within a larger sample. (p.305)

Paediatric neurologists Riccio, Sullivan & Cohen (2012) in Neuropsychological assessment and intervention for childhood and adolescent disorders summarize the neuropsychological research in a range of neurological disorders, including cognitive late effects of childhood cancer. They discuss case studies, assessment tools, treatments and interventions for disorders. They suggest measures and a battery of tests applicable in discerning neurological disorders in domains of functioning, including: cognition, auditory-linguistic language function, visual perception and constructional praxis, perceptual/sensory perception, learning and memory, processing speed and tracking. The broader areas they define as areas of particular difficulty for childhood cancer survivors are; executive function and problems with sustaining attention and concentration, motor function, achievement/academic skills, slow processing speed, emotional/behavioural functioning, executive function deficits, impaired performance in working memory, behaviour inhibition difficulty, problems with cognitive flexibility and self-monitoring and they explain that these are; “all impairments associated with stress, behaviour and coping strategies that ultimately affect quality of life”. (p.207)

The researchers also cite the frequency of mathematics difficulty, which they believe to be associated with memory function and psychomotor speed as follows: “The pattern of
strengths and weaknesses associated with childhood cancer is more consistent with specific learning difficulties as opposed to diffuse lowering of abilities.” (Riccio et al., 2012, p.218)

Riccio et al. (2012) provide a snapshot analysis of learning deficits in the table (Appendix C), Deficits following treatment for childhood cancer (p.214) which gives a simple breakdown of neurocognitive abilities affected by central nervous system treatments for cancer. This table could serve as a useful reference tool for school psychologists as well as teachers of students with the typology of central nervous system treatments during childhood cancer. For teachers, it would be a valuable tool to use as a starting point for the construction of any Individual Education Plan document, as it clearly and succinctly breaks down the terminology for neurocognitive deficits into easily understandable concepts, more suitable for use by non-medical or non-psychological professionals. Riccio et al. (2012) also provide another table; Evidence - based status for intervention with childhood cancer, (p.218) which demonstrates different types of interventions, their targets and the current status of the intervention. Most interventions are “emerging.” (p.218)

Askins & Moore (2008) outline the very serious implications for brain tumour survivors in particular, noting that IQ testing shows these survivors suffer an alarming decline in IQ from year to year as such:

Impairments in these cognitive functions resulting from cancer therapy are responsible for declines in intelligence quotient (IQ) and in academic achievement. Intelligence quotient may decline 1 or more standard deviations (average IQ is 100 with a standard deviation of 15); some children experience a drop of 3 to 4 points a year, perhaps reaching a plateau, or not. (p.1163)

Butler & Mulhern (2005) have undertaken extensive testing and trialled cognitive rehabilitation therapies to address attention and concentration issues in paediatric cancer
survivors. They believe some of the major difficulties for CNS therapy survivors are attention, focus and distractibility, as:

Most descriptions of core neurocognitive deficits in survivors of ALL and malignant brain tumors involve attention/concentration deficits. Other researchers have documented (1) deficits in the ability to focus and execute under conditions of demanding attentional processing and (2) susceptibility to distraction. (p.67)

Armstrong & Horn (1995) also discuss the way attention and concentration difficulty can appear to educators as behaviour issues or a lack of motivation. They believe school staff should be made aware of this issue and comment on this as follows: “Some of the difficulties faced by the child with cancer appear to be motivational, and are often viewed by unsuspecting educators as behaviour problems instead of cognitive disabilities.” (p.301)

In the table Deficits following treatment for childhood cancer, (Appendix C) Riccio et al. (2012) list Visual Perception/Constructional Praxis deficits as; “visual perception ability impaired, visual-motor integration impaired, perceptual motor skills impaired, visual-motor constructional skills impaired”, (p.225) Armstrong & Horn (1995) describe “visual-motor integration” (p.298), “fine-motor coordination” (p.298) and “demonstrating what has been learned (e.g., fine-motor coordination involved in handwriting)” (p.300) as important areas of difficulty. Hockenberry et al. (2015) describe “below-average fine motor dexterity” (p. 542) seen in the survivors. Stevens (2011) describes “visual perceptual skills” (p.19) as one of the problems survivors face and Butler et al. (2008a) mention “spatial awareness” (p.372) difficulty.

This may explain why working under time constraint is very difficult for students who have endured CNS treatments. Armstrong & Horn (1995) describe “deficits in processing speed” (p.298). Stevens (2011) also describes difficulties in “processing
speed”. (p. 19) Askins & Moore (2008) describe deficits in “mental processing speed”. (p.22) Krull et al. (2008) describe deficits in “information processing speed/sluggish cognitive tempo”. (p. 4138) Butler & Mulhern (2005) describe “reduced information processing efficacy” (p.67), “reduced information processing speed” (p.67) and “core deficits in attention/concentration” (p.67) as areas of concern. “Deficits in mental processing speed” and “attention deficit disorders” (p.1171) are also reported to be a problem for survivors by Askins & Moore (2008).


Fine motor integration and dexterity, along with visual perception and functional working memory are all necessary for the timely completion of written tasks, in all subject areas. Handwriting requires the full integration of all of these cognitive areas. For survivors of CNS for childhood cancer, handwriting and the timely and accurate completion of written tasks may be very difficult indeed.

The presence of Dysgraphia, demonstrated by poor writing, can be confused with fine motor issues. Berninger (2004) in Understanding the “Graphia” in Developmental Dysgraphia describes the way memory is intrinsically connected to writing thus:
The important point is that handwriting is “language by hand” which uses the graphomotor system to produce visible language, but neither handwriting nor composing is merely a motor act. Language by hand relies greatly on internal representations of letter forms and written words that must be retrieved from the memory during the writing process. (p.333)

Berninger & Alston-Abel (2009), in the PowerPoint presentation Differential diagnosis and treatment for Dysgraphia, Dyslexia, OWLLD and Dyscalculia, discuss the educational paradox of learning disabilities, in that the assessment and treatment of them are divorced from scholastic endeavour because professionals specialise in either one or the other. “Teachers teach: psychologists assess.” (p.30) Teaching is not tailored and individualised to assessment of the differential diagnosis of the learning disability. However, in the fields of medicine, physical, speech and occupational therapy, the assessment and treatment of the individual is; “entrusted to the same professional who develops conceptual models for linking them.” (Berninger & Alston-Abel, 2009, p. 32) Berninger (2012) used in vivo imaging using MRI and CT scans to link motor activity with cognitive processes. In her 2012 study, it was discovered that children with Dysgraphia had different white matter and circuitry in the brain to the control group and even to other children with Dyslexia. This altered white matter composition of the brain, common to paediatric cancer survivors who have endured central nervous system therapies, may explain the working memory and executive memory function deficits causing Dysgraphia and may be an important indicator, as the research literature consistently describes writing difficulty.

This section has provided an overview of the major areas of learning difficulty or disability demonstrated by survivors of central nervous system therapies for cancer. A number of learning disabilities consistently appear throughout the relevant literature. The areas of attention, working memory, processing speed, fine motor and executive
function are all mentioned in the literature describing neurocognitive late effects demonstrated by survivors of brain tumours and leukaemia. The following section investigates the different ways neurocognitive deficits are being addressed. The section describes Australian and international programmes and resources which are designed to tackle these learning difficulties related to neurocognitive late effects after central nervous system therapies used to treat childhood cancer.

### 2.6 How late effects neurocognitive deficits are being addressed

The fourth focus of literature in this area is the provision of “adjustments” (Australian Human Rights Commission, n.d., para 6), strategies or assistance for neurocognitive late effects identified in survivors.

The Learning Difficulties Australia site (2016) refers to the fact that the term “learning disability” originated in the United States as a result of policy to clearly define and fund students through the Individuals with Disabilities Education Improvement Act (IDEIA). In the United Kingdom, the two terms “learning difficulty” and “learning disability” are both used when referring to students with intellectual disability. (Learning Difficulties Australia, 2016) According to Learning Difficulties Australia (2016), Australian educators align their terminology with the United States and state that learning disability is:

“a disorder in one or more of the basic psychological processes involved in understanding or in using language, spoken or written, that may manifest itself in an imperfect ability to listen, think, speak, read, write, spell, or do mathematical calculations. This term includes such conditions as perceptual disabilities, brain injury, minimal brain dysfunction, dyslexia, and developmental aphasia. This term does not include children who have learning
problems that are primarily the result of visual, hearing, or motor disabilities; mental retardation; or environmental, cultural or economic disadvantage.”

(para 115)

In *Understanding terminology of teaching those with learning difficulties* (Learning Difficulties Australia, 2016) Learning Difficulty is described as a term used to refer to; “students who experience significant difficulties in learning and making progress in school, but who do not have a documented disability such as an intellectual disability.” (para 114) When learning difficulties “are more severe and long-lasting, these students are sometimes described as having a learning disability.” (para 114)

The United States Leukemia and Lymphoma Society (n.d.) provides an online brochure titled Back to school programme, which lists free programs and materials; “for patients, survivors, families, schools and healthcare professionals which can help manage the education needs of children and young adults who have been diagnosed with cancer.” (para 2) The brochure includes links to resources such as phone and web educational programmes, free education publications and online chats for young adults. The United States Leukemia and Lymphoma Society (n.d.) also has a webpage titled Children and families: Other helpful organisations, which provides descriptions and links to a variety of organisations involved with childhood cancer. One example listed is Grahamtastic Connection (Leukemia and Lymphoma Society, n.d., para 9) which; “Provides laptops and other technology to children when hospitalized or bed-ridden so that they can continue to connect with their teachers and classrooms, to obtain education materials and to submit homework assignments.” (para 9)

Another resource listed is The National Children’s Cancer Society’s (2015) Beyond the Cure Survivors (BTC) Program. (Leukemia and Lymphoma Society, n.d., para 22) which; “provides the most up-to-date information on survivorship to help survivors and their families adapt and celebrate life after diagnosis.” (para 22) Beyond The Cure is
described as an online community which: “provides a private network for parents, caregivers and survivors of childhood cancer to connect, share and offer support to one another.” ([Leukemia and Lymphoma Society, n.d., para 22]

Armstrong et al. (2005) in the comprehensive resource, *Learning and living with cancer: Advocating for your child’s educational needs* (Livestrong Foundation, 2016) identify the children at risk of having educational difficulties and list relevant advocacy agencies to assist parents. Armstrong et al. (2005) explain the laws protecting children with special educational needs, the types of physical and cognitive accommodation which may be needed at school and give a clear and specific guide to parents on the steps they should take in gaining assistance for their child if they are undergoing cancer treatment or experiencing late effects of treatment. Step three involves requesting in writing that an Individual Education Plan be developed by the school for the child if their special needs fall within the (“IDEIA”) Individuals with Disabilities Education Improvement Act. IDEIA relates to health impairment and mandates a section 504 plan if their “disability must substantially limit one or more major life activities.” (p.6)

According to Armstrong et al. (2005), this brochure gives specific examples of cognitive late effects so they may be easily recognisable and evident to parents. The following is an example:

Many parents are surprised to learn that the effects of cancer treatment may continue after treatment ends. These effects of cancer treatment — called *late effects* — can impact schooling for years. Sometimes late effects are noticeable right away. Others may take years to show up. Some cognitive late effects (those affecting thinking and memory) include problems with: organization (homework assignments may often be misplaced; school materials can be jumbled); reading or reading comprehension processing speed (children may work more slowly than their peers); visual memory for things that are new (such as decoding letters
and numbers or reading music); understanding math concepts or remembering math facts. (p.4)

Armstrong & Horn (1995) advocate educational plans which incorporate the use of tape recorders to capture oral instructions, word processors rather than handwritten work and use of calculators. They suggest the removal of time constraints and writing requirements in test taking. Some evidence (Wheeler et al., 2009) suggests medications such as dexamphetamine and/or cognitive remediation programs may improve academic performance and overall quality of life in some with a history of brain tumours. Armstrong et al. (2005) also discuss high school transitions and make it clear that the Individual Education Plan or 504 Plan must be used for accommodation at the high school and post-secondary levels.

Children in Australia with disability or special educational needs are equally entitled to such assistance through The Australian Human Rights Commission and The Commonwealth Disability Strategy of 1994 (currently under review). Individual Education Plans (IEPs) are widely accepted as “best practice” and used in Western Australia schools to flag, document, address and monitor students’ special educational needs and provide extra support where possible. The existence of an IEP or identification of special learning needs gives secondary students special consideration from the Western Australian School Curriculum and Standards Authority, particularly in relation to exam situations and even allows a secondary student to repeat a final year of schooling in any secondary school setting or college to assist transition or access to tertiary education opportunities.

British and American studies have focused on long-term employment and academic opportunities for this group. Wheeler et al. (2009) discuss the long term disadvantages of these learning difficulties thus:
Short-term memory impairment and concentration span problems, which may result from cranial radiation and intrathecal chemotherapy, reduce patients’ ability to complete tertiary education or even vocational training assessments. (p. 194)

Early identification of cancer survivors’ neurocognitive deficits and implementing appropriate intervention strategies for them will have an impact on the development of higher-level neurocognitive abilities and executive functions and will influence future educational success and opportunities. A thorough interrogation of the available literature has exposed the prevalence of “cognitive late effects” (Armstrong & Horn, 1995, p.4), “neurocognitive late effects” (Mountour-Proulx et al., 2005, p.129) or “neurocognitive deficits” (Cohn, n.d, para 3) in paediatric or adolescent cancer survivors with a medical history of treatments involving the central nervous system.

Australian and international anti-discrimination policy for students with learning disability is embedded in legislation. International programmes like Learning and living with cancer: Advocating for your child’s educational needs (Armstrong et al., 2005) aim to improve awareness and understanding of the learning difficulties such students may endure.

A phase III Cognitive remediation programme has been trialled in seven paediatric oncology institutions across the United States of America. Cognitive remediation is based on the theory of brain plasticity or the brain’s ability to rebuild neural pathways or functions which have been damaged in some way. (Doidge, 2010) Palmer et al. (2007) describe cognitive rehabilitation as; “a term used to describe therapeutic services intended to restore lost cognitive functions, or to teach the patient skills to compensate for cognitive losses that cannot be restored.” (p.1045)

Butler & Namerow (1988) explain the repetitive nature of cognitive retraining after injury to the brain as follows:
Cognitive retraining can be defined as a systematic therapeutic approach designed to improve cognitive functioning after central nervous system insult. Specific descriptions of the process underlying cognitive retraining are varied but they commonly emphasize the importance of repeated instructional practice on cognitive tasks. (p.97)

Butler & Namerow (1988) credit the work of Alexander Luria in 1963 for our understandings of cognitive remediation and describe the type of strategies now used as such:

A second method or process of cognitive retraining also emphasizes overlearning and has its basis in Luria’s theory of brain function. Luria theorized that the brain is not a static system and that functional reorganization of neural pathways can occur after insult. In order to improve the development of these pathways, the cognitive deficit is analyzed and broken into modular components. Training involves extended practice and overlearning, capitalizing on what strengths and intact cognitive abilities are present. (p. 97)

It is interesting to note that, during the six years this researcher has been studying the literature in this area, the term cognitive remediation is now less frequently used than the term cognitive retraining, reflecting the fact that the problems may not entirely be fixed (remediated) by such strategies, but that specific retraining or rehabilitation can be undertaken to improve neurocognitive deficits.

Cognitive rehabilitation researchers Sohlberg & Turkstra (2011) include cancer survivors who have endured central nervous system therapies in their case studies of brain injured patients and they recommend the same type of rehabilitation that would be used for Traumatic Brain Injury patients. In Optimizing cognitive rehabilitation, Sohlberg & Turkstra (2011) give detailed programmes of cognitive rehabilitation instructional methods for assisting brain injured patients in recovering lost skills and
cognitive processes, through accident, injury or cancer treatment. In doing so, they describe the case study of Esther, a 54 year old woman who had endured surgery, chemotherapy and radiation to treat brain cancer. Esther had lost her abilities of organisation and task completion following the treatment and after comprehensive testing, was found to have impaired executive functioning. The metacognitive strategies they successfully employed for her rehabilitation involved goal setting, self-monitoring and self-evaluation as well as task persistence, using her mobile phone alarm and the Notes application. Butler & Mulhern (2005) explain that the rehabilitation model draws upon three distinct fields of study, which are explained as follows:

The most systematic efforts at applying cognitive remediation principles to children with neurocognitive deficits associated with cancer and its treatment have been accomplished by Butler and Copeland. These authors have developed an innovative tripartite model that uses techniques and methods from three disciplines: brain injury rehabilitation, special education/educational psychology, and clinical psychology. (p.70)

Paediatric cancer survivors who have endured central nervous system therapies were the subject of studies by Butler & Namerow (1988), Butler & Copeland (2002), Butler & Mulhern (2005), Butler et al. (2008a) and Butler et al. (2008b). These researchers refined a psychologically based, cognitive remediation strategy; targeting areas of difficulty, repetition, timed tasks, achieving success and using metacognitive strategies such as self-talk and self-monitoring. Moore (2005) describes the Butler & Copeland (2002) cognitive remediation programme thus:

Butler and Copeland (2002) enrolled cancer survivors with documented attentional problems into a cognitive remediation program aimed at improving attention and neuropsychological abilities. The program was based on educational, psychological, and rehabilitation approaches, and it involved
approximately 50 hr of therapy over a 6-month period. When reassessed at 6 months, those children in the intervention arm of the program evidenced significantly improved attention skills relative to the control group. (p.59)

Assessment and screening tools for the identification of neurocognitive deficits have been developed (Krull et al., 2009) and cognitive rehabilitation therapies have been successful. (Sohlberg & Turkstra, 2011). Technology such as computational modelling may provide easier and more accurate assessment of deficits in the future. However, simple, structured cognitive rehabilitation programmes using PIE (Plan, Implement, Evaluate) (Sohlberg & Turkstra, 2011) is already producing positive results. Butler & Mulhern (2005) discuss the success of these strategies thus:

The clinical validity of these interventions is further advanced by a recent article documenting the effectiveness of remediation efforts to improve attention, memory, functional communication, and executive functioning in adults (Cicerone et al., 2000). A resurgence in the field of cognitive remediation is documented by the publication of five textbooks on this subject within the past half-decade. (p.68)

The first technique used in the tripartite model described by Butler & Mulhern (2005), initially used for brain injury rehabilitation, is Attention Process Training or APT. This uses sustained, selective, divided, executive, attentional control monotonous tasks, which are performed for fifteen minute blocks, then alternated with computer software or game activities. APT is programmed in twenty sessions of two hours duration. The tasks have a 50 – 80% rule; if the child cannot achieve 50% on a task, then the task must be substituted with an easier task.

Secondly, from the area of special education/educational psychology, fifteen metacognitive “teaching the individual to monitor their own thinking” (Butler & Mulhern, 2005, p. 69) strategies are taught. They are grouped into three areas; task
preparedness, on-task performance and post task strategies. Participants have a one-to-one therapist who monitors the progress of the drill activities in the cognitive rehabilitation programme. If particular taught strategies work well for the student, they become part of the participant’s repertoire of individualized strategies and, in this way, a group of successful strategies become unique to the individual. Innovative strategies can be developed using this basis of success. Thirdly, this cognitive retraining uses psychology to assist the child or adolescent to achieve success. Butler & Mulhern (2005) describe the positive approach used as follows:

From the clinical psychology discipline, a cognitive-behavioral approach is used. This approach embodies the concepts of reframing cognitive struggles into a positive light, psychotherapeutic support, acknowledging weaknesses and roadblocks to successful improvement in addition to strengths, monitoring internal dialogue, stress inoculation, becoming one’s own “best friend” rather than “worst enemy,” and ensuring realistic, positive, and optimistic self-statements. In the CRP, cognitive-behavioral methods are specifically directed toward the ability to withstand distraction. (p.70)

Thirty five articles in One Search were concerned with physical health issues for paediatric and adult cancer survivors; skin cancer prevention, nutrition, vaccination, fear of needles, complementary or alternative therapies, sleep disturbance, coping with pain, cancer risks, the prevalence of skin cancer, genetic factors and epidemiology. Ongoing medical issues continue to dominate search engines on the subject of childhood cancer survivors. Early intervention for health risks in this group is a priority for Australian agencies. Associate Professor Richard Cohn, in the Children’s Cancer Institute Australia (n.d.) website describes the long term, medical, follow-up programme thus:

This long-term follow-up benefits survivors by providing (through secondary interventions) them with health education, cancer screening and risk-reducing
health interventions. Beyond this, knowledge gained from the follow-up of survivors allows clinicians to identify factors associated with adverse health and modify the use of cancer therapies accordingly. The aim is to minimise the risk of long-term side effects, thereby improving the quality of life of all those treated for childhood cancer. (paras 5-6)

Krull et al. (2008) explain that; “full neurocognitive evaluations take an average of 8 hours to complete and routinely cost in excess of $1,500” (p.4138) so they used a cost-effective and brief neurocognitive screening test battery to identify long term survivors who were at risk for neurocognitive problems. They tested a group of 240 patients between the ages of 6 –18. The subjects of the testing battery were attending the Long-Term Survivors Clinic at Texas Children’s Hospital and they had endured cranial radiotherapy or intrathecal chemotherapy. The researchers describe the testing battery as follows:

The battery was comprised of standardized clinical performance-based measures and included the Digit Span Test, the Verbal Fluency Test, the Grooved Pegboard Test, and the Trail Making Test (hereafter referred to as DIVERGT). (p.4139)

This battery, although brief (20-30 minutes), exposed the fact that 47.9% of the long term survivors were at risk for neurocognitive disability. The successful trial of this screening test battery will enable large numbers of long term survivors to be quickly and easily screened at regular and frequent intervals throughout their long term survivorship.

As the international research literature indicates, socio-emotional issues for paediatric cancer survivors are heavily represented in articles and journals. In Australia, the socio-emotional factors affecting these students have been investigated in a recent study by McLoone, Wakefield, Lenthen, Butow & Cohn (2011). This joint project,
involving The Sydney Children’s Hospital, The University of New South Wales and
The University of Sydney, Returning to school after adolescent cancer: A qualitative
examination of Australian survivors' and their families' perspectives, concludes:

Additional support is needed to help parents navigate the education system and
to advocate effectively for their child's academic needs beyond the immediate
re-entry period. There is strong potential for school counsellors to increase the
level of support they provide adolescents and their parents during the school re-
entry period. The impact of this period on siblings' education is under-studied
and warrants further research. (p.87)

Neurocognitive late effects are not mentioned in the study, as it focuses on the socio-
emotional needs of the students, their siblings and parents. The Children’s Hospital
Education Research Institute (CHERI) at The Sydney Children’s Hospitals Network is
collaboration between The Sydney Children’s Hospital Randwick and The Children’s
Hospital at Westmead, which, in partnership with the Fight Cancer Foundation provides
the ‘Back on Track’ program at The Children’s Hospital at Westmead. The programme
has been successfully operating at Westmead since March 2006, its purpose being; “to
establish partnerships that support and promote a strong interface between health and
education systems and to keep school aged students with cancer educationally and
socially connected with their school and peers whilst they are undergoing treatment.”
(CHERI, The Children’s Hospital at Westmead Education Research Institute, n.d., para 2)

Three education programme coordinators collaborate with health and education
professionals to facilitate educational and social opportunities by consulting with the
school and family and implement strategies that develop sustainable connections
between the student’s peers, education and their school community. The coordinators
also provide tutoring. Back on Track identifies students diagnosed with cancer that will
experience three months or longer absence from their regular schooling and provides support until the students return to school on a regular basis.

The Sydney Children’s Hospitals Network and Kaleidoscope – the Hunter Children’s Health Network in Victoria, in partnership with Ronald McDonald House Charities have developed the comprehensive resource “What about school?” (Donnan et al., 2011) for parents of children, adolescents and young adults with cancer. The resource offers advice for assisting students to reintegrate into their school settings, including proforma letters to communicate with schools regarding infectious illnesses, a school year summary page and a sibling support page. It outlines the type of difficulties the student may face thus:

In relation to education and learning, some chemotherapy drugs may lead to long term treatment effects and changes in cognitive functioning. (p.35)

A child who has undergone cancer treatment may experience changes to their executive functioning. This may be due to some forms of cancer treatment. (p.111)

The Ronald McDonald Learning Program offers free assessment and tutoring for seriously ill children whose education is compromised because of long stays in hospital and school absence due to their illness: “The Learning Program is often the first step towards normalcy for seriously ill children and their families and sends a clear message that we believe in their future.” (Ronald McDonald Learning Program, n.d., para 1)

From the information gained by the use of a range of assessment tasks, an individualised programme is formulated for each child, which is delivered over approximately forty sessions with a teacher and other professionals if necessary. The programme is described as follows:

When a child applies for the Ronald McDonald Learning Program, they'll first undergo a thorough comprehensive assessment that may include the areas of:
Psychometric (IQ), Academic, Speech pathology and Occupational therapy. The written reports of these assessments are then used to obtain a better understanding of the needs, strengths and weaknesses of the individual student's learning. This then forms the basis of their educational plan. Each program is tailored depending upon the child's needs, location and family situation. Most children will receive up to four school terms of one-on-one tuition with a qualified and registered teacher, along with speech and/or occupational therapy if required. The program is provided free to families and available in both metropolitan and country areas. (Ronald McDonald Learning Program, n.d., paras 5-6)

The Ronald McDonald Learning Program also provides EDMed – a free, one hour professional development session accredited by the NSW Institute of Teachers on how to better handle seriously ill children.

Although adverse neurocognitive late effects are discussed in the Australian literature for survivors of central nervous system cancer therapies, there is no research regarding schools or education departments addressing the academic issues arising in the classroom in Australia. Experienced classroom teachers may have written Individual Education Plans for children with a wide range of educational difficulties including Behaviour Educational Plans, Individual Education Plans for children diagnosed with Autism and Asperger’s Spectrum syndrome, Dyspraxia and Dyslexia, children with Speech, Reading, Fine-Motor, Gross-Motor and Language difficulties, children diagnosed with A.D.H.D. and Perceptual Memory difficulties or children with a low IQ. It is unlikely, however, that teachers would know where to start in developing an Individual Education Plan for a cancer survivor in the classroom experiencing learning difficulty. They would require much more than an IEP template and some handy ideas for short-term remediation because the difficulties or disability their student (with the
typology of central nervous system therapies for cancer) may encounter are related to an insult to the structure and function of their brain. Professional help is essential to diagnose the difficulty or disability and create a plan of action for the student, which should include assistance and expertise from expert professionals, linking their therapies and expertise with the teacher’s Individual Education Plan in the classroom.

2.7 Summary

The central question of this study was: How do teachers deal with paediatric cancer survivors returning to their classrooms after remission? The vast amount of knowledge about the late effects of neurocognitive deficits in the research literature may not be apparent to the Western Australian classroom teachers dealing with brain tumour and leukaemia survivors in their classrooms after remission. The literature which informed the research questions covered six main areas: neurocognitive late effects, the prevalence of cancer survivors’ cognitive late effects, the factors responsible for cognitive difficulties, how late effects learning deficits appear in survivors and how late effects neurocognitive deficits are being addressed.

According to the research literature, children and adolescents with a medical history of central nervous system treatments for cancer are likely to suffer neurocognitive late effects. Brain tumour survivors who have been treated with radiation therapy have a much higher risk of late effects. Leukaemia survivors who have had intrathecal chemotherapy are also at high risk of neurocognitive late effects. There are estimated to be 950 children diagnosed with cancer every year (Children’s Cancer Institute Australia, n.d.) and at least half of those will have the typology described in the literature review in this study.

The interrogation of the literature identified the need to undertake this study, as there is very little information about how teachers deal with cancer survivors in the
classroom, despite the high probability that paediatric cancer survivors (especially brain tumour or leukaemia survivors who have had central nervous system treatments) may have neurocognitive late effects affecting their learning. Teachers may be struggling to understand and assist their students who are demonstrating some or many of the learning difficulties or disability outlined in the research literature. Recent Australian studies focus on the socio-emotional aspects of school re-entry. (McLoone et al., 2011) Western Australian teachers dealing with paediatric cancer survivors returning to the classroom after remission can also benefit from such studies, but there is an urgent need to provide support and information to them so they can confidently provide the assistance their students require for complex learning difficulties and specific educational needs. As the number of children diagnosed with cancer and their survival rate continues to increase, so does this rapidly growing group of special needs students. The research literature defines many areas of neurocognitive difficulty faced by these survivors. The severity of the difficulty may vary, being dependent on the type of cancer endured and its treatment, as well as the age of the child at diagnosis. The following chapter will describe the theoretical approach taken in this research.

CHAPTER 3
METHODOLOGY

3.1 Introduction

This chapter will justify and define the methodology chosen to investigate the Central Research Question which is: How do teachers deal with paediatric cancer survivors returning to their classrooms after remission? This research question was at the core of the methodology structure and provided the anchor required when dealing with so much research literature leading in so many directions. The theoretical framework used in this
study was symbolic interaction theory within the paradigm of interpretivism. Despite the literature informing the abstract theory of the study, the symbolic interactionist approach taken, within an interpretive paradigm, demanded that the research questions were answered by the participants themselves, within their own settings and describing their own experiences. The simple concept: how teachers deal with cancer survivors who have endured central nervous system treatments returning to the classroom when in remission was the primary focus.

This chapter will explain the research questions, which were related to; teacher perceptions of the phenomenon, strategies or adjustments they were or were not using and the main issues perceived by them to be the most important factors in dealing with CNS cancer survivors returning to school after remission. The chapter will disclose the justification for selection of participants and the resulting difficulties involved in locating them, due to tight ethical constraints and such specific typology of the purposive sample.

The location of participants is described in detail, along with the way in which they were contacted. Gatekeeper and ethical challenges required modification to the pathway originally selected for recruiting teacher participants. Neither local hospital school services nor the local hospital could assist without a parent consent letter and Western Australian schools could not be approached either. Therefore it was necessary to seek a new way to locate participants, which fortunately eventuated through the Ronald McDonald Learning Program.

Individual, semi-structured interviews were undertaken, using the research questions and a “Guiding question matrix” (Appendix D). The interviews were transcribed verbatim, this collection of data becoming the voices of the participants. Qualitative data analysis followed, with creative memoing occurring during interviews. Open coding was used to categorise the data, then axial coding ensued, whereby important
clusters of concepts were categorised, compared and connected and became the five major themes. These themes were the most important issues for the teacher participants.

Ethical issues and confidentiality are described in detail in this chapter. The teacher participants were totally unaware that their students may be suffering the late effects of their treatments, resulting in cognitive disability and therefore, could not be expected to provide accommodation or adjustments for something they didn’t know existed.

Lastly, the trustworthiness of the study is explained, which is strongly connected to the ethical considerations of the research. It was important, first and foremost, to draw empirical data from the teacher participants, without pre-empting their responses by focussing with binocular vision on the existence or lack of existence of late effects in their students, which may or may not have been causing neurocognitive disabilities. Teacher perceptions about how they themselves cope with their students returning to the classroom after remission, it will be recalled, was the key research question.

### 3.2 Theoretical framework

The pre-empirical question (Punch, 2009) for this study is how teachers deal with cancer survivors of a certain typology in their classrooms. Thus, ‘empirical’ means based on direct experience or observation of the world. On this, Punch (2009) comments:

> To say that a question is an empirical question is to say that we will answer it - or try to answer it – by obtaining direct, observable information from the world, rather than, for example, by theorizing, or by reasoning, or by arguing from first principles. The key concept is observable information about (some aspect of) the world. (p.32)

The central aim of this study was to generate theory about the perspectives of teachers from Western Australian schools teaching students after remission who have
returned to their classrooms after enduring cancer protocols involving the central nervous system. Within the major theoretical frameworks in sociology, this research is based on symbolic interactionism theory within the interpretivist paradigm, whereby people transmit and receive symbolic communication whenever they socially interact, creating perceptions of each other and their social settings. Since people’s actions are based upon their perceptions, their thoughts about themselves and others are fundamentally connected to their interactions. (Neuman, 2000) O’Donoghue (2007) describes the symbolic interactionist theoretical approach as follows:

In summary, a researcher adopting a symbolic interactionist theoretical approach when conducting research within the interpretivist paradigm is concerned with revealing the perspectives behind empirical observations, the actions people take in the light of their perspectives, and the patterns which develop through the interaction of perspectives and actions over particular periods of time. (p.20)

O’Donoghue (2007) describes the interpretivist paradigm as follows:

This approach emphasises social interactions as the basis for knowledge. The researcher uses his or her skills as a social being to try to understand how others understand their world. Knowledge, in this view, is constructed by mutual negotiation and is specific to the situation being investigated. (p.22)

This study aims to generate theory from gathering empirical data about teachers’ perceptions of cancer survivors in their classrooms. To get a “feel for” (Neuman, 2000, p.58) the issues affecting the participant teachers, it was important to listen to and understand their subjective opinions about their social world. This social world involved Western Australian teachers’ mainstream classrooms where children who had survived cancer were returning to normal school life. Neuman (2000) explains interpretive theory in action as such:
The purpose of interpretive explanation is to foster understanding. The interpretive theorist attempts to discover the meaning of an event or practice by placing it within a specific social context. He or she tries to comprehend or mentally grasp the operation of the social world as well as get a feel for something or to see the world as another person does. Because each person’s subjective world view shapes how he or she acts, the researcher attempts to discern others’ reasoning and view of things. (p.58)

In the symbolic interactionist theoretical approach, people’s experiences, feelings and thoughts about their social settings are discovered. Neuman (2000) describes interpretive research in this way:

For interpretive researchers, the goal of social research is to develop an understanding of social life and discover how people construct meaning in natural settings. An interpretive researcher wants to learn what is meaningful or relevant to the people being studied, or how individuals experience daily life. (p.71)

Silverman (2006) simplifies qualitative, interpretive research by condensing the approach into the “how” and the “what”. As such, he comments that:

One real strength of qualitative research is that it can use naturally occurring data to find the sequences (“how”) in which participants’ meanings (“what”) are deployed and thereby establish the character of some phenomenon. (p.44)

In the research reported in this thesis, the interactions between teachers and students of a particular typology are explored, to identify teacher perceptions of how they deal with these students in their learning environments. Neuman (2000) explains the key questions interpretive researchers should ask as follows:
Important questions for the interpretive researcher are: What do people believe to be true? What do they hold to be relevant? How do they define what they are doing? (p.72)

The more specific theoretical orientation of this research was symbolic interactionism, as the research generated theory about “how participants ‘manage’, ‘deal with’ or ‘cope with’ a phenomenon.” (O’Donoghue, 2007, p. 27) The phenomenon in the study was the presence of cancer survivors in remission participating in mainstream classrooms in the Western Australian education system. Using grounded theory methods of analysis, the empirical, comparative data collected produced generalisations about how teachers deal with cancer survivors in the classroom. The research, therefore, was used to develop substantive theory about how these teachers in Western Australian schools cope with this group of students. At present, there may be an imbalance between the existence of neurocognitive late effects in the cancer survivor student population and practical assistance for them in the classroom. The research revealed insights about teacher perspectives of the issues involved with these students returning to mainstream classrooms after CNS cancer treatment. In the long term, this study may enable such students to gain increased understanding and consideration from within their school communities.

3.3 Research questions

The central research question for the study was: How do teachers deal with paediatric cancer survivors returning to their classrooms after remission?

The guiding questions for the initial collection of the data were:

- What are teacher perspectives of learning difficulties in children who return to school after remission?
• What strategies or adjustments are being used by teachers in response to perceived learning difficulties in students after remission?
• What do teachers perceive as the main issues when dealing with children who return to school after remission?

3.4 Selection of participants

In order to investigate the empirical question; how teachers deal with paediatric cancer survivors returning to their classrooms after remission, it was essential to carefully define the parameters of the research participants’ students’ typology. Most critically ill children would face socio-emotional and physical challenges at school because of absenteeism related to their physical health (immunosuppression, fatigue, nausea, medical appointments and maintenance or recurrent therapy). Teacher participants teaching student cancer survivors in remission were selected by using more specific criteria to try to lessen the adverse effect of absenteeism on the research results and only teacher participants teaching students who had endured central nervous system therapies were selected, to investigate the issues for teachers dealing with these students.
Silverman (2006) describes how research participants may be in ‘closed’ or ‘private’ settings (p.196) As the teacher participants were in schools, purposive sampling was used to locate them.

The selection of participants involved purposive sampling (Silverman, 2005) of teachers in Western Australian government and independent schools, matched to the criteria for teaching students who had undergone cancer treatments involving the central nervous system, now in remission, after a year “off therapy” (Butler & Mulhern, 2005, p.66) and attending school once again. The students had been attending school regularly for at least a term. As Butler & Mulhern (2005) explain, a fifth of children will relapse
within the first year after treatment ends. Silverman (2006) describes the accuracy required for using purposive sampling thus:

Purposive sampling demands that we think critically about the parameters of the population we are interested in and choose our sample carefully on this basis. (p.306)

The specific population this research targets are Western Australian teachers, currently teaching; a child who is in remission from cancer and who has endured central nervous system treatment, who has been off treatment for a year and who has been back at school for at least a term. This population was extremely difficult to reach, requiring the exploration of a number of possible avenues to be used to contact potential participants. Purposive sampling is used; “to select unique cases that are especially informative.” (Neuman, 2000, p.198) Therefore, teachers were sought on the basis that they were teaching a survivor of leukaemia, head or brain cancer, now in remission and back at their mainstream school. Purposive sampling can be used “to select members of a difficult-to-reach, specialized population.” (Neuman, 2000, p.198) The teacher participants required for this study had highly specific attributes and it was difficult to locate them.

Children who have had other cancers which were not treated with central nervous system therapies do not have the same level of risk for neurocognitive late effects. Buizer, de Sonneville, van den Heuvel-Eibrink & Veerman (2006) compared behavioural functioning and school performance in acute lymphoblastic leukaemia survivors with Wilms’ tumour survivors. The ALL group had received central nervous system intrathecal chemotherapy while the Wilms’ tumour survivors had received chemotherapy which had not been administered to the spinal cord. There were significant differences in the behavioural and academic results of these groups. The groups were also compared with siblings and another group of healthy schoolchildren
for control group validity. Academic performance in the ALL group was poorer and there was an excess of behaviour problems. Although academic performance in the ALL group was poorer than their peers, the rate of utilization of special education services for this group was low. There were no dysfunctions of behaviour or academic performance in the Wilm’s tumour group. The researchers recommended the careful follow-up for survivors of ALL. Teacher-rated mathematics performance and behaviour rankings correlated with attention difficulties in the ALL group too. Therefore, the purposive sampling used for this study was carefully constructed to include only those teachers teaching students who had survived ALL intrathecal chemotherapy treatment and brain tumour survivors, who may have had a number of different central nervous system treatments; chemotherapy, radiotherapy or neurosurgery.

Initially it was hoped that teachers in Western Australian schools with such cancer survivors in their class were teaching students who were eleven years or older, who would normally be at the formal-operational stage of their cognitive development. For Piaget, the formal-operational stage is the pinnacle of logical thought. Peterson (2004) defines formal operations as follows:

> When fully mastered, formal operations enable the adolescent to think rationally, hypotheco-deductively and thoroughly. Genuinely qualitative cognitive development ceases, according to Piaget, with the attainment of formal operations. (p.59)

Selecting teacher participants with students at Year five or higher year level may have given a snapshot of executive functioning in the survivor students, as they would be involved in higher order thinking skills and problem solving tasks at school commensurate with their age; complex mathematical concepts, evaluative writing and analytical reading tasks, all completed within the limitation of time constraints.
However, it became evident that this criterion was too narrow because of the difficulty in locating participants of any age. Only one of the teacher participants was teaching a student of eleven years of age.

According to Buizer et al. (2006) not every paediatric or adolescent cancer survivor is at risk of demonstrating neurocognitive deficits. In selecting participants, it was critical to focus only on teachers who were teaching survivors of the typology the literature implies are most at risk; leukaemia and brain or head tumour survivors who have had central nervous system therapies during their treatment. These students had completed at least a term back in their classrooms after treatment and had been in remission for a year. By including these criteria, it was hoped that there would be less variation in their academic performance related to absenteeism because of illness or hospital treatment, which might result in missed work. It was hoped that the inclusion of the criterion for students to have been off treatment for a year would reduce the chance of a teacher participant becoming ineligible because their student had unfortunately relapsed.

To locate teacher participants, it was essential to seek them on the basis that they were teaching students in remission from cancer, who had been off treatment for a year, who had been at school for at least a term and who had endured central nervous system therapies during their treatment. This narrowed the potential participants down considerably as the criteria for inclusion were very specific. Using such specific purposive sampling created the likelihood of participants experiencing common challenges in their dealing with students in remission from cancer. Denzin & Lincoln (1994) describe here the reasons for using purposive sampling:

Many qualitative researchers employ purposive and not random sampling methods. They seek out groups, settings and individuals where the processes being studied are most likely to occur. (p.202)
Seeking such a specific group of participants created considerable challenge and difficulty. At one stage, ethical and gatekeeper problems threatened the viability of the entire project.

### 3.5 Locating participants

Initially it was hoped that research participant teachers could be located through the local Hospital Schools Services. However, despite the support of the principal and staff, finding records of school contacts for the student cohort described in the proposal was problematic because once the students are in remission, Hospital Schools Services has no reason to keep contact details for them. Educational support for oncology patients is only available whilst they are inpatients. Neurocognitive late effects may appear in paediatric or adolescent survivors at any point post-remission. (Armstrong & Horn, 1995)

Locating research participant teachers through the local children’s hospital database was also problematic. Once oncology outpatients are in remission and attending their own schools again, the hospital only retains contact details of their parents for the purpose of attendance at medical follow-up clinics and would not have records of the schools they attend. Only parents could be the gatekeepers to locating the teacher participants at the students’ local schools. The local hospital did not provide ethics clearance for this project as, without a parent consent letter available for issue to the parents, the teachers of children identified by the purposive sampling could not be contacted.

The Hospital Schools Services’ Principal suggested the Ronald McDonald Learning Program could be used for snowball sampling to locate participants, as parents of previous oncology patients may use their services to access remediation for their children, in the form of forty hours of free tutoring, available to any child or young
person who has endured life-threatening illness. The snowball sampling analogy is explained by Neuman (2000) thus:

Snowball sampling (also called network, chain referral, or reputational sampling) is a method for identifying and sampling (or selecting) the cases in a network. It is based on an analogy to a snowball, which begins small but becomes larger as it is rolled on wet snow and picks up additional snow. It begins with one or a few people or cases and spreads out on the basis of links to the original cases. (p.199)

The Ronald McDonald Learning Program National Coordinator and Head of Research agreed to assist in locating teacher participants through their state databases and a plan was formulated to communicate with schools via parents and disseminate the sealed information packs. (Appendix E) Participant Information Sheets (Appendix F) were forwarded to parents of students with the typology of previous central nervous system treatment for oncology. A letter from the Ronald McDonald Learning Program National Co-ordinator was also forwarded to parents to introduce the project and communicate the verification of ethical permission for it. Very careful attention needed to be paid to the distribution of letters to parents on this database, as some of the students may have passed away and the arrival of such a letter could cause distress to parents. If students had relapsed and were no longer in remission nor at school, their teachers became ineligible participants.

Along with these introductory letters, parents could then choose to forward Participant Consent Form letters (Appendix G), (conforming to; Department of Education Ethics Committee, University of Western Australia Ethics Committee and Ronald McDonald Learning Program Ethics Committee) to the principal of their child’s school who would, in turn, forward Participant Consent Form letters (Appendix H) to the potential teacher participants.
At the researcher’s own school, a graduate teacher had taught a student with the typology for the purposive sampling whilst on her Final Teaching Practice in the previous year at another school. Approval for participation was given by the principal and she agreed to participate. This teacher was a pilot participant, as the first interview was conducted with her, giving the researcher insights into the interview questions which might be especially valuable when interviewing other teacher participants.

Thirty packs were sent to parents via the Ronald McDonald Learning Program in Perth. Of these, two teacher participants replied by mail, returning their and their principals’ consent forms. Three months later, a reminder email was sent to the parents who had previously been sent information and consent form packages by the Ronald McDonald Learning Program Coordinator. It was hoped that a reminder may assist in recruitment, taking into consideration the fact that these families could be under significant stress, possibly dealing with children returning to school after illness whilst continuing (during maintenance) with schedules of hospital visits and treatments. Snowball sampling occurred when one of the participants contacted the researcher after her interview, indicating that a previous teacher of her student was also keen to be involved in the research project. This made four participants.

Completed Participant Consent Forms (Appendices G and H) were returned by teacher participants via stamped, self-addressed envelopes to the researcher. Teachers either returned the form with their telephone number attached or communicated via email. Country participants were interviewed via telephone and metropolitan participants were given the option of either attending telephone interviews or participating in a face-to-face interview, depending on their proximity to the university. As all teachers were currently teaching full-time, they elected to be interviewed in their Duties Other Than Teaching (DOTT) time at school.
3.6 Data collection

In accordance with the theoretical framework, two qualitative strategies for the collection of data were initially planned; semi-structured focus group interviews and individual, semi-structured interviews. (Punch, 2009) Due to the difficulties in finding teacher participants, the semi-structured focus group interviews were abandoned as it became apparent that only a very small group of participants could be found, only enough for a few individual interviews. Initially it was hoped that several focus groups could be assembled, with at least six teachers in each group. The location of participants was a factor for individual interviews as well, given that one participant was located in rural Western Australia. The ethical limitation that teacher participants could only be contacted after securing the permission of the students’ parents made the logistics of the project even more challenging. However, given the sensitive nature of the project, it was important to protect all participants – student, parent, teacher, principal and school from any potentially adverse consequences related to the research questions.

3.7 Individual, semi-structured interviews

The purpose of this method of data collection was to bring the broad issues of the phenomena into more detail. The teacher participant located in the researcher's own school was interviewed as a pilot participant for the first interview. As a newly graduated teacher, she was only a few months on from teaching a student who fitted the selection criteria and was keen to assist the research project. In the previous year, (her last year of study) she had taught the student, while she was on her Final Teaching Practice in another school. She had the support of the current principal and was an invaluable participant. Ethics approvals were not breached since confidentiality of the school and student was maintained because the teacher was no longer teaching the student but had done so very recently. Three other interviews were conducted with
teachers identified by The Ronald McDonald Learning Program, using the purposive sampling criteria. The interviews were structured to identify the key issues and strategies as perceived by the participants. The pilot participant was crucial in identifying the key issues that could be investigated further in the main round of interviews.

O’Donoghue (2007) explains the importance of focussing on the issues which are important for the participants, rather than focussing on the issues the researcher believes might be a problem and which; “he or she deems worthy of investigation.” (p.20)

A “Guiding question matrix” was utilised to identify the potential key issues. (Appendix D) The “Guiding question matrix” was designed to provide opportunity for the teacher participants to comment on broad areas of learning, to capture data about responses related to learning difficulties (if any) and to indicate the presence of Individual Education Plans, special strategies or assistance within the learning environments. Teachers were asked to identify the main issue they believed to be involved (if the student was facing any difficulty). The “Guiding question matrix” was sent to each teacher prior to the interviews to allow participants time to think about the focus of the questioning.

The interviews were audio recorded by mobile phone (with permission from participants) and then copied onto a hand held dictaphone. The sound quality of the mobile phone was excellent, but reviewing and re-listening as well as finding an exact point in the recording was difficult. Dictaphone emerged as the preferred tool during transcription. The audio recordings supplemented memory during data analysis, as; “they help a researcher recall events and observe what does not happen, or non-responses, which are easy to miss.” (Neuman, 2000, p.366) The interviews were transcribed verbatim and coding occurred during and after transcription. Already some open coding had occurred during the interviews, when the main issues for the
participants became apparent. Through memoing, whilst listening to participants’ answers, major themes or categories emerged.

Ethics limitations meant that setting foot on school sites was not possible, so face-to-face interviews at the participants’ schools were not possible either. One of the participants was in a rural school and the others were in areas which were a considerable distance from the metropolitan area, so it became evident that telephone interviews would be the most appropriate method of interview. All but one of the teachers preferred to be interviewed during their Duties Other Than Teaching (DOTT) time so telephone interviews became the only course of action. Unfortunately the only face-to-face interview was with the pilot participant and the value of this style of interview was evident, as the participant’s non-verbal responses pointed to the most important issues.

The semi-structured, individual interviews were between forty five minutes and one hour duration. Two of the teachers had both taught the same student, one in the prior twelve months, so these teachers were able to give a progressive snapshot of the student transitioning from one year level to the next through the earlier stages of remission. These interviews were especially valuable, as they offered unique insights into the research questions over a much greater time period and also revealed rich data about how two different teachers deal with the same challenges within their own teaching environment.

### 3.8 Documentary data

Another important means of gathering data is through an examination of documents and other records, and on-site observations. Donoghue (2007) explains how these methods; “rely on the interactional, adaptive, and judgemental abilities of the human inquirer. Also, they can lead to the production of a vast amount of data about a small number of
Initially it was hoped that documentary data might be sighted in order to gain information, especially about Individual Education Plans. Unfortunately, due to the confidentiality requirements of the Ethics approvals of this project for schools, staff, students and parents, sighting documentary data was not possible. Within the Western Australian Department of Education’s inclusion guidelines, an Individual Education Plan is a recommended document for a child with special needs or learning disability. When asked the question: “Have adjustments been made to learning programmes to accommodate learning difficulty?” teacher participants were asked whether they had formulated an Individual Education Plan to document strategies they had trialled or introduced to adapt the learning programme or make adjustments for the students. They were also asked whether they had sighted or been aware of any Individual Education Plan which had been formulated by previous teachers.

None of the participants referred to Individual Education Plans, although two of the participants chose to view summative formal reports which were at hand to them during the interviews and used them as a memory prompt to discuss their student’s strengths and weaknesses in the interview. Although this form of documentary data was not viewed, the discussion of the presence or absence of Individual Education Plans exposed how teachers accommodated students; how they have developed, sought or trialled new strategies; how or whether adjustments had been made to learning programmes and how teachers have or have not used other interventions or assistance from support staff or agencies. Discussing the existence and content of this type of documentary data assisted in exposing how teacher participants deal with or cope with students in their classrooms.
3.9 Qualitative data analysis

Conceptualisation or concept formation relating to the central research question began during the data collection. One of the categories which arose was parent communication and teacher access to critical information about the students’ ongoing medical treatments. Several of the self-constructed categories converged with the learning difficulties described in the literature review, such as fine motor integration and working memory issues.

Neuman (2000) explains the process of data analysis as follows:

A qualitative researcher analyses data by organizing it into categories on the basis of themes, concepts or similar features. He or she develops new concepts, formulates conceptual definitions, and examines the relationships among concepts. (p.420)

Grounded theory methods were used to analyse the data collected. This process comprised two stages of coding which are now examined in turn.

3.9.1 Open coding

Audio interview recordings were transcribed electronically and printed. Then open coding was used, with handwritten initials representing major themes placed into the hard copy of the transcripts. Later, these codes were inserted electronically into the transcript so that quotes could be arranged into themes for reference accessibility whilst writing the thesis. Some of the first themes to emerge which were given code initials were; absence (A), fine motor skills (FM), gross motor skills (GM), communication (C), health issues (H), literacy (L), reading (R), numeracy (N), bereavement (B), learning difficulties (LD) and support (S). Some examples of open coding used in the transcripts are as follows:
He’s actually quite a strong student and he doesn’t have trouble with any of those L/R – he’s really good but something that he does struggle with is that he’s quite lagging in gross GM and fine motor skills FM and I don’t know if that’s related to the treatment or not. H (Teacher A)

He would have had support S at the LDC but then he was, you know, pushed into mainstream as they are at year 3 and Mum fought to the death C… S? but there was nothing S….from local members and it made no sense to me whatsoever that this child, that, as a teacher, it was quite obvious, visually and you just had to hear him speak L, it was quite obvious that he had deficits LD as far as his learning and yet had no aide time. S (Teacher B)

Initially, open coding was used to “fracture” or “break open” (Punch, 2009, p.152) the data. The conceptual categories or substantive codes guided the direction of the data analysis and the generation of theory. Glaser & Strauss (1999) describe how the researcher begins by coding incidents into as many categories of analysis as possible, as they emerge or as new data emerge which fit an existing category. During this coding, the incident is compared with previous incidents in the same and different groups coded in the similar category. Glaser & Strauss (1999), in describing grounded theory methods of open coding, write: “This constant comparison of the incidents very soon starts to generate theoretical properties of the category.” (p.105)

Glaser & Strauss (1999) suggest that two types of categories and their properties will emerge; self-constructed and those abstracted from the language of the research situation. As the interviews were completed, self-constructed categories emerged. Categories such as bereavement and parent communication emerged as teachers discussed their concerns and thoughts. These were common to other participants so
Open coding allowed the category to be comparatively viewed. Neuman (2000) describes this process thus:

Open coding brings themes to the surface from deep inside the data. The themes are at a low level of abstraction and come from the researcher’s initial research question, concepts in the literature, terms used by members in the social setting, or new thoughts stimulated by immersion in the data. (p.422)

Significant categories of analysis which arose from the participants were; absenteeism, parent communication and contact, physical issues such as development, effects of medication on student performance and stamina, comparisons with peers in the classroom and issues around the teacher being prepared or informed in order to cater to the child’s educational needs as well as providing appropriate duty of care in an unusual and medically serious situation. Other categories which emerged were; diagnosis and illness and hospital treatment. The main issues for the participants were; absenteeism, decline in academic ability and the identification of various learning difficulties their students were struggling with, including; fine and gross motor skills, memory and recall (especially noticeable in retrieval of phonics and grammatical rules), problem solving and difficulty with writing.

Other important issues were; communication with parents, preparedness for teaching a student in remission from cancer and lastly, students still undergoing treatment regimes in hospital while resuming academic and social life with their peers at school. It was clear that the teacher participants were facing the confusion of having their own expectations for a student in their busy, mainstream classroom and recognising that allowances and concessions needed to be made because their student was not entirely well. The teachers were unsure as to the extent to which the student could or should be encouraged to achieve their best performance. Open coding exposed the fact that there were many more constructs to be considered apart from the teacher
participants dealing with their students’ abilities or disabilities, as described in the relevant literature.

### 3.9.2 Memoing

Contiguous with open coding, memoing was required to make connections between the ideas emerging through the data. Creative memoing was undertaken during one-to-one interviews. Neuman (2000) describes the messy stages of memoing as follows:

In the early stages, it happens through editing, segmenting and summarizing the data. In the middle stages, it happens through coding and memoing, and associated activities such as finding themes, clusters and patterns. In the later stages, it happens through conceptualizing and explaining, since developing abstract concepts is also a way of reducing the data. (p.424)

During the first participant interview, notes were taken whilst the participant answered questions. Important themes suddenly emerged. Memoing whilst listening assisted by noting important issues for the participants as they spoke. This enabled the researcher to invite the participant to expand on some statements to further explain their comments. An example of such messy memoing during the participant interview with Teacher A now follows:

<table>
<thead>
<tr>
<th>Issue</th>
<th>energy</th>
<th>wellness</th>
<th>energy</th>
</tr>
</thead>
<tbody>
<tr>
<td>Phys. Development</td>
<td>FM skills</td>
<td>writing going to be a problem</td>
<td></td>
</tr>
<tr>
<td>Drug related</td>
<td>“Don’t know anything about it”</td>
<td>chemicals can do that “stunted”</td>
<td></td>
</tr>
<tr>
<td>Pumped into</td>
<td>Not having treatment</td>
<td>once every 3 weeks/2 weeks?</td>
<td></td>
</tr>
<tr>
<td>BOY Keen to please</td>
<td>not enough detail/tires easily</td>
<td>HW</td>
<td>twice as long</td>
</tr>
<tr>
<td>PHYS. tiring</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Neuman (2000) explains how this stage of coding starts to match a researcher’s thoughts with the facts as exposed in the data thus:
The analytic memo forges a link between the concrete data or raw evidence and more abstract, theoretical thinking. It contains a researcher’s reflections on and thinking about the data and coding. (p.424)

3.9.3 Axial coding

Axial coding puts categories back together again, but in conceptually different ways. Punch (2009) describes how; “axial coding is about interrelating the substantive categories that open coding has developed.” (p.154) During one-to-one interviews, each occasion was tabulated when teacher participants expressed a positive or negative response to the observation of learning difficulties in their cancer survivor students using the “Guiding question matrix” table (Appendix D). Simple tabulation of the number and type of difficulties they have observed also provided valuable data. By labelling this data with codes, the most important constructs were identified: “Descriptive and topic codes focus on identifying and labelling what is in the data. Pattern and analytic codes go further, interpreting and/or interconnecting and/or conceptualizing data.” (Silverman, 2006, p. 300)

Silverman (2006) suggests repetition of ideas and themes by the different participants starts to add up and certain themes begin to outweigh others in terms of importance to them as such:

Simple counting techniques theoretically derived and ideally based on participants’ own categories, can offer a means to survey the whole corpus of data ordinarily lost in intensive, qualitative research. Instead of taking the researcher’s word for it, the reader has a chance to gain a sense of the flavour of the data as whole. In turn, researchers are able to test and to revise their generalizations, removing nagging doubts about the accuracy of their impressions about the data. (p.301)
O’Donoghue (2007) explains that concepts can be developed; self-constructed or from participants’ perspectives, and that a category is a “classification of concepts.” (p.85) Concepts become categories when concepts are compared to one another and relate to similar phenomenon. O’Donoghue (2007) elaborates as follows:

The concept then which is developed is a higher order, more abstract concept, called a category. A category can, in turn, be developed into its ‘properties’ and its ‘dimensions’. The properties of a category are its characteristics or attributes. (p.86)

Once categories are established, new data can be compared to existing data. O’Donoghue (2007) explains how categories enable generalisations to be made, namely:

With such categories at one’s disposal one is armed with a framework by which one can speak about phenomena in ways hitherto not possible and one can locate specific instances of a phenomenon somewhere within the framework.” (p86)

The researcher; “moves toward organising ideas or themes and identifies the axis of key concepts in analysis. During axial coding, a researcher asks about causes and consequences, conditions and interactions, strategies and processes, and looks for categories or concepts that cluster together.” (Neuman, 2000, p.423) Clusters of concepts started to build during axial coding. These became the major categories or themes.

The major concept clusters were related to; teacher preparedness, absenteeism of the students, communication issues, learning difficulties or disabilities and support from school or other agencies. Other concept clusters appeared within these categories, for example, in learning difficulties or disabilities, many other clusters emerged in the data analysis. These were related to different learning areas such as literacy, numeracy, fine and gross motor skills, organisation, attention, working memory and recall. Within the
concept cluster communication issues, there were concept clusters related to; parent-to-teacher communication, staff-to-teacher communication, as well as types of communication used by participants (face-to-face, phone and electronic). Some of the data are displayed in table form, such as in the “Guiding question matrix” (Appendix D), bearing in mind that this is a qualitative and not a quantitative study.

3.10 Ethical issues and confidentiality

Three major ethics considerations needed to be taken into account in this study; the purpose of the research, the individuals or groups who may be interested in the research and the effect of the research findings on the parties involved. Silverman (2006) advises researchers to carefully consider; “the implications for these parties of framing your research topic in the way you have done.” (p.327) Teacher participants were the focus for this study as the research concentrates on how teachers deal with student needs in their mainstream classes rather than the capabilities the students bring to their learning. Neurocognitive and psychometric testing was not relevant here.

The issue of teachers observing their students and noticing a previously overlooked and unknown learning disability in their observations was a highly sensitive one. For this reason, confidentiality was crucial and students, teachers, parents and administrators were assured through the Participant Information letters that their responses to the research questions were and will continue to remain strictly confidential. The Government of Western Australia Department of Education’s Ethics Committee, from the outset of the ethics application, requested that teacher participants were to be made aware of the psychology resources available through their psychology services agency, as they suggested teacher participants could become “overwhelmed” during individual interview sessions. However, this did not occur.
In this sensitive situation, code names were devised for the participants and students, as students, teachers and schools would certainly not be named. Real names were recorded for reference purposes but not divulged in the data analysis. Students’, teachers’, principals’ and schools’ anonymity was protected by the use of code names. Consent or permission forms were signed to ensure that participants were aware that the results of the research may be made public and discussed in the public arena. However, all participants were assured that names or identities of participants would not be divulged in the thesis or in any ensuing publication. Extreme sensitivity and confidentiality was required when discussing students’ performance as reported by their teachers. Sensitivity and professionalism were essential when describing the results of the research. Teachers and schools required protection from exposure of identity, as negative consequences could have resulted if their perceptions or opinions differed from the beliefs of other teachers, parents, school psychologists or administration in their teaching environments.

The literature review provided the background information which alerted the researcher to the possibility of neurocognitive late effects in the participant teachers’ students. It also highlighted the fact that there is very little literature describing how teachers deal with paediatric cancer survivors returning to their classrooms after remission. Therefore, it was important, in this study which used the symbolic interactionism approach within the paradigm of interpretivism, that the teacher participants were able to give their own, honest accounts without being influenced by the issues the researcher believed to be the most important. The trustworthiness of the study corresponds with the ethical considerations in this matter.
3.11 Trustworthiness of study

The literature review undertaken prior to and during this project provided solid evidence for the existence of neurocognitive late effects in children or young people who have survived central nervous system therapies in cancer treatments. It gave insights into the type of learning difficulty or disability students with this typology might experience. Various studies on the topic strongly concurred in their identification of specific neurocognitive impairments; working memory and attention problems, fine motor difficulty, and working under time constraint. Initially, the guiding question matrix centred around these difficulties or disabilities, but focussing only on these problems would have given bias to the interviews as the participants raised other issues regarding how they coped with the students resuming school life in their classrooms and the study focus was centred around how these teacher participants coped with their students, not whether or not their students experienced learning difficulties, identified or not.

None of the teacher participants were aware that their students could have neurocognitive late effects as a result of their central nervous system cancer treatments. It was essential that their responses were not pre-empted or influenced in any way, ensuring objectivity was maintained and bias was limited. The truthfulness of the study would be compromised if the teacher participants were biased by the information that their students fulfilled the criteria defining the group of paediatric survivors most likely to experience neurocognitive late effects from their cancer treatments. Neuman (2000) states: “Qualitative researchers are more interested in authenticity than validity.” (p. 172) Neuman (2000) describes authenticity in qualitative research thus:

Authentication means giving a fair, honest, and balanced account of social life from the viewpoint of someone who lives it everyday. Qualitative researchers are less concerned with trying to match an abstract concept to empirical data and more concerned with giving a candid portrayal of social life that is true to the
experiences of people being studied. Most qualitative researchers concentrate on ways to capture an inside view and provide a detailed account of how those being studied feel about and understand events. (p.171)

Using data collected in this research through one-to-one interviews and comparing the data through the conceptual categories, the data were triangulated and provided rich insights into the empirical research questions. Taking one’s findings back to the subjects being studied also enhanced the study’s trustworthiness. Silverman (2006) describes how participants can validate research findings thus: “Where these people verify one’s findings, it is argued, one can be more confident of their validity. This method is known as respondent validation.” (p.291)

Once the data were collated and a draft of the research findings was complete, respondent validation or internal validity (O’Donoghue, 2007) was sought by sharing the five major conceptual categories with the participants. Participants were given the opportunity to comment on the research findings by email or phone. They received by email a description of the five conceptual categories and were invited to comment but none of the participants made comment so it can be assumed that they were satisfied that the findings were valid and accurate. Conclusions were drawn after checking the validity and trustworthiness of the data with informant participants. The results of the research will be shared with The Government of Western Australia Department of Education, as this was a condition of their Ethics approval. A copy of the results of the research will be shared with all principals and teachers upon request.

3.12 Summary

This chapter has described the theoretical approach taken in this study, which was symbolic interactionism within the paradigm of interpretivism. It has described the pre-empirical question which was: How do teachers deal with paediatric cancer survivors
returning to their classrooms after remission? It has explained the guiding questions, which were: What are teacher perspectives of learning difficulties in children who return to school after remission? What strategies or adjustments are being used by teachers in response to perceived learning difficulties in students after remission? What do teachers perceive as the main issues when dealing with children who return to school after remission?

Purposive sampling was undertaken to find participants who were teaching paediatric cancer survivors returning to their classrooms after remission in Western Australian government and independent schools. Finding participants was challenging because of ethical limitations, but a small group (all except one) was eventually located through the Ronald McDonald Learning Program, as cancer survivors’ parents had already accessed educational support from this agency.

Individual, semi-structured interviews were undertaken with the participants and the interviews were transcribed verbatim. After this, the qualitative data analysis began, firstly using creative memoing and then open coding. Axial coding began to interconnect clusters of concepts. Major categories or themes emerged, which were the most important issues for the participants. Many other clusters of concepts appeared in the data, but the five themes which were the most significant to the participants were; teacher preparedness, absenteeism of the students, communication issues, learning difficulties or disability and support from school or other agencies. The trustworthiness of the study was sought by describing the five major themes to the teacher participants and inviting comment from them.

The following chapter Description of Findings outlines the five major categories or themes which emerged from data analysis. The first category, preparedness for teaching the students relates to the way teachers felt prepared to teach students who are cancer survivors returning to their classrooms after remission. The second category,
absenteeism of the students, involved the difficulties caused by frequent student absence due to ill health or hospital treatment and appointments when the students were in remission. The third category, communication issues, involved difficulties associated with communication between teachers and their students’ parents. The fourth category, learning difficulties or disability, was developed after teachers discussed various learning challenges students were facing at school and the fifth category, support from school or other agencies, took into consideration either the provision or lack of support for students facing educational challenges. These categories were interrelated and each influenced the others.
CHAPTER 4

DESCRIPTION OF FINDINGS

4.1 Introduction

After a difficult and lengthy search for a way to reach participants in schools, without a ‘gatekeeper’ parent letter, four teachers were located and contacted as participants to be interviewed about their perspectives of teaching a student who was in remission from cancer after enduring central nervous system therapies during treatment. These students were either brain tumour or leukaemia survivors. Their treatment had involved radiotherapy and/or intrathecal chemotherapy as a preventative against cancer cells lingering in the brain or spinal cord. The students were now in remission and attending school regularly again. Some were still attending fortnightly outpatient clinics and were also receiving maintenance therapies (usually oral medications taken regularly at home). Hospital visits entailed regular blood tests and physical check-ups.

After coding had been completed, five major themes emerged from the data and became the five major constructs discussed in the findings. These themes are; preparedness for teaching the students, absenteeism of the students, communication issues, learning difficulties or disability and support from school or other agencies.

The first construct, preparedness for teaching the students, was the extent to which each teacher felt they had been prepared to deal with the needs of their student, in the light of the gruelling treatments they had previously experienced and, to a much lesser extent, which some students were still enduring.

The second construct was absenteeism of the students – its causes, its difficulties and how it affected the student and the teacher. The third construct was communication issues – between teacher and parents, between teacher and school regarding the student’s needs, communication about medical history or ongoing treatments and
communication between the teacher and other agencies which might offer insights into the students’ special needs, on returning to mainstream education after remission. The fourth construct was learning difficulties or disability, which all students were experiencing, to a greater or lesser extent and the fifth construct was the support from school or other agencies or sources for any learning difficulties or special needs these students might have.

All four teachers were highly empathetic towards their students and had made careful observations of them, all being aware that the therapies the students had experienced and were now, in some cases, continuing to endure, may have an impact on their academic participation and success, however they were unsure as to what this impact may be as they had been given little information about the students’ diagnosis or ongoing health or education issues, even being unsure as to what their students were taking time off school to do at their hospital appointments. All of the teachers had noticed what they had perceived to be indicators of academic struggle, with one teacher in particular being concerned that the student was facing major academic challenges with obvious, disastrously negative consequences for their learning. This was the student who had endured a brain tumour and had undergone ensuing radiotherapy. Only this student was considered a student at educational risk (SAER) student, but even this student had not been placed on an Individual Education Plan.

All teachers were concerned about the implications of cancer therapies for their students’ physical development but were at a loss to understand how to assist the students, as there had been no liaison from outside agencies to update them about their students’ ongoing or past medical histories, nor the problems they might be facing in the classroom. None of the teachers had received any type of formal case conference, re-entry interview documentation nor information, nor history to be able to ascertain the learning needs of their students in regard to their physical or academic issues, nor their
ongoing medical situation. None of them had a previous or current Individual Education Plan as a reference point for future accommodations or adjustments.

All of the teachers were keenly aware of the desire of the student families to regain normalcy for the student within their school environments among their peers and it became evident that two of the teachers were determined their students were working at a peer appropriate level, although when questioned about areas such as problem solving, writing and fine motor skills, they identified difficulties. All of the teachers were keen to identify positive elements of their students’ participation in normal, mainstream classroom life. The students’ parents were providing minimal information about their child’s cancer history and treatments and the difficult, ongoing, physical treatments and stressors during their remission phase, because their children were adjusting to normalcy, resuming life at school with their friends.

Of significant importance is the existence of Dysgraphia, identified in all of the participants’ students. Fine motor issues, such as writing difficulty, may be being confused as being motor-related limitations, due to tiredness caused by treatment or medication; however, they are more likely to be caused by central nervous system dysfunction, resulting in Dysgraphia. The existence of Dysgraphia and its relationship to working memory in the participants’ group of students may hold the key to further understandings identifying the source of cancer survivors’ learning difficulty and the way forward addressing this difficulty in the classroom.

4.2 Educational settings of the four participants

The first teacher, Teacher A in a country government school some hours from the metropolitan area, was interviewed by phone during her Duties Other Than Teaching (DOTT) time. Her participation form and that of her principal was posted immediately upon receiving the information letter and was received by me in the same week it was
sent. At first, the teacher described her male, eight year old student in Year three as a “strong student”. The student was in remission from leukaemia. Teacher A’s student was still receiving maintenance treatment in a country hospital and had been in treatment for several years. The student was regularly absent attending appointments at the larger regional hospital in another town.

The second teacher, Teacher B, was teaching the student with the typology selected during her Final Teaching Practice as a pre-service teacher. Her student was eight years old, in Year three at a metropolitan primary school and had endured a brain tumour in his early childhood at the age of two. When in remission, he had attended a local Language Development Centre in Pre-primary and Years one and two. Year three was his first experience in a mainstream classroom. Several of his classmates had attended the same local Language Development Centre for other issues. Once in remission after treatment for the tumour, he had attended the LDC.

The third teacher, Teacher C was in a private metropolitan primary school which was double-stream, with two classrooms of each year level. Teacher C’s class of twenty six Year five students was one of the largest classes in the school. The student in her class was eleven years old, was in remission after enduring leukaemia and her diagnosis of leukaemia had come at very young age. Teacher C remembered the student returning to school sporadically at some point during Year three and she was aware that the student had been seriously ill at that time during early remission, visibly unwell and with no hair. The student’s frequent absenteeism now in Year five was caused by headaches, tiredness and illness, attending many appointments at the children’s hospital as well as participating in camp opportunities specifically planned for such survivors and run by a charity.

The fourth teacher, Teacher D had been “snowball sampled” by Teacher C at the same school. She had also taught Teacher C’s student in Year three. The student had
undergone intensive chemotherapy in Year two and then commenced maintenance therapy when in remission, gradually returning to school that year in Year three.

The following section of the thesis outlines the five major themes in more detail and gives examples of each of them in the participants’ own voices. As the interviews were transcribed verbatim, the teachers voice their own perspectives, thoughts, feelings and beliefs.

Although the teachers were in different school settings – rural and metropolitan, government and independent schools, common elements emerged and were interrelated. The five themes; teacher preparedness, absenteeism of the students, communication issues, learning difficulties or disability and support from school or other agencies are now reported in detail.

4.3 Theme 1

Teacher preparedness

There are many areas in which a teacher needs to be prepared to teach a CNS cancer survivor returning to the classroom after remission. Unfortunately the four teacher participants in this study did not feel well-prepared to teach students who had survived CNS cancer, who were now in remission and had returned to their classrooms.

All Western Australian teachers are encouraged to use the Australian Institute for Teaching and School Leadership (AITSL’s) Reflection on Practice Tool and 360 Reflections Tool to reflect upon their own teaching and how it fits into the AITSL’s Australian professional standards for teachers. There is even a free My Standards app so teachers can reflect on their own performance on the go. AITSL, the Australian Institute for Teaching and School Leadership (2014) describes its mission as follows: “To promote excellence so that teachers and school leaders have the maximum impact on student learning in all Australian schools.” (para 7) AITSL has three areas of focus;
for initial teacher education, school leadership and teaching. The focus for teaching is defined as such:

Assisting Australia’s teachers to increase their impact on student learning is a large scale exercise. Teachers must be supported to implement practices that have been shown to improve teaching: evaluating their impact, seeking feedback about their practices, working together, and engaging in effective professional learning. (para 7)

In AITSL’s *Statement of intent*, the organisation describes its “ways of working” (para 2) which include; developing national policies, “high quality tools and resources to support improvement in teaching and school leadership” (para 3), planning, commissioning and conducting research and creating partnerships with schools, universities, “systems, sectors and other organisations” (para 4) “to create a scalable impact.” (para 4)

In AITSL’s *Australian professional standards for teachers*, the professional knowledge domain 1.5 which is; “Differentiate teaching to meet the specific learning needs of students across the full range of abilities” (para 17) describes the performance criteria for a graduate teacher: “Demonstrate knowledge and understanding of strategies for differentiating teaching to meet the specific learning needs of students across the full range of abilities.” (para 17) For the professional knowledge domain 1.6; “Strategies to support full participation of students with disability” (para 21), the criteria for a graduate are described as follows:

“Demonstrate broad knowledge and understanding of legislative requirements and teaching strategies that support participation and learning of students with disability.” (para 21)

In AITSL’s *Australian professional standards for teachers* reflection tool, every one of the seven standards relating to professional knowledge, professional practice and
professional engagement, would represent a stumbling block to a teacher who was teaching a CNS cancer survivor, now in remission and back in the classroom. For example, standard 6 recommends teachers engage in professional learning. The teacher participants in this study may ask themselves what kind of professional learning would offer insights into neurocognitive deficits in CNS cancer survivors. They may also ask where or how could that professional learning be accessed. In standard 1, teachers are instructed to know students and how they learn. Teachers with CNS cancer survivors in their class may be struggling to understand the learning problems faced by their survivor students. Teacher preparedness was a major theme for the teachers in this study. Their perspectives on this theme are now described.

Teacher A was a graduate teacher in a rural school and she was aware her student had a leukaemia diagnosis, was now in remission and was still visiting the local country hospital. She was not sure what the visits involved or how they were affecting him. The student had not been on an IEP before so she had not seen any documentary data about his progress during his return to school in Year one. Regarding his current medical situation she said:

He’s actually still receiving treatment - he only goes to the regional hospital. I think he’s been in treatment for a couple of years. (Teacher A)

Teacher A was unsure about the side effects of her student’s treatment but she suspected chemotherapy was the reason her student was demonstrating fine motor difficulty and on this she said:

I mean I don’t know anything about it really but when I see the history and when I see his fine motor development, over two years… in my mind chemicals can do that and maybe that’s affected his physical development or stunted him in some way or is inhibiting him in some way. I don’t know if that’s related to what’s been pumped into his body to fight his leukaemia. (Teacher A)
Teacher B believed the small group of students, of which her student was a member, (who had come into the school at the same time, in Year three, from a local Learning Development Centre) had been on Individual Education Plans at the Language Development Centre but she hadn’t seen these, nor any current IEP. She believed the classroom teacher was distressed as there was no support to deliver best practice for the student. When questioned about prior information available to her and the classroom teacher about the student, she responded thus:

The child had had a brain tumour at age two. He had gone to LDC after remission and had come to primary school at Year three - in that year. His classroom teacher was almost at her wits end because here’s this poor little fella with no help, no nothing, she hadn’t got any extra support in how to…you know, deliver best practice for him. There was nothing for her and so she just had to wing it. (Teacher B)

The opportunity to teach the student in an intensive support situation presented itself with the addition of Teacher B taking up responsibility for the class and writing a Group Education Plan into her programme of work for the term for the students who had been at the LDC. The classroom teacher was “released” from teaching the whole class, to provide support in the small group situation to these students at educational risk, while teacher B taught the class. Teacher B felt that there were emotional issues involved for the student but was unsure whether these were related to his cognitive abilities or behavioural issues. When asked what the main issue for this student appeared to be, she answered:

Without knowing exactly because I think there’s an issue with working memory and I think that’s the major issue. I think learned behaviour comes into it because he did get very….he was very stubborn and even when he seemed
capable of doing something he would shut down. He had emotional issues, which is understandable. (Teacher B)

Teacher C’s student was in Year five and had returned to the school sometime during Year three. This student was still attending appointments but the teacher was unsure what they were for. When asked about the prior information she had been given about the student’s medical progress, she answered:

She’s still having…I don’t think she has chemo any more but she has a lot of time off to go to…appointments. I’ve just got an email from the Mum to say she’s not going to be there Monday, she’s not going to be there Friday - she’s got to go to appointments. She’s in remission from what I understand of it. I don’t really know anything about… it’s been a long time and they don’t really talk about it. I just know she must have been quite young because she’s ten or eleven now and she was away from school a lot. When I came to the school she was in Year three and she’d just come back from taking quite a lot of time off - it’s sort of like - nobody talks about it and I don’t have any paperwork on it so I don’t know. She had leukaemia. That’s all I know. (Teacher C)

Teacher C believed the important thing for her student was a sense of stability after treatment, now getting on with her life, eager to put her experience behind her and developing confidence again with her peers within a normal classroom setting. Teacher C felt that making life as normal as possible for the student was important, as was her overall social development, as a student at Year five wants to fit in socially and not be different. There had been no support from any agency to explain or assist her and the teacher felt “out of the loop”. In response to being asked whether she had received any information about the student’s medical situation and current status, she said:

No one. Nothing. Nup. Nothing. Absolutely nothing. Nup. For me, not hearing anything from the parent or not being told anything, I only know she had
leukaemia and she’s in remission. That’s all I know. So as far as I’m concerned she must be on the road to recovery and it’s all good. (Teacher C)

Teacher D recalled that this student reintegrated into school life quickly in Year three and she was not aware of any social issues affecting the student. However, the health and well-being of the student was a serious concern for the teacher, along with anxiety about providing adequate duty of care for a student with such a fragile medical condition. When asked about the prior information or knowledge she had received about the student, she replied:

I did wonder about her physical well-being – she was taking some high levels of steroids so her bones were a bit compromised. I used to worry about her, you know, hurting herself at school. Mum always kept me informed about… I was worried about playground incidents, if she got pushed or whatever. By Year four she was in remission but when she was in Year three she had the tube in her nose and there were A LOT more concerns but by Year four her condition had improved greatly so there were not so many concerns. It just took a bit of extra vigilance to make sure everything was OK. (Teacher D)

The main sources of information for Teacher D were the staff at school and the student’s mother. The student’s mother had, on one occasion, informally explained emotional factors affecting the student to the teacher, which she described as follows:

To me, she (the student) always held it together really well at school. Mum informed me about how the trauma had impacted her psychological state but if Mum hadn’t told me I would have known nothing. You could say she (the student) was extremely compensating. She was not overly emotional, no crying episodes or anything. She was very stoical. (Teacher D)

Teacher D, having taught the student two years previously, was able to evaluate the level of communication she had experienced and said that if there was one thing which
would have made a difference to her ability to cope with this student it would have been receiving more information. She reflected here on the ways information could have been provided:

You need to be well informed. It was much more difficult for her teachers when she was first diagnosed. For young children, it's hard for them to explain what’s going on with them. You need different types of information at different stages so you have some knowledge base to build on. There needs to be lots of meetings and information exchanges to begin with. You become more confident with the situation as time goes on.

(Teacher D)

Teacher D had had a close association with the family prior to the diagnosis and felt emotional about seeing one of her students suffering. She expressed her personal grief and her own spiritual beliefs when describing the way she had dealt with the student’s return to school life in her classroom:

She’s a lovely soul, beautiful. It was a privilege to be entrusted with her care. It must have been really difficult for Mum to leave her at school. No one wants to see anyone so sick, especially a child, when you’re a parent yourself. When you see them so thin, her poor little face so bloated. It’s so regretful, she is a lovely person and her spirit really did shine through. (Teacher D)

All of the teacher participants had experienced a lack of information about their student’s medical situation, the impacts (if any) of their treatments on their academic progress and they felt unprepared to deal with the student returning to their classroom.

The second theme, absenteeism of the students, described in the following section, was a problem for three of the teacher participants, as their students were still attending hospital regularly as outpatients and were still on maintenance therapies. They were still being monitored closely for signs of relapse. The other teacher participant, Teacher B’s
student had finished treatment years ago and was no longer involved with outpatient treatments. Her student had suffered the most severe central nervous system therapy, and was at a very high risk of neurocognitive late effects, as described in the literature. He was a brain tumour survivor who had endured radiotherapy treatment to his head. The other three teachers were teaching survivors who were in remission from leukaemia and who had been given central nervous system intrathecal treatments.

4.4 Theme 2

Absenteeism of the students

Absenteeism of the students concerned three of the teacher participants as their students were involved with the lengthy monitoring process in the “off therapy” (Butler & Mulhern, 2005, p.66) phase of their cancer treatment. Teacher A’s, C’s and D’s students were receiving maintenance therapy as they were in remission from leukaemia. Teacher B’s student was a brain tumour survivor who had completed treatment and gone into remission some years previously and his schooling was not interrupted by any treatment apart from annual check-up visits.

Teacher A’s student was absent once every two weeks to attend hospital appointments and apart from this, was not absent very often. Lethargy when the student was not feeling well was a problem, but even in these conditions, Teacher A had noticed the student could still produce correct work, was organised and understood new concepts. She had noted on the student’s report that he copes very well with frequent absences. Here, Teacher A described her student’s absences:

It’s once every three weeks or once every two weeks. He was away yesterday because he was not well but that doesn’t happen very often and often he’s straight back after treatment the next day. I think he copes really well with the absenteeism. Yes he picks things up easily. He was away yesterday, he came in
today and we’d been doing division. I mean I check them all anyway but he
doesn’t need anything more than the other kids need. He can get a bit on the
wrong track and I’ll show him and he’ll go “OK” and just get on with it. He’s
pretty good. I’ve got no concerns with him academically at all. (Teacher A)

Teacher A explained the difficulty in differentiating between treatment exhaustion or
other issues related to physical growth and development, but she insisted that these
absences were not affecting his progress:

His focus and attention are quite good. I mean he does have a few days when
he’s lethargic or tired but it’s not an issue, it’s not all the time and it’s certainly
not of concern. (Teacher A)

Teacher B was concerned that illness was still a factor for the student, despite not
currently being on any treatment and being many years beyond diagnosis, as she
remembered an incident where the student left the classroom to vomit and at times,
appeared to “blank out” with a vacant stare. However, she only remembered one
incident where the student had left the school afterwards and was absent for the rest of
the day. She recalled the concerning incident thus:

One day he looked at me and he looked really flushed and I said to him “Pop
outside and get yourself a sip of water” and he took three steps out of the
classroom and just vomited everywhere and that was it…he just completely
froze…and it wasn’t …he was gone…that was it….there was nothing….I don’t
know what happened and Mum has questioned whether or not there’s been some
epilepsy…the way he completely blanked out and of course we rang Mum
straight away she came and got him. I don’t know what the end result was. I’ve
never seen that sort of “nothing”. It was absolutely embarrassing for him.
(Teacher B)
The student at times seemed to be exhausted by school and Teacher B recalled many instances when her mentor teacher called his parents to come and pick up the student at lunchtime as he felt too tired to continue the day at school.

Teacher C’s main challenge was the frequent absence of the student, who was “missing a great deal of school” (Teacher C). There were also absences related to camps, involving breaks of a week or more at a time. Occasionally, the student was only at school for one day in the week and this was not unusual. The student’s compromised immunity meant there was a greater risk of catching viruses or chicken pox, especially during the Winter months, also contributing to her absenteeism. Teacher C described the challenge to her student’s immunity during Winter in the following way:

She seems to, of late, have taken a lot of time off. Whether that’s Winter and there are colds and stuff going around. There’s chicken pox going around.
We’ve had a few things going around so she can’t be in contact with them and so she’ll go home. (Teacher C)

Other reasons for absence included being involved in special camps and other activities provided by a charity, designed specifically for paediatric cancer patients like Teacher C’s student. In the comment below, Teacher C described her ambivalence about her student being away from school to attend them:

She misses a lot of school, like in the last week of school she went to Broome for a week and then a couple of weeks later she went to this cancer camp thing. She goes to a lot of those things and she goes to a lot of appointments and also if there’s any chance of kids getting flus and colds, like last week she was probably at school one day and over the last… well I haven’t seen much of her, let’s put it that way, like the end of the term and this week I haven’t seen her much in the last six weeks so I don’t know how she is now academically, because she’s missed a whole lot of stuff but then you’ll find that she, the kids
help her, like they’ll give her the information or they’ll say… I don’t know, she seems to pick it up. Whether she does it at home or whether she’s got a tutor I don’t know. (Teacher C)

As there was little communication from the parents about the student’s health condition, the teacher could only make assumptions about the absences. Fatigue seemed to be an issue for the student on a daily basis and parents often notified Teacher C about the student’s tiredness, requiring rest at home. As well as this, the student needed numerous breaks throughout the school day – extra drink breaks and toilet breaks, especially through the afternoon teaching programme. Teacher C expressed her frustration about the frequent absences in the following way:

She does a lot of blood tests and I don’t know if they’re paranoid or whatever but I check the emails then, like every week I’ll get an email lately saying that OK, Monday she won’t be there, she’s got a different blood test in the morning and then she won’t be there because she has to go to this other check-up for this blood test so I don’t know. I mean like last week, Mum said she’s not going to be able to go to school because she’s got a headache, she’s tired, so she can come, but she’s got to go to this appointment so I’ll bring her, so last week she was there a day and a half. So I don’t know what it is. (Teacher C)

Camp opportunities offered by the charity were recognised by the teacher as being a valuable experience for her student, yet, when she was already worried about the student’s absences, these further absences gave her even more cause for concern. Her student had just spent two weeks at camp but here she explains her reasons for supporting the absence:

The mother had asked me, she’d said that when she went to that camp thing or whatever they do in Broome would she be missing out from school? and I said, “Well no, because that’s something she could look forward to and it’s a fantastic
Teacher C’s student, being older and more independent, was able to access some of the teaching programme through wireless internet opportunities, using her ipad. She explained how the student tried to keep up with the class, despite her absences:

They try to keep up with everything - she doesn’t want to be different in Year five. They don’t want to be different and if we’ve had stuff on and she’s not up to being at school she’ll come for as much as she can. Like we’re doing these talks, so she came in to give the talk and then she went home. So whatever we’re doing, she manages and she doesn’t miss out. They plan it so that if she’s not 100% then they’ll plan it so that she can come in and do her stuff and then go.

(Teacher C)

The class was involved with a lot of “project type” (Teacher C) work, using technology and enterprise and enquiry learning, especially Webquests. The school was using the Ed Canvas programme in history and the student was able to follow this using the ipad, whether she was at hospital appointments or travelling in the car. The school is committed to a strong ICT policy and has a generous allocation of time for students to access devices in class. There were one-to-one laptops for each child in the class, enabling the use of mind maps, brainstorming, Webquests and collaborative tasks to be done electronically and via wireless connectivity. The student could access this type of work on her home ipad or laptop, enabling her to still participate in collaborative tasks even when not at school. Programmes of work were explained to the student and she
would complete tasks independently, either at home or during the days when she was absent but feeling well. Her participation in drama presentations which were related to Webquest challenges with her classmates had increased the student’s confidence during the year and she had made many friends during group work and collaborative projects.

On this, Teacher C made the following comment:

I’ll send stuff home for her to do and as I said, a lot of our stuff is ongoing; we’re making catapults, so she can do that at home and then it’s just reporting on that and a lot on inquiry learning. So a lot of it is on the computer, like Web-quests and we’re doing Edcanvas on the Swan River Colony so you can do that anywhere on a device, laptop or ipad or whatever, where they have to input information. We use a lot of technology. So with that, I’m sure if she’s waiting for appointments from what I understand of it, she can do a lot of stuff like that. The mum will email me if she needs help with something she doesn’t understand or whatever. (Teacher C)

Teacher D remembered that her student had missed a great deal of school in Year three; however she felt that it was more important at that stage of her recovery, to fit in with her cohort group and maintain her social network at school. The following comment is indicative:

Instinct tells me she was away a lot, she was absent a good 25% to a third of the time and there were obvious things that she’d miss out on but the advantage was that she’d been at the school since kindy so when it was explained to the cohort group that she was unwell, they were very accepting and supporting of her and she was able to slip back into her friendship group easily. She was absent most Tuesdays with a regular sort of hospital appointment. She’d be away for the morning and then come in the afternoon, away for a day a week. If she had a cold or virus she’d have a few days off. (Teacher D)
Teacher D admired the student and her family for their commitment to school during her treatment and into remission and said: “I found her to be quite an exceptional student. Mum wanted her to be at school whenever she was not at appointments.”

(Teacher D) Teacher D believed the student’s difficulty in Literacy in Year three was due to the periods of absence she had had in Year two, especially with phonics and basic facts in Maths. She explained this as such:

She’d missed a lot of school at quite a critical time. She had so much absence when she was first diagnosed and missed a lot of that important foundation learning. Some gaps are hard to bridge. Some days it was hard to do any learning. (Teacher D)

Absenteeism was certainly a major factor for the teacher participants whose students were still regularly visiting the hospital as outpatients in remission. The participant teaching the oldest student could see that the social opportunities offered by a charity for survivors of paediatric cancer were extremely beneficial for her student and therefore she acquiesced to her student’s participation. Immunity challenges such as chicken pox or virus outbreaks at school created nervous tension for the teachers and the families of the students. Fatigue due to treatments and also due to the students trying to cope with school life was also a factor which teachers had to consider.

The next theme deals with Communication issues, which were intrinsically connected to absenteeism of the students. This section mostly deals with teacher-parent communication. The ways parents and teachers communicated or did not communicate with each other; the topics of communication and the need for more communication were all areas in which teachers were facing challenges.
4.5 Theme 3

Communication issues

The third theme that was identified was communication issues; how teachers communicated with parents, with other teachers or school staff, or with other agencies. All kinds of communication were explored, with participants reporting email, telephone and face to face communication. Communication subjects, as reported, gave insight into the issues with which teacher participants were dealing.

The Leukemia and Lymphoma Society of Canada. (n.d.). provides a helpful web page entitled; School, which explains the necessity for good communication between school administrators, teachers and parents, as follows:

Take these steps to ensure that your child gets the support he or she needs at school: Meet with school administrators, teachers and counselors before your child returns to school. Make sure the staff is aware of your child's medical condition, and address any special needs or concerns with them. Let your child meet with his or her teacher(s) before returning to school to reduce anxiety. Ask school staff to promptly identify any issues that arise and provide you with relevant information. Ask your child's doctor to write a letter outlining your child's physical limitations or medical needs, such as the need for extra snacks, water or bathroom breaks. (para 5)

The Leukemia and Lymphoma Society of Canada. (n.d.). also recommends careful discussion (preferably involving a hospital team member) with the student’s classmates to help alleviate fear and reduce negative reactions, which may result in teasing. This strategy is described as follows:

An age-appropriate class presentation, either before or after your child returns to school, can let school friends and classmates know that it's okay to discuss the
illness. If your child has undergone physical changes, such as hair loss, weight gain or scars, it can help to include this topic in the talk. Your child can participate in a way that makes him or her comfortable. (para 4)

Teacher A had limited communication with the student’s parents and felt the parents were extremely “private” about the student’s illness, as they were still involved in treatment schedules. Here, she reiterates the lack of information available to her:

I’m actually not sure about him…I mean he doesn’t talk about it and Mum is quite a private person so I haven’t really been given information. I know that he’s still receiving treatment and I don’t know if that’s an issue or not, I don’t know that much about it and there’s not much about it on file. Mum’s quite private. She’s so quiet. (Teacher A)

Teacher A had had a conversation with her student’s mother regarding his fine motor difficulties and the possibility of the children’s hospital providing occupational therapy for him. Despite seeing his mother frequently, Teacher A had not interrogated her about professional referral as she felt that the mother may already feel over-burdened with more important appointments. On this, she explained:

I see her quite often and I will revisit it with her but I did mention it to her and she said she would follow up with, you know, he’s obviously got doctors and is involved with the hospital and I didn’t get feedback so I’m not sure what’s happened so I need some feedback about that. It will be interesting to see whether she wants to do a referral or whether she’s got access to physios or maybe she’s had enough and they don’t want to go to any more appointments. I could quite understand that. I can quite easily see… (Teacher A)

For Teacher A, there had only been one main discussion with parents, when she had spoken with the student’s mother who had said she was going to mention the student’s fine motor problem to his doctors as the teacher believed that he “should be referred”
(Teacher A) for professional assistance with his fine motor difficulties. Teacher A was intent on revisiting the subject of his fine motor issues with the mother as there had been no feedback to the teacher about her request for follow-up at the hospital. Given that the teacher had not received an answer as to whether occupational therapy would be available through the hospital, in the meantime she had suggested purchasing pencil grips and the mother had bought grips which the student had been using ever since. She spoke of her unease about the situation, which is captured in this comment:

I have spoken to mum but she just said to me that she’d mention it to the doctors and I’m guilty of not following up on that because he really should be doing something for his grip. (Teacher A)

Teacher B experienced a high level of parental involvement on a daily basis. Teacher B was deeply concerned that the mother of this student was anxious because she had struggled to acquire some in-class extra support for him but had been unsuccessful in her requests. Her concerns were regularly communicated to the teacher but the situation was unresolved as described here:

Mum fought tooth and nail. She’d been anywhere and everywhere trying to get some help for him, but because there was no diagnosis as such of anything, the teacher didn’t get any aide time and it had got to the point where someone had said to Mum, you know, “Lie on your form and say that he needs someone to take him to the toilet and then you might get some aide time.” That’s how bad it was. (Teacher B)

This student’s mother intervened in the organisation of the morning routine each day, as the student was unable to organise himself for the start of the daily routine. Other students were also constantly stepping in to prompt and assist the student. Teacher B described the daily routine in this way:
All of them had to have the classroom routine in the morning, red pen, grey lead sharpened first thing in the morning so they were sharp and ready to go...the kids were pretty good with him, the kids would also come in and say “Come on, have you got this ready or that ready?” and the teacher had a list of things on the board and I guess at times, because he wouldn’t have been able to read that, he would watch the other kids, you know, the same if we were doing Maths etc. Mum did everything in the morning, came into the class and did everything.

(Teacher B)

Teacher B defended the mother’s actions because of the confusion surrounding the student’s cognitive issues. Teacher B described here how the student has enormous difficulty with simple classroom systems and is dependent upon his mother to assist him in the mornings:

I honestly don’t know with him, whether awareness of issues… and you know I’m a mum and I would mollycoddle to the nth degree, I think, if I’d been through that, so I don’t know if there is an element of Mum doing everything for him and therefore he’s sort of losing that awareness that he actually has to do some things for himself or if he is completely… there’s just no awareness that there are systems that you need to follow. (Teacher B)

Whether or not the student was capable of organising himself at school each day was in question and Teacher B believed that he probably was not and that the reality of the situation was that he required a great deal of extra support which was being provided by his mother. She reflected:

There were issues there constantly, but then I think about other things and I think, “Well, how capable would this poor little fella have been anyway, of organising himself?” (Teacher B)
Teacher C had limited communication with the parents and if there were parent concerns they were not expressed. Communication by email was merely formal notification about absences related to appointments. Teacher C would normally expect a weekly email from the student’s mother, with updates informing her of impending absences or reasons about absences involving headaches, tiredness, attending appointments or illness. Here, however, Teacher C describes how the student’s mother only ever gave brief details about absences:

Because they don’t - she doesn’t really tell me, she just emails me and tells me basic information and then what happens is, when she does come back, all the work that she’s done or what we’ve done, I just sort of explain it to her (the student) or the kids explain it to her. A lot of our work is ongoing so then she’ll just take it home and she must do it in the car. (Teacher C)

Often the student would come to school for assessment tasks, like short presentations of projects, then go home. The school had an important responsibility to inform the parents promptly if an infection or immunity threat was in the school: “If there’s chicken pox or things in the school we have to inform them because obviously, the immune system is still compromised.” (Teacher C)

Teacher C’s perception was that the student was coping physically with the demands of the school day but that the parent may be overly concerned about the student contracting illness by being at school. Chicken pox had been in the school community and this was a genuine concern. She described the communication between her and the student’s parents thus:

I never see them. She pretty much emails me with basic information. I hardly ever see them. The Mum will just email me…this is the one I got recently, this is today’s one, ____ has an (hospital) appointment Monday 10.15 and again on Friday 2nd at 9. I will drop her at school straight afterward. Thanks. I just get
messages like that. So 10.15 so she won’t be at school til lunchtime. Maybe she’s tired after that and she might not come. I don’t know. Friday she’s got 9 o’clock. She might rock up at 11. She might actually come at…I don’t know…and it’s been a lot lately. But I hardly ever see them. I just get emails like that. (Teacher C)

Teacher C was well aware of the social issues a Year five student would be confronting and she believed that this was a major factor in communication between her and the student’s family. In this comment, she imagined the mother’s thoughts:

I think Mum’s allowed to become a bit more, to say more, ―Oh the illness is gone - you’re going to live! You’ve been at a horrible point in your life that you’ve gone through and so now you can actually think about ooh! you know, I don’t have to worry about this anymore, you can just be a Year 5 student with your friends.‖ (Teacher C)

As there is so little face to face contact between Teacher C and the parents, she can only make assumptions about their attitudes or wishes. Here she describes the way she must guess:

The mother’s very quiet. I don’t know much about what’s gone on for the child …how she feels… I don’t know a lot about it. They don’t tell me stuff so whether they want to just lead a normal life or…I don’t know. The mother emails me like I just read, and she hardly ever sees me and this child just wants to be normal and she just wants to be like everybody else. She doesn’t like attention drawn to her. (Teacher C)

Teacher C felt strongly that the student was at an age when it was important to be socially accepted by her peers and that privacy around her disease and treatments was essential to her wellbeing. She emphasised her belief that the family, especially the student, just wanted to resume normalcy. She explained her intuition about the way
there was so little communication with the parents, despite there being a great deal of information to communicate, in this way:

I think this girl just wants to be like everybody else. Maybe they just want to live a normal life and just try to forget about it. I don’t know. “Let’s just do what we need to do and make things as normal as possible.” And also the child could be saying, “I’m Year 5. I don’t want you talking to the teacher, Mum. Let me just do it, Mum”. You don’t know what’s going on before they get to the classroom door. That’s what my feeling would be, that’s she’s saying “I don’t want you to come to the classroom. I just want to be left be”. She just wants to be normal, like everybody else. (Teacher C)

Teacher C was empathetic as to the reasons why it was important for her student to attend camp events with her friends, stating that bereavement could be something her student was facing, since some of her friends from hospital may not have survived. She went on to comment that: “Obviously kids might not be there from the last time they were together.” (Teacher C)

Teacher D found it awkward to communicate with the parents because of the sensitivity and seriousness of the situation. She explained her awkwardness as follows:

When communicating with Mum, I was conscious about, am I showing enough interest without going into every gory detail, having known the family and taught the older sister, maybe they made some assumptions about what they thought I knew already. It was hard to strike a balance between being supportive without being obtrusive. (Teacher D)

Teacher D’s student’s parents communicated mainly through brief verbal exchanges and email, even when it was very early in their child’s school re-entry. As the teacher pointed out: “There were the occasional emails, but usually communication would be a quick verbal exchange from Mum.” (Teacher D)
Teacher D described here how she felt reluctant to pry and she refrained from seeking details from the parents:

I didn’t like to probe. She’d been a different, exceptional student. I didn’t go digging for lots of information but I do know she had lots of hospital visits and if there was an activity on that day then she missed out. (Teacher D)

Teacher D also felt reluctant to bring up sensitive issues with the student or her parents, as this would be focussing on issues not relevant to the classroom. She explains below how there may have been issues affecting the student, but that they were not evident to her:

I’m sure there were issues relating to bereavement but she was coping so well. You don’t want to draw attention to any issues if they weren’t apparent at school. (Teacher D)

Communication appeared to be a difficult area for all of the teacher participants. They had been given very little information about their student’s medical situation and had not received any special advice about communicating with parents about very serious and sensitive issues so therefore felt reluctant to delve into awkward or difficult conversations with the parents. The teacher participants were reliant on other staff members to inform them about the students’ medical histories, academic progress and learning issues. Email was the preferred manner of communication for families, but difficult or challenging topics were unlikely to be raised. There was also a clear indication that the students (and their families) wished to get on with life at school with their peers and not dwell on cancer, their hospital treatments or being different from their classmates. This was even more significant for the older student.

The desire to get on with their lives, put cancer behind them and participate in normal school activities made the next theme all the more challenging for the participant teachers’ students, as their CNS cancer survivor students were certainly
experiencing learning difficulties or disability. The teacher of a brain tumour survivor was particularly challenged by the presence of a range of learning disabilities in her student.

Theme 4, Learning difficulties or disability, will explain the current situation for students with learning difficulties or disability in Western Australian schools and then describe how the four teacher participants deal with them in their classrooms.

4.6 Theme 4

Learning difficulties or disability
The fourth theme is learning difficulties or disabilities. This theme emerged very early on in the participant interviews and corresponded with the literature review.

In 2015 The Government of Western Australia Department of Education completed its first Disability Register for the Nationally Consistent Collection of Data on School Students with Disability, with all schools being asked to categorize the type and level of disability amongst their student groups. This register is intended to ensure that all Western Australian students who have a disability (cognitive, social/emotional, sensory or physical) have been categorised under the correct disability description and that any adjustments made in classrooms for them; none, quality teaching strategies - supplementary, substantial or extensive - have been accurately recorded and documented.

It would be difficult for the participant teachers in this study to place their students into categories as listed in the Disability Register as the source of the difficulties or disabilities their students are experiencing could only be properly diagnosed by a psychologist or neurologist, testing with (among other things) a battery of neurological “soft signs” tests (Barlow, 1974, p.605) or “neurological soft signs” (Berninger 2004, p.330) as well as a range of conventional cognitive assessments. Such testing would
confirm or negate central nervous system anomalies which would have implications for learning. Only with testing such as this could the students’ cognitive difficulty or disability be properly identified. It would also be difficult to place a student onto the Disability register if they had never been on an IEP before and were not on one at the time of the census. None of the participants’ students had been or were now on an IEP. Three of the teacher participants were confident that, despite obstacles presented by absenteeism and the evidence of what they perceived to be minor learning difficulties, their students were coping well compared with the progress of their peers. There was a substantial amount of confusion as to the effects of treatments or illness having an impact on the students’ education and all teachers were unsure as to the extent of these. Little was known about either.

Teacher A described her student as being one of the “top students” in the class. Reading speed and comprehension were reported as “good” and her assessment was based on a regime of whole school testing for year 3’s, using a range of standardized tests like SA spelling, Waddington reading test and a school constructed maths test for year 3’s. Within the school based testing, her student ranked above average, or “strong” - B - for number and she believed his partitioning and mental calculation skills were strong. In Literacy, Teacher A described her student at C level, stating that he was having difficulty with his writing and found the mandatory year 3 writing genre of exposition very hard.

Teacher A believed that her student’s attention and concentration was not a problem, but was unsure whether his reluctance to write and his lack of persistence with fine motor tasks were related to him being lethargic or tired some days because of treatment, but it was not of concern initially. As Teacher A continued to describe the difficulties, she was reminded of how she had previously raised the issue with his
parents. He had not been on any IEP for any subject area before, as far as she knew, and he was not on any IEP now.

Despite Teacher A’s confidence in the student’s academic ability, stating that he produced “acceptable, ‘at standard’ work”, she was concerned that the student was struggling with age-appropriate development of fine and gross motor skills, which she suspected was related to treatment or to physical growth and development. She explained his difficulties thus:

    Something that he does struggle with is that he is quite lagging in gross and fine motor skills and I don’t know if that’s related to the treatment or not. No he really doesn’t struggle with anything except handwriting. It’s appalling. He can’t even hold a pencil properly. (Teacher A)

Teacher A’s student was having difficulty completing written tasks and she partly attributed this to his poor “fine motor” skills, which physically restricted him from completing the written work. She tried to explain this problem as follows:

    I think he’s tired from writing a lot. We’ve just started doing handwriting with them and he’s very, very slow with it because it takes him five minutes to try and form letters properly. I think he’s trying to – I’ve been trying to get him to hold his pencil properly all year. He still holds it with his four fingers on one side and his thumb on the other side. I don’t know what that grip’s called but that’s how he’ll hold it and I’ll have to remind him to hold it properly on the triangle grip - I’ve recommended a triangle grip - to me, that’s really delayed…that’s a three year old grip, you know, so he’s obviously finding that strength for the grip difficult. (Teacher A)

In the playground, Teacher A’s student enjoyed physical activity with his friends, being an active participant with his classmates and coming up with ideas for games. She had observed him playing on many occasions and said:
He’s often playing either soccer or playing chasey games and he is one of the leaders. I don’t know if he’s an alpha male but he’s one of the ones that controls the games, leaps into the game. Tiredness may affect him, so he might not be the one that stays there the whole of lunch but they quite often play chasey. It (treatment) doesn’t seem to slow him down socially at all.

(Teacher A)

However, Teacher A could see several anomalies with his physical skills also and believed them to be related to gross motor difficulties. As well as this, energy and wellness fluctuated between treatments. She could see that his physical development on the whole - fine motor and gross motor - will be an ongoing difficulty, continuing to be a problem from now on, since there is so much more writing required by students from Year three onwards. She believed that her student’s physical development, fine and gross motor skills had been affected over his two years of chemotherapy and she believed chemicals were continuing to affect him adversely, making him stunted or inhibited in some way. Teacher A believed that her student’s fine and gross motor capability was connected by a lack of physical strength. When asked to elaborate on the type of motor problems her student demonstrated, she commented as follows:

Messy work, not forming letters properly. He’s got messy colouring in, very slow with his handwriting because he’s trying to make it neat and if we were playing a ball game or anything like that, you know he’s OK, he can catch a ball but he’s not great. He’s not a very fast runner, he’s got an unusual gait when he runs and he tires easily from playing games, he’ll tire quite quickly. He doesn’t bump into anything or fall over, things like that, but just I think it’s more to do with strength, like muscle strength. I don’t think it’s to do with physical coordination. I think it’s physical strength. It seems to be that he just doesn’t have strength that I would expect in order to be able to hold the pencil… and run
what the other kids are doing, that’s what I see it as. I think it’s more strength than coordination. (Teacher A)

She believed his attention and concentration were being affected by his fine motor difficulty. Teacher A felt that composition in writing and handwriting are difficulties for him and that writing seems to exhaust him but she was unsure whether he was physically or mentally tired by writing and made the following observation:

I’ve really noticed that when we’ve been doing handwriting, because he’s trying so hard, that the goal’s for it to be neat and the letters to be formed properly, it takes him twice as long as everybody else to get a page done, takes him a really long time and I’ve noticed that in all his writing, so to get him to write neatly is probably time consuming and physically tiring and whether it’s mentally tiring for him I’d probably say yes. He certainly doesn’t like to write a lot when he doesn’t have to. Whether that’s making him physically uncomfortable - do you know what I mean? It’s hard to differentiate. But he does produce work that’s acceptable and at standard but trying to push him on further…I don’t know. (Teacher A)

Teacher A believed her student’s physical development is compromised by his cancer treatments, as she has observed several unusual characteristics in his movement. She went on to explain in the following comment:

He struggles with sport because of his gross motor – I mean, he can still participate but to me it looks like his body has ….his development physically has taken a bit of a blow…that’s what it looks like to me…because his fine motor is quite weak and I can see - it looks to me like a bit of a delay.

Like his gait and everything is different. (Teacher A)

Fine and gross motor difficulties were affecting his work in all subjects, with the student minimising his writing. The student “gets tired” during the process of writing.
The teacher believes this was because he was so slow in forming letters. She described how the student holds his pencil with a four finger “clench” in a “delayed” style, like a “3 year old grip”, (Teacher A) apparently having no strength in his fingers.

The teacher has assisted the student by providing triangular grips for him to use and she wondered whether he should be doing physiotherapy to improve these skills.

The student had not been on an IEP for writing literacy nor for his fine motor difficulties and the teacher believed that no support was required for extra tutoring. Processing speed, organisation, and memory for Maths concepts was “totally fine” and she described the student as a “switched on kid”. When giving instructions, the student understands and responds quickly. When learning new concepts in maths, the student picks ideas up quickly and easily, even division – he doesn’t need any extra assistance and the teacher had no concerns academically with his maths at all. She described his memory for music and LOTE at average or above average level.

His hand-eye coordination and fine/gross motor difficulty resulted in messy work, with the student not forming letters properly. The student participated in all playground and sport games and could catch, but his gross motor skills are poor, he has difficulty running, tires quickly in games and Teacher A believes these difficulties have “more to do with muscle/physical strength”. On this, she said:

I think probably just energy sometimes, his wellness I guess sometimes, really energy but he’s pretty good and the other thing is the physical development. I mean, fine motor is such an issue, from now on there’s so much writing.

I have mentioned it to (Mum) and she’s bought grips. (Teacher A)

Teacher B was distressed that her student was not receiving any extra assistance for a whole range of learning disabilities which she saw were affecting every aspect of the student’s academic life. Teacher B described her student as having “big problems with reading” and reading skills being at a very low level of competence. The teacher was
troubled that the student was operating at such a low level but was receiving no assistance, with neither Education Aide time nor teacher support time. Describing the type of difficulties he was having with literacy, she said:

There were big problems with reading speed and I guess the knock on effect comprehension because the student was in Year three but operating/reading at a pre level Pre-Primary and after listening to the student read over time, for example, with certain sight words like “the” I could have it sorted for a week and then two weeks later it’s gone, so we go back and start over again. Anything on the page really, then it got lost. (Teacher B)

The student had serious recall issues with all reading and literacy activities. Teacher B was frustrated that there was no assistance available to work in the small group situation with this student and the others from the same LDC, so she created a programme for the duration of her teaching practice whereby the classroom teacher would work only with the small group of three students from the LDC whilst Teacher B taught the rest of the class, following a different programme of work. She lamented the way the student was not given any extra assistance in class:

No support, wasn’t taken out for anything, no support, there was nothing and it was only that during I was on my prac, I wrote into my programme that the teacher was his aide and (that was the only time) he got some intensive aide time for that whole year. (Teacher B)

The classroom teacher’s differentiated programme involved an intensive focus for the most part on literacy skills, as maths was seen as a much lesser priority, given the difficulties with literacy these three children were all experiencing and the time required completing literacy activities and tasks. Here she describes the paucity of help:

The reading and literacy was that bad and there was no aide time whatsoever for this student despite having come from a Language Development Centre and
operating at the level I said before. No aide time. He didn’t really get maths time it was just literacy for that student. So while everyone else was doing maths it was still literacy for him. (Teacher B)

When, in the limited time working on maths concepts with the differentiated group, the activities involved a great deal of concrete experience with manipulatives, such as playing trading games using MAB blocks. Several other children had also come from the same LDC class so an informal group education plan was operating, despite it not being labelled as such. It was a differentiated programme of work specifically designed for the three students.

Teacher B explained how the student could become frustrated and then it became difficult to deal with him. She described this as learned behaviour, being stubborn and “shut down” by his emotional issues. She believed his frustration was due to difficulties with working memory because Teacher B felt that the student’s main problem was memory and recall. The student was articulate and verbal reasoning seemed good, with general knowledge being good; however memories of recent learning, concepts, letters and words “didn’t stick”. She went on to describe here the way symbols and letters “got lost”:

Yep, the main problem was the memory, recall, and I say that because this was a relatively articulate little fella and verbally, if I read him something he would be able to add as I was going along, he was able to add his own information with science based things, you know, those sorts of things, he loved it. However when it came to reading - and maybe there were some visual processing issues going on - the memory just didn’t stick. (Teacher B)

Learning new concepts was painstaking and repetition was a strategy Teacher B used for her differentiated programme. As she explained: “It would take maybe three or four times as many exposures or whatever, with absolutely explicit and repetitive strategies.”
(Teacher B) She emphasised repeatedly that there was no support for this student, nor for the other two students at educational risk in the classroom and the classroom teacher filled a role more like a teacher aide during the duration of Teacher B’s final teaching practice period. Teacher B believed that the fact that there was “no diagnosis” of the student’s learning disability meant that no aide time had been allocated to him.

The highly structured morning routine for all children in the class involved organising materials ready for the day and the teacher had a list of lessons for the day on the board, all of which benefited her student. The student was also prompted by other classmates as he couldn’t read.

Teacher C was teaching the oldest student of any of the participants in the study, who was at Year five level and there was an emphasis on the student fitting in with her cohort a great deal more so than for the other students in lower year levels. In this regard she said:

I know that in Year three she was probably not at school much because I remember I’d just started at the school when she came back and she had no hair from the treatment and now I just know that she tries to keep up with everything and she just doesn’t want to be different. In Year five that’s what it’s all about.

(Teacher C)

Teacher C was confident in her student’s abilities and did not have concerns about her academic progress despite her frequent absences over the past two years. Teacher C emphasised that her student was working at a peer appropriate level, as she described in this comment:

Average. She is “at standard”. She’s doing average Year five level. Our B is quite good work and our A is, like “She does everything in Year five perfectly.” That’s what I’m saying, there’s nothing I could pinpoint. She’s fine. Ours (C grade assessment) is “at standard”. She’s alright. She just seems to pick it up.
She’s quite good at that. She doesn’t want to be different, so she takes it home and she’ll work on it. (Teacher C)

Although teacher C was confident that the student was coping well with school she felt that she would benefit from tutoring because she had missed a lot of school in Years two and three and in writing, she “can see gaps” (Teacher C) in grammar, spelling and forgetting grammatical rules. She felt that “teacher style revision” (Teacher C) in literacy skills and numeracy skills was the extra help required for her student. Errors in reading, writing being “difficult to follow” (Teacher C) and recall difficulties in literacy were perceived by Teacher C to be the result of cumulative absenteeism. On a comparative level, the teacher believed that there were other students requiring a great deal more assistance than this student. Teacher C said that she was surprised this student was not a “student at educational risk” (SAER) student, for the amount of time she had spent away from school. She tried to explain the “gaps” to which she had referred as follows:

So grammar and spelling, there are bits missing…there are gaps, so when she writes you can see “Oh, there, their, they’re going to my house”, some of that grammatical…some of the rules, are the bits that are missing. She’s missed out a lot of that I’d say over the past years. I don’t think she learnt it, because you know when you miss out those years - the gaps in phonics and phonemes and blends - there are gaps. Not unusual in this group of children in my class. But she hasn’t been at school so she’ll miss it. She obviously takes a lot of time off and over the years that has not been beneficial. (Teacher C)

The “gaps” in the student’s learning, Teacher C described, were wholly attributed to absenteeism in previous years. She elaborated on this with the following comment:

I find, with her in year five, is that she still takes a lot of time off so she misses things but she’s actually quite alright in the classroom. She’s actually trying
really hard to catch up so the only thing I can see is spelling but that’s not unusual because half the class can’t spell and their grammar’s… I really don’t find her suffering too much academically; she’s actually average in the class. Problem solving… when you’ve got a three step problem they’re all as bad as each other. So put it this way, if I didn’t know that she had missed a lot of school I would never have picked her. I’ve got weaker children, so that’s what I’m saying, like her memory’s fine, for the amount of time she misses from school she’s doing quite alright. (Teacher C)

For Teacher C, the issue of absenteeism also extends to the amount of breaks her student requires, but this is seen as a necessary concession. Full time schooling appears to be a physical challenge for her student. Here, Teacher C describes her student’s need for rests and breaks during the day:

She looks alright and does alright in the classroom and the Mum will say “She’s not here today, she’s not coming today because she’s tired or she’s got a headache or whatever”, but in the classroom you don’t notice it. She does what she’s supposed to do, you know, she comes up and asks for help when she wants help and all I know is, she asks to go to the toilet a lot and will have drinks of water, like in the afternoon, and I say “Yeah, yeah, go and get a drink “, but that’s the only thing that I would say about her. She manages but I don’t know how she’s going to be after missing so much over the last six weeks. I think she’s quite OK academically. It’s catching up on what she’s missed out on. (Teacher C)

Teacher C’s student had not had any IEP before or since she had resumed full-time schooling in Year three as she was not considered to be a “student at educational risk” (SAER) student. The student’s academic standard was considered average – C, or “at standard” in every subject area. Despite being classified as an “average” ability student,
Teacher C had real concerns in several areas. She believed there were difficulties in spelling and grammar, consequently a weakness with writing:

In writing, in the written language, you can see the gaps that she’s missed in grammar and spelling so that’s where she would need some help. She’s not too bad but that’s where I’d say she has problems. Spelling and remembering grammatical rules and things. With her writing you can see there are big gaps. Like, you know, you read it and think, “Ooh you’ve chosen the wrong thing here.” (Teacher C)

Teacher C did not view these weaknesses as learning difficulty or disability, but viewed them simply as missed learning due to frequent absences from school over a number of years. On this, she explained:

We build with that, with the spelling and grammar, so between each year level is such a big difference and if you have had so much time off, then, yeah, you’re going to struggle a bit. She’s not that bad. But if I was going to pick something, that’d be it. All I know is that she’s coping really well in the classroom. She would obviously benefit from extra help that would be great for her, just to keep her moving ahead and catching up with things where there’s gaps, things that she’s missing in the language area but she’s gorgeous and she’s got friends and she loves being at school and when she’s there she works really hard.

(Teacher C)

Learning numeracy concepts was another area in which Teacher C’s student was struggling. She also believed that absenteeism was a factor in this learning difficulty as revealed in the following comment:

Maths, yeah, the applications are fine but then if you’re putting it into problem solving then, it’s the same, (laughs) she needs some help. I don’t think she is getting tutoring. I revise the maths all the time, like we do division and I do it
all the time just to keep them remembering. I’m always revising the work because I know that they’ll forget it. The problem solving…getting them to think laterally and move out of that, you know, looking for the answer, what do you think it might be? How would you think about fixing it? She’s in the middle and she copes very well. She would benefit from extra tutoring because that would reinforce the things that she’s missed, not just what I’m doing.

(Teacher C)

Teacher C was integrating a great deal of Information Communication Technology, including research and group projects, so much of her student’s work was completed electronically. Her written work contained grammatical and spelling errors, possibly “slips of the pen” (Ellis, 1979, p.265) demonstrating difficulty with retrieval of allographs and grapheme information. This type of difficulty, characterised by omissions and substitutions of letters, as well as incorrect spelling of high frequency words could be grapheme or allograph level impairment. (Ellis & Young, 1988) Teacher D also attributed the student’s difficulty with literacy to absenteeism and “missed” work or concepts during treatment, as she points out here:

Her actual writing from what I remember wasn’t great. I think it was a long term thing for her in terms of reading – she would not have had that level of phonics awareness to decode words as well as the other children. (Teacher D)

Here Teacher D again stated her belief that absenteeism had caused her student to miss out on earlier learning which was now affecting her literacy:

She’d missed a lot of school at quite a critical time. She had so much absence when she was first diagnosed and missed a lot of that important foundation learning. Some gaps are hard to bridge. Some days it was hard to do any learning. (Teacher D)
Teacher D recalled that her student was competent in reading comprehension, but would struggle with decoding. Again, she reiterated her belief here that missed work was the cause of her student’s difficulty in literacy at Year five level:

At our school we have levelled readers and students are on a reading record, and she was so ambitious to do well, she was relatively high performing. She was constantly seeking a challenge, pushing herself, so motivated. Actually, she was over-compensating, I think, making up for the loss she’d had in terms of her education. Her phonological awareness was not good because she’d missed a lot. She was in Year two when diagnosed and that’s when there would have been a lot of work on sounds, with the emphasis on reading and decoding. I found in her spelling and oral reading, if she came across an unknown word she’d have difficulty and she seems as if she’d lost her sounds. Now who’s to say if she hadn’t been sick, that would have happened anyway? She needed extra time on reading and decoding. She wasn’t extremely behind. (Teacher D)

Teacher D’s student, who was now in Teacher C’s Year five class, was unable to participate in regular physical activity throughout her first year back in mainstream schooling in Year three. Her health was an issue as well as the risk of injuring herself so teacher D explained how she tried to find ways to compensate:

By the end of the year she liked music and dancing. She had done some ballet before treatment but she couldn’t do it any more so we’d put the radio on and give them a bit of free time, to let her and her friends dance. The kids knew if they got her to ask me, they knew they had more chance of me agreeing. It became transparent after a while, what was going on! (Teacher D)

In this instance, temporary physical disability prevented the student from participating in normal school life for the best part of Year three. Teacher D described this limitation in the following way:
The main issue involved was that she loved sport, and was always trying to participate to the level at which she was able, wanting to join in. There were times when we had to be more careful. (Teacher D)

Teacher D was impressed by the keenness shown by her student to fully participate in her school life again after treatment. However, despite her student’s enthusiasm and diligence, she was having difficulty with retrieval of the allographic store and this was evident in her writing. Teacher D described the student’s written work as follows:

I remember setting an assignment asking the class to do some research at home, well she came back and had done the whole report and was SO motivated. She was very keen. All of her work was well presented and she showed pride in what she could do. Her formation of letters wasn’t textbook. (Teacher D)

All of the participants in the study described their student as having experienced “a loss” in terms of their education. Teacher B’s student had not “lost” any time at school because of his treatment, as he had been too young, yet even this teacher believed he had suffered a loss because of it. All of the teachers at some point described a sense of sadness about what their student’s educational outcomes might have been had they not had to endure cancer treatments, as Teacher A describes here:

I thought it was interesting when I went through, yeah the things that were on your matrix, like I just thought wow he must be doing really well but who’s to say that if he were not having treatment then he would be even stronger. I don’t know the only thing that I wrote down on there was the fine motor really. Was it already an issue before he got sick? I don’t know. (Teacher A)

None of the teachers had received or sought any information about the consequences of central nervous system therapies upon a young survivor’s educational outcomes, yet all of them identified difficulties with learning that their students were experiencing. Apart from Teacher B’s observations of serious learning disability in her student, these
difficulties were not perceived as anything but minor problems. All of the learning
difficulties or disability, as described by the participants, were consistent with the type
of difficulties caused by neurocognitive late effects of CNS treatments for cancer, as
described in the literature review in Chapter 2 of this thesis.

A learning disability in common for all of the participant teachers’ students was
difficulty writing or Dysgraphia. Rather than these difficulties being a fine motor
control issue or simply related to absenteeism and “missing” the learning of spelling
words and phonic sounds, it is more likely that this difficulty stems from working
memory problems related to their central nervous system treatments. The use of non-
word spelling and dictation tests, as well as using both oral and written spelling of word
and non-word dictation tests (Ellis & Young, 1988) could help to shed more light on the
difficulty with writing which the participants’ students are experiencing.

McGill-Franzen & Allington (2010) in *Handbook of Research on Reading
Disabilities* describe the research of Ellis & Young (1988), explaining how these
researchers discovered there are two cognitive routes for pronouncing a written word,
which are grapheme to phoneme conversion and visual lexicon through the semantic
route. They explain how real words and non-words can be used for testing reading as
non-words cause more errors because of conflict between these cognitive systems.
McGill-Franzen & Allington (2010) explain that; “the main characteristic of reading
fluency is the ability to do at least two tasks simultaneously, ie, decoding and
comprehension.”(p.178) McGill-Franzen & Allington (2010) warn of the dangers of
relying primarily on assessments such as the number of words read correctly in one
minute, because this type of assessment is simply decoding.

Barlow (1974), while acknowledging that it is not practical for students with central
nervous system dysfunction (resulting in learning disability) to have
electroencephalogram, encourages the use of neuropsychological “soft signs” (p.605) to
make important observations of central nervous system dysfunction. Barlow (1974) recommends using many different tests, including Goodenough Draw-A-Man, representation of geometric figures, listening to the child read and watching them write, looking at disparity between verbal and performance items on the Weschler Intelligence Scale for Children, Bender Visual Motor – Gestalt Figure test as well as various achievement tests in reading (such as non-word tests) and mathematics to accurately diagnose difficulty or disability. Only school psychologists could assist teachers with this kind of testing in the school setting. The following section explains the last theme, Support from school or other agencies, and a school psychologist would be an example of such support.

4.7 Theme 5

Support from school or other agencies

The final theme is related to support or assistance for teachers dealing with paediatric cancer survivors returning to their classrooms after remission. This assistance or support could come from within the teachers’ schools, from school psychologists, from hospital or departmental liaison staff or from other agencies. This support could also be in the form of resources like information packs, literature, brochures or webinars.

Support is a general term describing a wide range of resources which may be available to a school or a teacher to assist them to provide the optimum education for a student. The Glossary of Education Reform (2014) website describes academic support as a term encompassing many concepts; tutoring and extra programmes for enrichment or underperforming students, teacher advisors and mentors and alternative ways of grouping or instructing students. It states that support strategies can be specific to a particular student population, such as English as an acquired language/dialect (EAL/D)
students, students with disabilities or behavioural problems and gifted students. Support can be used to help accelerate students, meet learning standards or simply achieve success at school. This glossary suggests a number of commonly used strategies, grouped into; classroom or school-based, after-hours, vacation or outside-of-school based or technology assisted strategies, using digital or online learning – visual simulations or game based learning.

Relationships-based support includes team teaching or skills-based advisory staff and mentoring by expert or experienced staff. Specific, needs-based support can be used to target the specialised needs of groups of students. The glossary points out that support systems will vary from school to school, according to each school’s perceived requirements and their interpretation of the school’s purpose and obligations – whether it is performance improvement, teacher effectiveness or the school’s philosophical stance. The relevant excerpt from the glossary is as follows (The Glossary of Education Reform, 2014):

In the first case, the school may view academic support as something that is “added on” to an academic program and that is provided only upon request or in response to clear evidence of need. Unless school regulations require the provision of academic support, a student, parent, or guardian may be seen as having the primary responsibility for requesting support services. Teachers are responsible for teaching courses and helping students succeed in those courses, but other forms of academic support and guidance are the responsibility of counselors, support specialists, and parents. (para 14)

The glossary describes another example of a school in which academic support is viewed as a necessity for all students, in which the school would provide; “that support by modifying schedules, adjusting workloads, or offering specialized training.” (The
Glossary of Education Reform, 2014, para 16) The glossary explains that many initiatives will fall in between those two extremes.

In the USA, the Individuals with Disability Education Improvement Act (IDEIA) mandates that students with disabilities are supported by their school to achieve success. The Government of Western Australian Department of Education, through its Statewide Support Services branch, provides Individual Disability Allocations to schools to address the needs of students with a diagnosed disability. Provision of funds to support the student depends upon the type of disability, the degree of disability, the teaching and learning adjustments they require and the type of school the student attends. Such information is now obtained through the Nationally Consistent Collection of Data on School Students with Disability (NCCDSSD) annual census. Decisions about the provision of support for students with disability are also made by the Disability Services and Support Directorate, according to the Disability Resourcing Eligibility Requirements. (The Government of Western Australia Department of Education, 2016)

It would be unlikely that the participant teachers’ students in the study reported here would be eligible for such support as they would probably not be fitted easily into any of the eight categories of eligibility, according to the Disability Resourcing Eligibility Requirements. They would not fit the low IQ criterion for Intellectual Disability and once they are in remission, they would not fit the Physical Disability criteria either.

None of the four teacher participants in this study had received any support from any agency regarding their student’s prognosis, ongoing treatment or the consequences that their treatment may have for their academic development. None of their students had received any assistance in the classroom on a day to day basis, from a teacher assistant or an educational aide. None were involved in regular in-school support classes. Two students had previously been recipients of tutoring from the Ronald McDonald Learning
Program, at an earlier time, closer to the completion of their treatment journeys, sometimes in-school and sometimes outside-of-school.

Teacher B was worried and upset about the lack of support available for her student, despite having come from a Language Development Centre, a fact in itself which already flagged the child as requiring a great deal of extra support on a daily basis at school. She expressed her amazement in the following way:

The reading and literacy was that bad and there was no aide time whatsoever for this student despite having come from a Language Development Centre and operating at the level I said before - with no aide time! (Teacher B)

Teacher B provided a short term arrangement whereby she replaced the class teacher so that the teacher was free from her regular classroom responsibilities and could work intensively with a group of identified SAER students, one being her student who was a brain cancer survivor. This type of support could be described as an in-classroom, relationship-based support strategy, albeit a temporary one. Although this was a positive arrangement, Teacher B felt indignant that no support had been provided or would become available to that student in particular. Responding to questioning about the level or type of support provided for the student, she said:

No support. Wasn’t taken out for anything. No support. There was nothing and it was only that, during I was on my prac, I wrote into my programme that the teacher was his aide and that intensive support time was all he got for the entire year. If I hadn’t been there and the teacher hadn’t had that opportunity he would never have had that extra assistance. (Teacher B)

Teacher B described here the student’s extreme disability in literacy, and being unable to cope with basic reading tasks:

There were two other kids from the LDC in the group the teacher took for support. There was an ADHD, and another one with global delay. In the little
group the other two were nowhere near as behind as him. Sight words, anything on the page really, then it got lost. (Teacher B)

Since the student required so much extra assistance to achieve simple tasks in literacy, little time was left for maths. On this she pointed out: “He didn’t really get maths time, it was just literacy for that student. So while everyone else was doing maths it was still literacy”. (Teacher B) Her suggested strategies for the student involved repetitious learning as described in the following comment:

Following instructions, “chunking” information, repetition, reminding.

Focussing on listening…it would just be breaking down instructions and repeating each chunk the whole way along. You need to do this - and then we’ve done that - so you need to do this. (Teacher B)

Another of the classroom teacher’s strategies was to provide a very structured timetable through the day as she describes here:

It wasn’t geared towards him but it helped because it was the same thing, very regimented, but that was how the teacher would have run things regardless of whether he was in there or not but it worked out well for him. He needed that very strict, very regimented routine. (Teacher B)

The student participated in the range of school subjects with his classmates, but with little comprehension of the subject matter. However, as the following comment highlights, he enjoyed the variety of these experiences:

He enjoyed Music and LOTE but had minimal understanding. He enjoyed Art which was taught as a classroom subject by the teacher. I think he really liked music. I don’t know that he took anything in. I think he liked music for the sound. I don’t think there was any focus on reading notes. His art was great and he would pick up any technique. He was good. (Teacher B)
Teacher B was adamant that there was; “no written IEP (and) If anything, it was an informal group education plan.” (Teacher B)

Teacher D saw provision of support in a different light as she viewed pastoral care as the most important factor in dealing with her Year three student. She drew strength from the wider school community as well as other staff members who supported her emotionally. This too would be described as relationships-based support. On this, she explained:

There was a lot of support from staff who had taught her in previous years and there was continuity for her as the Year four classroom was right next to the Year three classroom, where her past teacher was. The main issue was to support her so that she could increase her wellbeing, give her the educational assistance.

I felt a lot of it was to make her feel comfortable and safe. (Teacher D)

Her school had a system of identification of students with medical or behavioural difficulties and this was communicated to the rest of the staff. She described the school protocol regarding students with a medical disability thus:

Support from staff, getting the history from other teachers. We have a printout at school for any child at school with a special condition or behaviour problems we need to be aware of so all staff were aware of her condition. (Teacher D)

Teacher D believed a spiritual element was also responsible for the reintegration of the student into a healthy school life and she described the actions of the school community demonstrating this element of support for the student as such:

The child was supported by the whole school community. With every situation we confront like that, we have a nurturing, very supportive community and when children are unwell we may pray for them in class or in a whole school mass. The whole school will pray. This faith brings an extra dimension and
brings people together in the community. We’d hope that faith was one of the main reasons parents would choose to send their child to our school. (Teacher D)

Teacher D believed that supporting her sick student benefitted the whole school community, as it drew them together, strengthening their faith. She explained the way all of the students benefited from supporting the student in the following way:

With her peers, it’s not easy for children that age to sustain that support for the sick child, but the fact that it was ongoing and unconditional. She was so self-aligning, so courageous. This is the model that Christ gave us which helps everyone to bring out the best qualities in themselves. For the children around the sick child, it helps them to develop, being part of a faith community. (Teacher D)

Teacher D could not remember this student being on an Individual Education Plan when she returned to school. On this, she said:

I don’t think she was on an IEP but she might have been on a group education plan. There were certainly gaps, but she was not far behind the other children. There were many little individual interventions. We have an awful lot of community support from the faith base. (Teacher D)

Teacher D’s student had been involved in extracurricular tutoring but this was not provided by the school, despite taking place within the school and in school hours:

“I think she had some sort of funded tutor to help her every week. I think it was done in school time, she was withdrawn. An ex staff member ran it”. (Teacher D)

Relationships-based support was, therefore, the main type of support offered to the teacher participants in this study. The teachers were left to their own devices to come up with ways to support the students, as they had limited prior information from which to plan support programmes, no provision of staff assistance to devise strategies to support
their students educationally and no access to special testing regimes to assess their students for learning disability or difficulty.

4.8 Summary

This chapter has described the findings according to five substantive themes generated from an analysis of the data. The key research question which guided this study was to generate theory about how teachers deal with paediatric cancer returning to their classrooms after remission. From these interviews with the teacher participants, the five major concept clusters emerged and became the major themes. These themes were consolidated and expanded by the participants. Teacher preparedness, absenteeism of the students, communication issues, learning difficulties or disability and support from school or other agencies were explored in detail. From this data, theory was generated and became the content in the subsequent chapter, Discussion of the Findings.
CHAPTER 5
DISCUSSION OF THE FINDINGS

5.1 Introduction

This chapter discusses the five themes with reference to the literature. There are five major conceptual categories to be considered when understanding how teachers deal with cancer survivors who have endured central nervous system therapies and who return to their classrooms after remission. Although there were many challenges described by the teacher participants dealing with paediatric cancer survivors returning to their classrooms after remission, these five themes were of most importance to them. From the qualitative data which, after analysis, became the research findings, these five major themes emerged and became the constructs discussed in the findings: teacher preparedness, absenteeism of the students, communication issues, learning difficulties or disability and support from school or other agencies. From this comparative data, generalisations could be made about the teachers’ perceptions, thoughts and feelings. Although there were many areas of concern for these participants, these five themes were the most important to them.

Teacher preparedness – being equipped with the knowledge and understanding necessary to provide exemplary differentiated curriculum to students, based on their unique needs, is high on the list of required attributes for graduate teachers, according to AITSL’s *Australian professional standards for teachers* (The Australian Institute for Teaching and School Leadership, 2014). The teachers in this study had been given the minimum of information about the special needs of paediatric cancer survivors returning to their classrooms after remission.

Absenteeism for paediatric cancer survivors in remission is necessary to continue prolonged treatments and hospital check-ups, as they make the day-by-day, month-by-month, year-by-year, gradual transition from hospital patient to long-term survivor. This
lengthy period is risky and may result in relapse. The immunity challenges of being a school community member but still a cancer outpatient can also result in absence from school. Without clear understanding about these absences, teachers may find it challenging to cope with them.

Communication about the socio-emotional, psychological, educational and medical obstacles of childhood cancer is essential for teachers and parents of the child or adolescent returning to school. Parents who are keen for their children to return to normal school life may be disinclined to discuss serious issues related to their child’s cancer with their teacher. Communication between teachers and parents of paediatric cancer survivors may be difficult and teachers may not be equipped with the high level of expertise required for a task more suited to the school psychologist. A team approach, involving school administration, parents, teachers, the school psychologist and other professionals with specialist expertise is necessary to monitor the student’s progress through school re-entry and beyond. Documentary data from previous meetings and school re-entry plans is critical in optimising the educational experience for paediatric cancer survivors, in the short and long-term future.

Neurocognitive late effects in children who’ve endured CNS cancer treatments are a real risk. Teachers and school psychologists need to be alerted to the risk and given support to deal with them in the classroom. These late effects can occur at any time after treatment, so even long-term survivors who may be at secondary school still need special consideration from their schools, which need to be prepared to provide extra assistance and maintain close monitoring of the student. Although the changes to the brain are irreversible, research into cognitive rehabilitation has proved it to be beneficial. Although schools may not have the staff or resources to be able to implement cognitive rehabilitation strategies, some elements of it can be used by the student when confronted with learning challenges. Teaching students metacognitive skills for learning
can help minimise learning obstacles and can have a lasting impact on their education. Positive or successful strategies can become an individualised repertoire of life skills.

AITSL’s *Australian professional standards for teachers* (The Australian Institute for Teaching and School Leadership, 2014) has high aspirations for teachers dealing with students with disability, but, at present, the framework does not provide any scaffolding for teachers with CNS cancer survivors, struggling to understand and provide support for their students’ learning difficulties and disabilities.

The support of the school is also of critical importance to teachers with CNS cancer survivors in their classrooms. Informal, relationships-based support from school staff was evident for the teachers in this study. The literature review emphasises the need for hospital schools, school psychologists, school administration, teachers, parents and other support personnel to work as a team to facilitate successful school re-entry of the student returning to school after childhood cancer. As well as this, the close monitoring of the student over time is recommended, to review Individual Education Plans and health plans, to organise specialist assessment (such as neurological testing) or specialist intervention (such as occupational or speech therapy) if required and to adjust learning programmes where neurocognitive late effects are causing difficulty for the student. A detailed description of the findings now follows, with reference to essential literature related to each theme.

### 5.2 Theme 1

**Teacher preparedness**

School re-entry for students who have survived cancer and are resuming school life after remission is a major milestone. Not only is it a school re-entry, it is a return to normal life with their peers after extended periods of absence due to life-threatening ill
health. Socially and emotionally, there are challenges to be faced. For students who have received central nervous system therapies (those who have survived brain tumours or leukaemia), the school re-entry can be even more challenging because of the risk of neurocognitive late effects related to their treatments. Joshua (2010) describes the emotional impact of the school re-entry for students returning to school once in remission from cancer as follows: “The point of school re-entry can be one of the most exciting as well as one of the most frightening times for a patient returning to school after a cancer diagnosis.” (p. 25)

Joshua (2010) explains the importance of the school re-entry meeting to prepare teachers for the issues and challenges they will experience. If a school re-entry meeting had taken place when the participants’ students first returned to school in previous years, these teachers were not aware of it, and consequently, had not received important information which may have emanated from it. They were not aware of case conference notes from such a re-entry meeting either, so were reliant on informal sharing of experience by other staff members who may have been involved with re-entry of the student at the time they returned to school.

All of the teacher participants in this study voiced concerns about not being given enough information about their student’s diagnosis or ongoing health or education issues. None of them had any IEP documentation to refer to and their preparation for teaching the students was generally informal verbal information from other teachers within the school. None of them had any prior information from any outside agency about the students’ medical situation or treatments. Three of the teachers believed that there was a strong desire for their student’s family to regain normalcy for the student within their school environments and among their peers. This was especially true for the oldest student. For the older student, the importance of working at a “peer appropriate
level” while still undergoing treatments was being balanced against still being susceptible to illness and experiencing ongoing medical problems.

For all of the teacher participants, there was a great deal of uncertainty as to the impact past cancer treatments or ongoing maintenance treatments after remission may be having on the students’ health and daily stamina, about the implications of cancer therapies for their students’ physical development and about how best to cope with the learning difficulties the students were faced with now. Teacher D believed that being given more information would have made a big difference to how she was able to cope with her student who was only just in remission and returning to school, still visibly affected by her treatments. Teacher B, in particular, felt that she did not have enough information to deal with the learning difficulties and disabilities that her brain tumour survivor student was experiencing.

The Glossary of Education Reform (2014) describes the concept of Professional development, listing many “common professional-development topics and objectives for educators.” (para 3) Some of these areas are; furthering education and knowledge in a teacher’s subject area, earning certification in a particular educational approach or programme, developing analytical skills that can be used to analyse student-performance data, learning new technological skills, working collaboratively with colleagues and improving fundamental classroom management techniques. Two areas of professional development in The Glossary of Education Reform (2014) which would be useful for the teacher participants in this study are described as follows:

Developing specialized skills to better teach and support certain populations of students, such as students with learning disabilities. (para 10)

Training or mentoring in specialized teaching techniques that can be used in many different subject areas, such as differentiation (varying teaching
techniques based on student learning needs and interests) or literacy strategies (techniques for improving reading and writing skills), for example. (para 4)

The Australian Institute for Teaching and School Leadership AITSL (2014) has produced a framework which is *The Australian professional standards for teachers.* In the Professional Knowledge domain of the standards, element 1.5; “Differentiate teaching to meet the specific learning needs of students across the full range of abilities” (para 5), offers two video illustrations for the graduate teacher, which demonstrate best practice. The two videos are involved with differentiated music curriculum and guided reading. Similarly, in element 1.6; “Strategies to support full participation of students with disability” (para 6), there are no illustrations of best practice for graduates, but the proficient teacher illustrations involve; engaging students in Science, supporting Japanese language learners, palindromic numbers, using mental computational strategies and oral language.

AITSL’s objectives (The Australian Institute for Teaching and School Leadership, 2014) are explained as follows, in its mission statement:

Promoting excellence so that teachers and school leaders have the maximum impact on student learning in all Australian schools. The Institute's role is to: develop and maintain rigorous Australian professional standards for teaching and school leadership, implement an agreed system of national accreditation of teachers based on these standards, foster and drive high quality professional development for teachers and school leaders through professional standards, professional learning and a national approach to the accreditation of pre-service teacher education courses, undertake and engage with international research and innovative developments in best practice. (para 1)

Despite the high expectations in *The Australian professional standards for teachers,* for teachers to demonstrate excellence in teaching students with specific learning needs and
students with disability, AITSL (2014) does not offer any insights or assistance for teachers dealing with paediatric CNS cancer survivors returning to their classrooms once in remission.

To be prepared to teach students who have had CNS cancer, teachers require a great deal of information and need to be able to access strategies and support systems to deal with them. Teachers require information about the students’ cancer treatment and ongoing therapy after remission, including information about the reasons for immunosuppression, side effects and ill health. This would help to explain fatigue, headaches and the need for frequent breaks and possible absence. They need to understand that CNS cancer involves treatments which affect the central nervous system and that the neurocognitive sequelae of radiotherapy and intrathecal chemotherapy (or both) can lead to changes in the white matter of the brain. Learning disability is a real risk for these students.

Teachers also need to be equipped with strategies to communicate with parents about sensitive issues, such as students’ socio-emotional wellbeing, academic progress, learning difficulties or disability, effects of maintenance therapy and possibly bereavement. Teachers need to be supported in developing adjustments to their learning programmes, such as using ICT so that students can access the curriculum remotely or modifying assessment tasks with the cognisance that learning difficulties or disability (particularly Dysgraphia) may make it challenging to complete assignments, homework or assessment tasks in the same timeframes as their peers. Awareness of the neurocognitive late effects associated with CNS cancer treatments is essential for teachers dealing with survivors in their classrooms. Some of the learning difficulties or disabilities can include; working memory deficits, attention and concentration problems, slower processing speed and Dysgraphia.
Armstrong & Horn (1995) explain how the younger the age of the child at diagnosis, the higher the risk of cognitive decline over time, so secondary teachers must be prepared to monitor older survivors, who may demonstrate problems in attention and concentration, which to the unsuspecting teacher, may appear to be behavioural problems. Stevens (2011) reports that apparent carelessness, poor organisation and poor reasoning skills are likely to be related to neurocognitive late effects in older students who have survived CNS cancer. Askins & Moore (2008) describe the declines in IQ over time attributed to CNS cancer survivors, particularly brain tumour survivors. Armstrong & Horn (1995) emphasise here the importance of enlightening teachers about CNS cancer neurocognitive late effects:

Understanding of the complexity of the potential neurodevelopmental and academic outcome in children with cancer has been limited to health care professionals. Clearly, expanding this understanding to educational professionals and involving them in the development of effective intervention models is critical to success in helping children who survive a terrible disease, only to face a difficult and often overwhelming academic world. (pp. 301-302)

The school re-entry is a good starting point for sharing information about the needs of CNS cancer survivors when they return to school, but teachers many years later may notice irregularities in their school performance. An ongoing Individual Education Plan would at least give teachers advance notice of some of the challenges they may face dealing with paediatric cancer survivors in their classrooms.
5.3 Theme 2

Absenteeism of the students

According to Armstrong & Horn (1995), a paediatric cancer diagnosis will inevitably result in disruption to a child or adolescent’s school life. This problem is described as such:

For all children with cancer, there are multiple obstacles to normal school attendance and academic performance, including frequent school absenteeism, acute effects of the malignancy, acute effects of chemotherapy (medications), and infections. (p.292)

There are many educational, health and socio-emotional problems associated with absenteeism of students who are cancer survivors, due to ill health, immunity threats, hospital appointments and check-ups. The teacher participants in this study were teaching students in remission from CNS cancer, with three teachers’ students still receiving maintenance treatments and regularly visiting hospital for blood tests and check-ups. For survivors who have had CNS treatments and who may be suffering neurocognitive late effects, these absences cause even more educational difficulties. Armstrong & Horn (1995) explain why CNS cancer survivors can face additional long term difficulties at school as follows:

For children with leukemias or brain tumors, school problems may additionally be related to changes across time in the structure and/or function of the brain following treatment with chemotherapy administered into the cerebrospinal fluid (intrathecal chemotherapy) and/or radiation therapy to the brain. (p.292)

Butler et al. (2008b) explain the far-reaching negative consequences of absenteeism for young cancer survivors, specifically:

During treatment, children encounter intermittent hospitalizations, frequent clinic appointments, and fluctuations in immune functioning, making
it difficult for them to attend community school regularly. Absenteeism from school can result in children having to repeat grades and may contribute to suboptimal social and educational outcomes, especially for those who experience cognitive late effects. (p.256)

Wheeler et al. (2009) describe the socio-emotional effects of absence on normal school life, for students who have CNS cancer returning to school as such:

Damaged frontal lobe function often impacts on group play, and children may be ostracised as a result. More subtle impacts are seen when children lose touch with their peers during long absences caused by treatment. Social awkwardness engendered by lack of hair or just the fact of having their peers feeling awkward about their diagnosis of cancer can impede normal interactions. They are also often caught between wanting to be ‘normal’, yet having a life-changing event acknowledged in some way. (p.194)

The teacher participant’s student in this study who had survived brain cancer was absent very rarely, since his treatment had been completed some years prior, so absenteeism was not a factor in his academic progress. However, according to the literature, his severe CNS treatments may have affected his social interaction with peers, as described by Wheeler et al. (2009).

Armstrong & Horn (1995) describe the short-term and long-term difficulties for the school when cancer students return to the classroom after remission. Here the researchers explain the challenges for school staff:

Childhood cancer and its treatment present multiple school-related problems. Some of these may be of short duration, resulting in school absence or specific performance problems, while others may be long-term problems needing ongoing assessment and intervention. (p.302)
The students of the teacher participants who were recently in remission and still visiting the hospital frequently for treatments and monitoring were regularly absent. For the younger of these students, absenteeism was not presenting any serious issues, but for the older student, it was taking a toll on her academic life. This student was having to “catch up” with class assignments and missed work; however the use of technology to keep up when attending treatments or because of illness was invaluable. This teacher’s school was well equipped with ICT and student ipads were essential to their daily work, so the student was still able to participate and work with her peers on group projects, despite her many absences, by using her ipad at home and during hospital visits. It was inevitable that there would be missed schooling during treatment and monitoring in the remission stages and it appeared that the older the student, the more significantly the time away affected their school work and academic progress. Relationships with peers was also more important for the older student and continuity was possible using ICT, with the school using programmes and sites where students could participate remotely in group projects using WebQuests in many curriculum areas.

For the teacher participants, there was a great deal of uncertainty whether “gaps” in students’ learning were attributable to treatment, illness, fatigue, absenteeism or other factors. They did not have any guidance as to the strategies they should use with these students and they had no means with which to diagnose their learning difficulties. Armstrong & Horn (1995) summarise the difficulties associated with absenteeism for students in remission from cancer returning to school as follows:

Finally, it is critical to recognize that the child with cancer presents a unique set of problems for the school system. The educational plan may need to accommodate frequent absences due to hospitalization, dual homebound/school based schooling between treatment cycles, and environmental reorganization for children who require wheelchair or walking device assistance. (p.301)
5.4 Theme 3

Communication issues

The literature review identified many programmes and resources applicable to the school re-entry period and the important information exchange opportunity – the school re-entry meeting. Joshua (2010) emphasises the importance of the school re-entry meeting, explaining that Individual Education Plans, health care plans and information session planning could all be initiated at such a conference. Key personnel, such as hospital representatives, school psychologists, teachers, school administration staff and parents can meet to discuss the different issues young cancer survivors might encounter and, if necessary, find ways to adjust school routines or programmes for them.

What about school? (Ronald McDonald House Charities, 2011) is a comprehensive resource with support pages and letters for school and parents to facilitate communication between home and school. The school year summary page, Sibling support page and Infectious illness letter would be excellent starting points for parents to communicate important information to the school. These documents could then be used for reference by the student’s future teachers. What about school? (Ronald McDonald House Charities, 2011) aims; “to assist parents and carers with the schooling and educational implications of a diagnosis of cancer.” (p. 9).

The book contains five different sections, each described as “An educational pathway”, which deal with early childhood (2-6 years old), middle childhood (7-10 years old), late childhood/early adolescence (11-14 years old), adolescence (15-18 years old) and young adults (19-24 years old). These sections contain information regarding age appropriate development, special challenges for their age group, areas for support or intervention, supporting the child at school, communicating with; schools, educational institutions or pre-school centres, as well as a list of assessments that may be conducted for a particular age group.
None of the participant teachers had had any liaison from outside agencies to update and inform them about their students’ ongoing or past medical histories nor the problems they might be facing in the classroom. There was also a lack of case conference documentation or interview history to be able to ascertain the learning needs of their students in the light of their physical and medical issues. Teachers were reliant on relationship-based support from other teachers, as this was the sole support available to them when advice about their students was required.

All teachers were focussed towards identifying the positive elements of their students’ participation in normal, mainstream classroom life and took the cue from the students’ parents who were also keen to see their children fully integrate into school life with their friends rather than dwell on the unpleasant and distressing aspects of their children’s life experiences as cancer survivors, still being monitored in case of relapse. This was demonstrated in a keenness to “keep up” with school work in the face of a great deal of absenteeism related to their tenuous medical situations – as cancer survivors meeting survivorship milestones and timeframes. Regular hospital outpatient visits to take blood tests and provide maintenance therapies were privately managed with little, if any communication to the teacher about this (apart from formal notification of absence dates and times).

Both Teacher A’s and C’s leukaemia survivor students’ parents limit their interaction with school to formal appointment notification only and it appears that they wish their child is treated “normally” like the other students. In this regard, parents of these students appear to be rather undemanding. The teacher participants experienced awkwardness around communication with parents, as emotional factors were a possible reason why parents were providing minimal information about their child’s cancer diagnosis and the difficult, ongoing, physical treatments during their remission phase, along with the uncertainty of “event free survival” without relapse.
The teacher participant whose student was a brain cancer survivor, long finished with frequent hospital visits, was also given very little information about the student’s medical background, learning disabilities and difficulties. As students grew older, it became even more important for student and parent alike to minimise issues related to their medical histories or ongoing medical treatments, as students were adjusting to resuming a normal life at school with their friends. Armstrong & Horn (1995) emphasise the importance of communication to school staff and they state here: “Education of teachers and other school personnel about the diagnosis, problems that might be encountered and reasonable expectations for the child will be essential.” (p. 301)

5.5 Theme 4

Learning difficulties or disability

According to Askins & Moore (2008), white matter changes to the brain caused by CNS therapies in cancer treatment cause neurocognitive late effects. Brain tumour and ALL paediatric survivors are at great risk of demonstrating such late effects, which can be evident at any stage post remission. Declines in academic progress and also in IQ have been reported by these researchers, namely: “Neurocognitive morbidity in attention, executive functioning, processing speed, working memory, and memory frequently occurs and contributes to declines in intellectual and academic abilities.” (p. 1160)

Cognitive rehabilitation is one of the strategies being used to address neurocognitive late effects, as CNS treatments have been likened to the effects of traumatic brain injury, with similar neurological outcomes. Askins & Moore (2008) describe the similarities as follows:

The importance of white matter to cognition has been documented by numerous studies of traumatic brain injury in which cognitive deficits have been correlated with the extent of white matter damage. The neurocognitive deficits commonly
resulting from traumatic brain injury are similar to those of pediatric cancer survivors (attention, executive functioning, processing speed, working memory, and memory). White matter changes in aging have also been associated with the cognitive decline leading to dementia. (p.1162)

Armstrong & Briery (2008) in Childhood cancer and the school, recommend comprehensive assessment for CNS cancer survivors: “Assessment of the child treated for CNS cancer should be carefully planned.” (p. 271) According to the researchers, a battery of testing is required to identify neurocognitive late effects. Along with global intellectual functioning and reading and math achievement tests, special testing is necessary for CNS cancer survivors. These tests include computerised testing of attention and concentration that: “permits errors of omission (likely to be detected) and errors of commission (infrequently identified in this population)” (p.272), standardized testing of auditory memory, visual memory, sequential memory, delayed recall, processing speed involving visual-motor abilities, language ability – expressive and repetitive language, verbal fluency and listening comprehension. As well as this, Armstrong & Briery (2008) recommend behavioural adjustment testing, including parent observation of adaptive behaviour. On the reasons such testing is necessary, the researchers explain as follows:

Inclusion of age appropriate measures of intellectual functioning and academic achievement may be necessary to meet local, state or federal guidelines for evaluation of children eligible for special education, but these will often provide insufficient data to appropriately plan for the education of the child with CNS cancer-related difficulties. (p.273)

All teacher participants in this study perceived indicators of academic struggle or difficulty in their students, with Teacher B being concerned that her student was facing very serious academic challenges. Teacher B’s student was having great difficulty with
many areas, such as problem solving, reading, writing and organisation. The memory for new learning or recall of grammar, phonic sounds and recalling basic facts was a major problem for Teacher B’s student who differed from the other students, being a brain cancer survivor.

The literature review highlighted the fact that brain tumour survivors, who have experienced radiotherapy are at much greater risk of neurocognitive late effects. Gerhard et al. (2007) describe the subgroup of survivors who are at greater risk, including very young children at diagnosis and those who had the most severe CNS treatments, cranial radiation. Teacher B’s student met both of these criteria. Wheeler et al. (2009) report the “devastating” (p.192) long term effects; “functional neurological compromise” (p. 192) in brain tumour or cranial irradiation survivors.

Askins & Moore (2008) describe the physical changes to the brain caused by CNS treatments. White matter damage occurs and can lead to progressive decline in measured IQ. Cranial radiotherapy is the treatment they believe to be particularly damaging to white matter, with chemotherapy also causing neurocognitive late effects. Hollen et al. (1997) studied long term survivors and defined the criteria for neurocognitive late effects, which were radiotherapy and intrathecal chemotherapy. Keene et al. (2007), Stevens (2011), Jain & Krull (2009) and Armstrong & Horn (1995) all concur that radiation treatment to the head for brain tumours in young children will mean that neurocognitive late effects are most severe for them and that leukaemia survivors who endure intrathecal therapies are also at risk. Female gender and younger age at diagnosis can make the late effects even more severe.

Teacher B’s male student had survived a brain tumour and endured cranial radiation. His neurocognitive problems were evident and he had attended a Learning Development Centre for three years to gain specialist support. He was now in mainstream education and his teacher was struggling to provide assistance for his special needs. His literacy
levels were very low and he could not read. Teachers C and D were teaching female students who had survived leukaemia and had had intrathecal chemotherapy. These teachers believed their students were at educational risk due to absenteeism, making them Students at Educational Risk (SAER), although they did not describe their students as such. They believed that part of the problem for their students was the fact that they had missed school due to treatments and illness and now demonstrated “gaps” in their learning, particularly in phonics.

Armstrong & Horn (1995) explain how learning difficulties may be attributed to absenteeism, but in fact, survivors of CNS treatments for cancer may be suffering the late effects of CNS treatments and the impact these treatments have had on their brains. All four teachers identified fine motor difficulties as a problem for their students, but rather than being a mechanical problem involved with the praxis of writing – forming letters and words – the problem was related to completion of written tasks. This would indicate that the students’ difficulties could be described as Dysgraphia, having more to do with retrieval from allographic or graphemic stores under time constraint. The use of pencil grips had been recommended for two of the students to try to rectify what was perceived to be fine motor problems. Whether or not the grip and fine motor issue caused difficulty with writing tasks or not, all of the teacher participants’ students found writing tasks very difficult and their teachers were concerned that this may become a more serious problem as they moved into higher grades when the volume of written work required would increase significantly. These students were not on any IEPs now and there was no past Individual Education Plan or Group Education Plan to provide a reference point for future accommodations or adjustments.

Teachers A, C and D, all teaching students who had endured intrathecal leukaemia treatments, reported that their students were having issues with writing. They were unsure whether this was caused by “fine motor problems” or by a loss of stamina or
concentration due to treatments or feeling ill or tired. The one conspicuous learning difficulty noted by all of the teacher participants in this study, described as “fine motor” problems or difficulties, may provide the key to identifying the “soft disability” (Berninger, 2004) Dysgraphia. Writing under time constraints and fine motor skill difficulty were common difficulties to all participants’ students to some extent – some minor, some major. Difficulty with writing was described as “fine motor difficulty” throughout the study. After further analysis of the teacher participants’ descriptions of the problems faced by this difficulty, it would seem that it is not only fine motor skills which are to blame for writing difficulty, but that this problem may be better described as Dysgraphia, which describes a difficulty related to retrieval and working memory rather than the praxia of holding a pencil in the hand and creating symbols.

Hockenberry et al. (2015) describe the risk of brain tissue change during chemotherapy for young ALL survivors, resulting in visual-spatial deficits and fine motor difficulties as follows:

A child’s motor system experiences rapid development during the first two to five years of life, the time when ALL most commonly occurs in children.

Childhood ALL treatment increases the risk for long-term fine motor problems that include peripheral neuropathy, sensory loss, reduced deep tendon reflexes, and motor function changes. (p.542)

Although this learning difficulty was discussed as “fine motor” difficulty, the literature review indicates that “Dysgraphia” might be a more appropriate term for the difficulty, as Dysgraphia intrinsically involves working memory function as well. The elements of Dysgraphia especially relevant to students who had received central nervous system therapies during their treatments relate to; the graphemic buffer, where letters are stored in working memory in preparation for fine motor implementation, allographic store retrieval, in which types and forms of letters and symbols are stored and retrieved and
the graphemic system, which is the system of creating symbols through motor function, also a working memory dependent function. (Berninger, 2004)

Dysgraphia, or difficulty with writing, in the case of these special students, is probably more about working memory than motor skills, although for ALL survivors, fine motor difficulties could also be implicated. This characteristic may be a marker to guide teachers towards catering for a disability caused by changes to cerebral white matter from central nervous system therapies during childhood cancer treatments.

As writing is “language by hand” (Berninger, 1998, p.333) and is dependent upon fast, automatic and successful simultaneous retrieval (McGill-Franzen & Allington, 2010) of phonemes, graphemes, symbols, letters, letter styles, case and sizing, all areas of literacy for these students require closer attention.

Butler et al. (2008a) used a battery of tests (pp.371-372) to facilitate cognitive rehabilitation programmes with young cancer survivors who had had CNS treatments. The battery included primary measures of academic achievement; working memory, brief focussed attention, memory recall, vigilance, parent/teacher ratings of attention, learning/learning strategies, and even self-esteem. Some of the tests include; the Rey Auditory Learning Test (Trial 1 RAVLT), Digit Span (WISC –III), Sentence Memory (W.RAML), Peabody Individual Achievement Test, Stories (Children’s’ Memory Scale), WRAT – 3 Wide Range Achievement Test, Calculation and Applied Problems (Woodcock-Johnson Tests of Achievement), CPT-II, Strategies Assessment Measure, Digits Backwards (WISC III) Trail making Test B, and CPRS:LV-R (Conners).

Gathering data from a range of assessment tools is essential in understanding the difficulties young cancer survivors may be facing. School and hospital psychologists have the expertise required to select and administer appropriate testing.
5.6 Theme 5

Support from school or other agencies

In this study, the teacher participants lacked support to optimise the learning of their cancer survivor students who had suffered CNS treatments and who may be experiencing neurocognitive late effects. Butler et al. (2008b) describe the lack of assistance for teachers to implement strategies which may help rehabilitate neurocognitive deficits as follows:

Pediatric brain injury rehabilitation for virtually all pediatric CNS insults, however, has now shifted to the educational system. Unfortunately, this system is extremely underfunded, professionals do not receive adequate instruction in brain injury rehabilitation, and few resources are devoted to children whose needs exceed what is available for individuals with idiopathic learning disabilities. (p.254)

Despite Teacher B’s student requiring a great deal of extra support – enough to warrant the involvement of a teacher aide, apparently he was not eligible for funding related to extra staffing nor any other support. A major difficulty for this teacher was the question of how to assist her student when learning accommodations and support were certainly required but none were forthcoming. The student’s mother was agitated about the situation but resigned to the hopelessness of it. The most serious learning problems were apparent for Teacher B’s student, who had endured a brain tumour. This student is much more at educational risk than the students who have had leukaemia as he is already well behind his peers in literacy and numeracy and demonstrating his frustration struggling to cope in class.

The temporary solution of using the classroom teacher to provide support whilst the Final Teaching Practice student taught the class was a successful, if short-lived initiative. Butler et al. (2008b) suggest that brain tumour survivors are at much higher
risk of suffering severe neurocognitive and neurobehavioural late effects, explaining this as follows: “In addition to whole brain treatments, patients who suffer from a brain tumor can also experience CNS damage with resultant neurobehavioral dysfunction associated with focal tumor infiltration, isolated CRT, and surgical resection.” (p.252)

Teacher participants’ students who had survived acute lymphoblastic leukaemia appear to be coping with their school work but all of these teachers identified fine motor skills as an area of concern. Writing, consequently, was difficult, and already, at Year three level, the teachers could see that this was going to be an area of difficulty in the future. There was uncertainty as to what may be available to support the struggling student in this area. Teacher C’s solution was to suggest her student uses pencil grips. Her efforts to broach the subject of professional diagnosis and assistance had been unsuccessful and she felt uncomfortable persisting in revisiting the issue with the parent. All teacher participants were seriously concerned about fine motor skills and their impact on everyday work in the classroom.

Teacher A’s Year five student was much more aware of keeping up with her peer group and more concerned with “appearing to be normal”. Support for this student, such as classroom withdrawal for remediation (a familiar learning support strategy), would not be appreciated by the student. The older the student, the more complex the provision of support becomes. Emotional and spiritual (relationship based) support was provided by other staff in teacher participants’ schools. Since there was no involvement or support from other agencies, teachers had to be self-reliant in coping with the problems their students were facing.

Armstrong & Briery (2008) describe the problems faced by parents trying to access support for their children who are CNS cancer survivors here:

Unfortunately parents of children with cancer have encountered many difficulties obtaining appropriate services, largely because the pattern of
difficulties are unfamiliar to many school personnel involved in determining eligibility for services. Whereas school reintegration programs facilitate a child’s return to school, and many school personnel are more than willing to provide accommodations to address emotional needs, long-term educational needs have not been well identified and addressed. (p.273)

According to Armstrong & Horn (1995), the diagnosis of learning difficulties or other late effects in CNS cancer survivors may offer justification for support or extra resources in schools. However, it must be understood that neurocognitive late effects deficits can change over time; therefore resources or support require close monitoring and adjustment in response to these changes. Armstrong & Horn (1995) explain this as follows:

Recognizing the developmental nature of the effects of cancer and its treatment is a first step in planning appropriate tracking and strategies to assist in learning. This must be followed by further understanding that cancer and its treatment is very complex, and the school-related effects will vary across children, types of cancer, and types of treatment. Individualized educational plans must be developed with the knowledge that a classification (e.g., physically impaired) merely provides access to resources; organization and application of these resources requires careful assessment, implementation, and readjustment over time to meet the often unique educational needs of children who survive. (p.302)

The participants in this study did not have the benefit of any support apart from relationship-based support from other teachers.

5.7 Summary

In Chapter 5, Discussion of the findings; teacher preparedness, absenteeism of the students, communication issues, learning difficulties or disability, and support from
school or other agencies were discussed. The findings revealed that teachers in this study had little or no preparation for teaching students in remission from cancer returning to their classrooms. Student absenteeism related to hospital visits and treatments, illness and other factors were concerns for three of the participants. The teacher participants were facing difficulty communicating with parents about absenteeism, learning difficulties and support. Dysgraphia was evident in all of the teacher participants’ students. One of the teacher participants was struggling to deal with the educational needs of a brain tumour survivor who was well behind his peers and demonstrating many learning difficulties and disabilities.

None of the participants were receiving any support other than relationship-based support from other staff members for the many challenging problems that their students’ school re-entry and ongoing education generated. The final chapter; Conclusion and implications of the study’s findings for future research, policy and practice will provide direction in the ways these phenomena can be addressed in the future.
CHAPTER 6
CONCLUSION AND IMPLICATIONS OF THE STUDY’S FINDINGS FOR FUTURE RESEARCH, POLICY AND PRACTICE

6.1 Introduction
This final chapter will summarise the aims and background of the study, how the thesis was constructed, the findings which arose from the analysis of the data about how teachers deal with paediatric cancer survivors returning to their classrooms after remission and the implications of these findings for future research, policy and practice.

The research aim was to generate substantive theory about how Western Australian teachers deal with students after remission from cancer who have endured therapies affecting their central nervous systems and who return to their classrooms once in remission. The teachers’ individual perspectives of difficulties they were coping with, including; teacher preparedness, absenteeism of the students, communication issues, learning difficulties or disability, and support from school or other agencies enabled theory to be generated about the situation in Western Australian government and independent, country and metropolitan primary schools.

This chapter describes the limitations of the study. Ethical and gatekeeper issues presented difficulties for which any future researcher in this area needs cognisance. Another major limitation was the small number of participants. Only three teacher participants were recruited, plus a pilot participant. Although the interviews could be closely analysed and easily compared, a larger cohort would have provided stronger data about the problems teachers were facing.

Teacher preparedness was the foremost challenge for all of the teacher participants. The literature points to the importance of liaison between the hospital and the school to initiate a school re-entry meeting for students returning to school once in remission from cancer. The documentary data produced in such a meeting can contribute to
teacher preparedness and be a guide for the student’s future teachers, as Health Plans or Individual Education Plans can be formulated and then modified in subsequent team conferences about the student’s progress at school.

Absenteeism of students returning to school and in remission after cancer treatment is inevitable but ICT can be a useful medium to keep students in contact with their school work and their peers. Teachers may feel reluctant to recommend screening for neurocognitive late effects when students are already regularly absent so frequently, but the research indicates the critical importance of early identification of learning problems so that rehabilitation or adjustments can be made or specialist assistance obtained. For the families of students who have survived cancer, remission is an extremely stressful time. The children are at an in-between phase, as they are outpatients still on treatment and not yet considered cured, whilst participating in the normal life of a child at school. Communication issues can be complex for teachers with student survivors returning to school during this phase. A team approach is recommended to alleviate uncertainty and confusion. This chapter outlines the resources available to teachers dealing with these phenomena in the classroom.

School is important to a child in remission from cancer, as it has a positive psycho-social impact, enabling the child to be, once again, socially involved with their peers. Achievements at school contribute to the child’s confidence. Neurocognitive late effects, evident in learning difficulties or disability at school, have a lasting effect on survivors’ quality of life, educational and life attainments. Limitations in educational accomplishment have been reported in longitudinal studies of CNS cancer survivors.

The learning difficulty described by all of the participants in this study was fine motor skills difficulty, but it would be better explained as Dysgraphia, because difficulty with the orthographic loop was evident too, demonstrated by errors recalling grammar rules or retrieving correct graphemes. Processing speed was in question too,
with teacher participants’ students needing more time to complete tasks. Attention and concentration problems, recall and working memory deficits, slower processing speed along with visual-motor integration are some of the neurocognitive deficits reported in the literature for children or adolescents who have survived CNS cancer treatments. Resources are available for teachers to provide support for students with Dysgraphia and Individual Education Plans are essential to document successful strategies used for each student. These adjustments could be recorded on the Nationally Consistent Collection of Data on School Students with Disability.

Researchers recommend a team approach to the challenges of young cancer survivors returning to school after remission. Support from the school or other agencies is essential for teachers dealing with paediatric cancer survivors in their classrooms. Hospitals, school psychologists, school administration, support staff and other professionals are essential for the teachers and their students.

This chapter reports the recommendations for future research. As new treatments are developed in the future, so will new late effects. Therefore, long-term survivors (as well as future treatment survivors) need to be monitored closely to note changing late effects and their implications for learning and academic achievement. Dysgraphia is an area which deserves close attention for CNS cancer survivors. Difficulties with writing indicate not only fine motor problems, but more complex neurocognitive deficits related to working memory and retrieval of elements in the orthographic loop.

The conclusion in this chapter summarises the negative impact neurocognitive late effects can have on a young cancer survivor’s future life opportunities and achievements. Researchers in this field stress that there is no time to lose identifying neurocognitive late effects and implementing a course of action to address them. There is a strong body of evidence to describe the type of learning deficits and how they appear. We already know that neurocognitive late effects exist for CNS (brain or head
tumour and leukaemia) cancer survivors so there is no reason to wait. Teachers may not be able to access assistance or support in dealing with neurocognitive late effects in their CNS cancer survivor students, but even without specialist assessments, teachers can still put Individual Education Plans in place and continue to seek support from their school or the school psychologist. Professional Development in identifying or dealing with the learning disabilities; Dysgraphia, working memory deficits, slow processing speed, attentional and concentration deficits, can all be useful in dealing with CNS cancer survivors. Specific Professional Development such as EDMed or other online resources for teachers dealing with cancer survivors is also extremely valuable. It is likely that the teachers involved in this research may have become more aware of the difficulties and challenges they were facing, as well as more curious about the learning difficulties their students were experiencing. These difficulties may have been previously attributed to socio-emotional factors, the consequences of absenteeism, or health or physical problems.

6.2 Background of the study

In *What is the nationally consistent collection of data on school students with disability?* The Australian Government Department of Education and Training (2016) states the importance of schools providing the best education possible for all students as such: “Schools are at the centre of the educational experience for all Australian students and every student, regardless of their needs, is entitled to a quality learning experience”. (para 4) The Australian Government Department of Education and Training’s (2016) website explains how the Nationally Consistent Collection of Data on School Students with Disability will benefit schools, by helping them to comply with current legislation involving students with disabilities as follows: “The national data collection process will help schools meet their existing obligations under the Disability Discrimination Act 1992 and the Disability Standards for Education 2005.” (para 4)
Askins & Moore (2008) describe the emotional importance of school life to all children, but especially to cancer survivors, as follows:

School is an essential part of a child’s life, even more so while undergoing cancer treatment. School can provide a sense of normalcy, comfort, and hope, which are healing experiences for children and families during an otherwise tumultuous and uncertain time. (p.1166)

Experiencing success at school is also important in countering the emotional pressures of being a cancer patient, as Askins & Moore (2008) explain: “In addition, promoting the child’s academic development during cancer treatment engenders a positive sense of self-efficacy, which may counteract the feelings of helplessness that can accompany cancer and cancer treatment.” (p.1166) Joshua (2010) describes how school presents many challenges for all children throughout their years of schooling, but cancer survivors face extra challenges. On this, he comments:

Every day healthy children face challenges related to school and academic development. From preschool students entering a structured school environment for the first time to high school students making plans for college and life after their senior year, each grade level poses its own obstacles and anxieties. For children with a chronic illness, like cancer, these things are also important. Imagine facing the normal challenges of being a student and then adding the big “C” to that scenario. Fortunately, resources exist to help young cancer patients stay on track with their academic goals. (p. 24)

Lancashire et al. (2009) definitively found that some childhood cancer survivors’ educational attainment was lower than the general population. Their research group of 10,183 cancer survivors was restricted to those survivors who’d endured central nervous system (CNS) neoplasm and leukaemia survivors who had been treated with radiotherapy. They found that those at greater risk of poorer educational outcomes
were survivors who had been treated with cranial radiotherapy, those who had been diagnosed with a CNS tumour, those who were younger at diagnosis, those who were diagnosed with epilepsy and those who were female. The research group did not include leukaemia survivors who had intrathecal chemotherapy only. These specific groups of paediatric cancer survivors achieved lower than expected academic attainment compared to the general population, comparative data found in the General Household Survey. The researchers concluded that educational support for this group of students must be specific and that long term cognitive assessments should be continued to monitor and assist them. Leukaemia survivors were not included in this study but according to the research literature, CNS (intrathecal) chemotherapy affects white matter in the brain (Askins & Moore, 2008) and intrathecal therapies consistently affect neurocognitive performance (Wheeler et al., 2009; Gerhard et al., 2007); therefore it is probable that extending the participant criteria to include leukaemia survivors would demonstrate that they also endure a similar lack of life opportunities and a lower educational attainment than the rest of the population.

Palmer et al. (2007) explain how medulloblastoma survivors are much less likely to complete high school than their siblings and that their future vocational choice and productivity critically rely on the successful completion of school. They comment on the serious life consequence of school failure for medulloblastoma survivors as follows: “Without an education, these survivors are at great risk of losing the ability to live independent lives.” (p.1042)

Ness et al. (2008) forecast a grim future for paediatric cancer survivors who have neurocognitive problems, specifically those affecting executive functioning. As well as lower educational attainment, they describe here their research which disclosed life limitations in this group: “This study also demonstrated that when compared with
participant survivors who did not report such limitations, this group were less likely to be employed, married, or have incomes greater than $20,000 a year.” (p.128)

Wilson et al. (2010) in Survivors of childhood cancer: issues and challenges, describe the challenge of adult productivity for long term cancer survivors who had CNS treatments and who are left with neurocognitive disability. They write as follows: “Difficulties securing and maintaining employment are often reported among survivors of brain tumours and leukaemia, and are generally attributed to neurocognitive deficits that can result as a consequence of CNS directed therapy.” (p.1061)

Wilson et al. (2010) foreshadow the life difficulties associated with long-term survivors who have neurocognitive late effects securing employment, and the effect of these difficulties on society thus: “In instances where survivors experience difficulties securing gainful employment, the burden of care may be transferred to the families of survivors and the community.” (p.1061) Krull et al. (2008) describe the sequelae of negative consequences for childhood cancer survivors who have had CNS therapies as follows:

Studies have suggested that up to 40% of childhood cancer survivors may experience neurocognitive impairment in one or more specific domains (eg, processing speed, attention, memory). Impairment in these specific domains can impede the learning of new information and interfere with the maintenance of previously learned information, which may ultimately lead to declines in global intellect. This, in turn, can result in poor academic and vocational success, low self-esteem, and behavioral or emotional disorders. (p.4138)

According to Ness et al. (2008), young cancer survivors who have had CNS treatments face serious executive function limitations later on in their education, due to neurocognitive late effects. These executive function limitations interfere with educational and job opportunities. Delayed onset of neurocognitive late effects means
that young adult cancer survivors considering further education or job choices may be significantly disadvantaged by their disability. Armstrong & Horn (1995) describe the “long-term learning difficulties” (p. 302) that “emerge over time”. (p.302) Hollen et al. (1997) describe the negative impacts of deficits in “abstract and/or analytic ability” (p.305) on long-term cancer survivors who have had CNS treatments and the researchers relate their concern that these deficits will affect a teenager’s decision making and risk behaviours.

The decline in IQ over time which has been seen in brain tumour survivors as reported by Askins & Moore (2008) and Palmer et al. (2007) lends more weight to the critical importance of monitoring survivors of brain tumours and leukaemia very closely throughout their education and even through the transition to employment after school. Success at school for paediatric cancer survivors is essential for their future lives as productive adults. Askins & Moore (2008) explain that: “Successful completion of school and the acquisition of academic concepts and information is the foundation for adult productivity.” (p.1166) Wheeler et al. (2009) describe the psychosocial impact of childhood cancer on life achievements as follows: “Survivors of cancer in childhood or adolescence are much less likely than their peers to marry, hold a job, reach the same socioeconomic status, hold insurance or complete tertiary education.” (p.194)

Butler & Mulhern (2005) believe it is essential to initiate new directions in assisting children who have endured CNS treatments because school provides the building blocks for creating a successful, productive adult life. Butler et al. (2008a) address neurocognitive late effects from childhood cancer in the same way as other brain injuries and state:

Childhood brain injuries can have a devastating effect both on the ability of the individual to benefit from schooling and develop his or her foundation for a
Butler & Mulhern (2005) emphasise that intervention for cognitive difficulties must not be delayed and there is no excuse for waiting because we can already predict the outcome if a child’s neurocognitive deficits remain unnoticed and unaddressed. They write:

There is clearly a need to advance the impact of our efforts at improving cognitive functioning, especially for children who are school age. Successful completion of school and the acquisition of academic concepts and information is the foundation for adult productivity. Now that cure rates are high, waiting until the patient is known to be a long-term survivor before providing intervention for neurocognitive deficits is no longer defensible. As with the development of cognitive remediation and pharmacotherapy approaches to the treatment of neurocognitive problems in survivors of childhood cancer, we may need to look outside of pediatric oncology for new directions. (p.74)

6.3 Summary of the study

This study used the symbolic interactionist approach, within the paradigm of interpretivism, to answer the central research question; How do teachers deal with paediatric cancer survivors returning to their classrooms after remission? Purposive sampling resulted in only four teacher participants; one pilot participant and three others, teaching in Western Australian government and independent primary schools. The literature review pre-empted an adjustment to the purposive sampling designed to answer the central research question because it revealed the existence of neurocognitive late effects in paediatric cancer survivors who had endured central nervous system therapies during treatment. These were survivors of head or brain
tumours and leukaemia who had been exposed to radiotherapy, chemotherapy or both, resulting in white matter changes in the brain. Therefore, participants were selected on the basis that they were teaching CNS cancer survivors.

Self-generated and participant-led themes or categories emerged from the interviews with the four participant teachers. These five themes were; teacher preparedness, absenteeism of the students, communication issues, learning difficulties or disability, and support from school or other agencies. These themes were intrinsically connected to the literature review which defined the neurocognitive deficits experienced by childhood cancer survivors who had endured central nervous system therapies during treatment (brain tumour or leukaemia survivors).

Teachers were unaware of these risks, but had observed examples of learning deficits, as described in the literature review. Learning difficulties or disabilities common to all four of the participants’ students were; fine motor skills difficulty, completion of written work under time constraints and memory problems. Dysgraphia has been linked to childhood CNS cancer survivors, where a difficulty with writing relates to problems retrieving letters, sounds and concepts from working memory. Many other themes arose from the data analysis, but these five main themes were of most importance to the teacher participants, who are quoted verbatim throughout the thesis. Unfortunately, the lack of support, including the lack of teacher preparedness for teaching such students meant that the participant teachers were unenlightened about the reasons and risks for neurocognitive deficits and about ways they could assist their students. They were also left to their own devices to deal with communicating with parents about the complex problems faced by their students.
6.4 Limitations of the study

The major limitation in this study was the small number of participants interviewed. Only four teacher participants were found, one of them a pilot participant who was in the researcher’s own school and who had taught a CNS cancer survivor in the previous year at another school. It is important to clearly and fully describe here the process of gaining ethical permissions, because any future researcher wishing to undertake studies in this area needs to understand that young cancer survivors and their families require very special ethical considerations. The researcher needed specialised expertise in navigating the pathways to participants in this study. This expertise came from researchers (McLoone et al., 2011) who had already successfully navigated ethics journeys during their research on the subject of socio-emotional issues for childhood cancer survivors returning to school, in Returning to school after adolescent cancer. Even the choice of wording on letters to parents was highly sensitive and needed to be constructed so as not to alarm or distress parents.

Ethical approval needed to be gained firstly from The University of Western Australia’s Ethics Committee, from The Government of Western Australia Department of Education Ethics Committee, from the Ronald McDonald Learning Program, from the parents of the students whose teachers had been identified as potential participants, from the principal of each school associated with the research and from the teacher participants. A parent letter was not permitted so a “gatekeeper issue” arose, preventing the researcher from approaching schools to find teacher participants. Protection of the privacy of paediatric cancer survivors and their families was at the heart of this limitation. The long and highly detailed ethical application was made to the local children’s hospital, but this application was unsuccessful, as, without a parent consent letter, the patient or outpatient’s teachers were unable to be located or contacted. Parents of the students who were identified by the Ronald McDonald Learning Program
national database gave their permission by; either agreeing to forward Participant Information letters to the principal and so doing, or denied their permission by simply not forwarding the letters. These parents had already accessed educational support for their CNS cancer survivor children through the Ronald McDonald Learning Program tutoring services, so it can be assumed they were already cognisant of the need for extra educational support for their children and would not be alarmed or concerned that a researcher may be wishing to contact their child’s teacher for participation in such research. No mention was made of neurocognitive late effects in the parent letters.

Out of the thirty packs of parent, teacher and principal information and consent letters, only three teachers responded and became participants in the study. It is unclear whether parents who had received the other twenty seven packs had actually forwarded letters to their children’s school principals or whether the packs had been forwarded but schools had chosen not to participate. Email reminders were sent by the Ronald McDonald Learning Program to the parents who had received packs but this did not elicit any further response. The criteria necessary for teachers to participate may have been factors further limiting eligibility. Teachers had to be teaching CNS (leukaemia or head and brain tumour) cancer survivors who had been in remission for at least a year and had been back at school for at least a term. If children had relapsed or if they had not yet completed a term back in their classrooms, their teachers would not be eligible to participate.

Having only four participants meant that focus group interviews (originally planned in the study) were not possible. However, the four participants gave rich insights into the central research question and their comments were able to be comparatively analysed very closely. It was fortuitous that the small sample of only four teacher participants were teaching brain tumour as well as leukaemia survivors and that there were equal male and female students. Comparisons about; how teachers deal with
paediatric cancer survivors returning to their classrooms after remission could be made and generalisations formed from the data collected.

6.5 Implications of the study’s findings for future research, policy and practice

6.5.1 Teacher preparedness

Butler & Mulhern (2005) highlight the need for teachers to be supported in dealing with students returning to school once in remission, by educating them about the disease the student has survived, the treatments used and the implications for their learning. They explain as follows:

It has been recommended that all pediatric oncology centers have a structured school re-entry program, one component of which is the education of the patient’s teacher about childhood cancer and the specific signs, symptoms, and special needs associated with the patient’s treatment and treatment outcome.

(p.74)

A school re-entry meeting is essential, so that parents, teachers, school staff, the school psychologist and hospital representatives can discuss important information about the student. Joshua (2010) describes his tips for returning to school thus:

In order to adequately prepare for re-entry into community school, be it public, private or parochial, there are a few basic things that can be done. Parents can initiate these steps or ask a school coordinator for assistance. Set up a school re-entry meeting with both hospital and school representatives. This meeting can take place face to face, via phone or via teleconference. This meeting should include discussion of and collaboration in planning for academic, physical, medical and social impacts of treatment. (p.25)
Any recommendations for school re-entry from the hospital can be documented at the meeting and Joshua (2010) provides a list of some of the common modifications. The list includes; rest periods and restroom breaks, water at the student’s desk, limited or no physical education, shortened assignments, locker breaks and an extra set of textbooks for use at home. Joshua (2010) also recommends that a Health Care plan should be established which should include; recently updated contact information for caregivers, medication information and supply if medications are to be administered during the school day and extra sunscreen and hat for outdoor activities kept at school. Joshua (2010) advises setting up an information session for teachers and peers; “to address any questions or concerns they might have prior to the patient’s return to school”. (p.25) It would be necessary to gain permission from parents of the student’s peers prior to setting up such a session and only age-appropriate information should be shared. The patient needs to be comfortable with the topics chosen to be disclosed to teachers and peers during the session.

6.5.2 Absenteeism of the students

Frequent absence will be a way of life for paediatric cancer survivors after remission, but strategies such as using WebQuests or project work can be successfully integrated into the regular classroom programme, so that the curriculum can be accessed from beyond the classroom and students can demonstrate learning in other ways apart from producing a hand-written assignment. This strategy is especially true for older students, who most value continuity in their peer relationships.

Gerhardt et al. (2007) foreshadow the problems associated with the quality of life of CNS cancer survivors. Some of the problem areas their research identified were; having lower levels of scholastic self-concept and lower levels of academic competence, high likelihood of school absences and repeating grades as well as higher levels of use of
special education services. All of these factors will have serious implications for the later lives of the survivors, as Gerhardt et al. (2007) state here:

Given the significant risk for cognitive and functional deficits after treatment, it is not surprising that research has found that survivors of childhood cancer may not reach certain developmental milestones, or they may have delays in achieving life goals, such as completing their education or finding employment. Furthermore, survivors may be less likely to graduate from high school or college, and they may have fewer plans for educational advancement. (p.448)

The teacher participants’ students in this study were primary school aged, with the oldest student being only Year five level. Hollen et al. (1997) discovered reduced decision making and increased risk-taking evident in their group of fifty two teenage cancer survivors and they recommend particular attention to this issue. Both of these indicators would have serious implications for academic progress and they state: “Intervention to improve decision making needs to be provided for teen survivors; this may be true especially when there is a history of therapy threatening cognitive function.” (p.305)

There are other important factors to consider for these young students who will, in all likelihood, become teenage survivors at high school. These factors are; the increasing importance of working under time constraints, the quantity of writing required dramatically increasing between primary and high school, the use of multiple choice assessments increasing and attention and concentration being challenged by busy timetables, an increasing number of subjects and peer group relationship concerns and pressures. Intervention to address cognitive problems for young students before they become teenage, high-school survivors is essential for their success not only at school, but in their future lives.
Long term CNS cancer survivors at secondary school should be monitored very closely, as neurocognitive late effects may result in serious learning disability and possible decline in IQ, even many years after remission. (Askins & Moore, 2008) There may also be executive functioning and decision making deficits. Poor decision making, higher levels of risk-taking behaviour and reduced analytical ability has been reported by Hollen et al. (1997) Careless, poorly organised work demonstrating a lack of reasoning skills is likely to indicate underlying neurocognitive deficits in attention and concentration. (Stevens, 2011) Compounded by the normal pressures of being an adolescent or young adult as well as the socio-emotional, neurocognitive and psychological issues of being a cancer survivor, reluctance or absenteeism in secondary school aged CNS cancer survivors should trigger warning to school staff.

Krull et al. (2008) recommend annual screening with the brief neurocognitive DIVERGT testing battery so that, year to year, survivors can be monitored for late effects and intervention can be planned. Krull et al. (2008) explain the importance for schools to address cognitive and learning problems as follows:

Early identification and intervention of cognitive and academic difficulties are extremely important. Untreated cognitive and academic difficulties have been associated with a host of negative outcomes pertaining to quality of life in cancer survivors. Children with untreated learning and attention problems are more likely to drop out of school, have a lower earning potential, and have higher incidence for development of emotional and behavioral problems.

(p. 4142)
The adverse consequences of cognitive function deficits or decline, due to CNS treatments, will affect child cancer survivors far into the future. Therefore, it is essential that further research is undertaken to discover ways to monitor, assist and plan for CNS cancer survivors in the classroom.
6.5.3 Communication issues

Teachers of CNS cancer survivors also require clear strategies in order to communicate with parents about the serious issues affecting these students, given that this is an anxious and stressful time for families who are existing from one blood test to the next, desperately hoping their child will not suffer a relapse nor contract an illness which might jeopardise remission. On return to school, cancer survivors’ parents and teachers should meet to discuss the situation, with conference notes being recorded in a document for the student’s file. The communication document templates in *What about school?* (Donnan et al., 2011) would be most useful in starting conversations involving re-entry. If learning difficulties or disabilities are apparent, an Individual Education Plan should be immediately commenced so that successful strategies can be documented for the student’s future teachers. A health plan should also be formulated so that medical considerations can be documented and then adjusted over time as required. Such a plan would also be useful to future teachers, who would gain a snapshot of the student’s medical history as it pertained to school. Joshua (2010) explains how successful school re-entry and ongoing successful schooling requires teamwork as follows:

> However, the process of maintaining academic growth and development post-diagnosis is a task that can be accomplished by patients and families with the assistance of medical professionals, school coordinators, community school officials, the patient and the caregivers. (p.26)

The Leukemia and Lymphoma Society of Canada (n.d.) also recommend good communication and planning: “Parents, educators and medical professionals can work together to develop a program tailored to the child's specific needs.” (para 6)

Childhood Cancer Canada Foundation (n.d.) highlights the importance of teachers diligently monitoring student progress and communicating concerns to parents or other professionals. Learning disabilities, physical problems, emotional and behavioural...
changes should be reported and teachers should take an active role in seeking resources to assist them. Childhood Cancer Canada Foundation (n.d.) outlines recommended strategies as such:

Make the necessary preparations to deal with students who are reluctant to return to school. Look out for potential learning disabilities. Observe any physical problems the student may be having at school and respond appropriately. Recognize emotional and behavioural changes, follow up with parents, and access professional assistance, if necessary. Be cognizant of the variety of resources available locally and nationally to students and their families. (para 7)

6.5.4 Learning difficulties or disability

The one learning difficulty consistently reported by all of the teachers in this study, “fine motor problems”, may signify the existence of Dysgraphia (Berninger, 2004) or difficulty with writing, described by Berninger (2004) as “language by hand” (p.332). Gross and fine motor skills play their part in the composition process, but for students who have changes to their cerebral white matter from central nervous system therapies during childhood cancer treatments, the learning difficulty is associated with working memory, processing speed difficulties and problems with the automatic retrieval of visual, phonic and graphemic input for writing. Berninger (2012) in Strengthening the mind’s eye: The case for continued handwriting instruction in the 21st century, explains how; “non-motor mental processes” (p.28) are involved in handwriting. These processes include working memory, which Berninger (2012) describes as; “a temporary memory system for storing and processing letter forms in the ‘mind’s eye.’ That is, our eyes provide a window through which the written language we read and write enters our mind, which in turn has an inner “eye” for viewing and analysing letters and written words as we read and write.” (p.28)
According to Berninger (2012), the other processes which are required for handwriting are:

- Naming letters, which helps find the letter form in long-term memory and then write it. Planning to form letters before the motor system writes them.
- Incoming visual and touch sensory information as letters produced are viewed and hands and fingers move. The orthographic loop of working memory, which integrates the letters and written words in the mind’s eye with the sequential hand and finger movements during writing. (p.28)

Therefore, “fine motor” difficulties in CNS cancer survivors, reported by researchers and described by the teacher participants in this study are connected to other non-motor cognitive functions. Reduced processing speed, difficulty with working memory and attention problems all contribute to CNS cancer survivors’ writing problems, as: “Contrary to popular belief, handwriting is not merely a motor skill; it is also a written language skill.” (Berninger, 2012, p. 28)

Berninger (2004) further explains the cognitive process of writing as such: “Language ‘by hand’ is a functional brain system in which the internal language code teams with the fine motor system that controls hand movement.” (p. 332) In the video podcast Evidence-based, developmentally appropriate writing skills K to 5: Teaching the orthographic loop of working memory to write letters so developing writers can spell words and express ideas, Berninger (2004) explains the neurocognitive research underpinning effective writing instruction, even including MRI images of students’ brains whilst writing letters and symbols. In this podcast, Berninger (2004) provides explicit teaching strategies which are immediately accessible to teachers.

Differential diagnosis and treatment for Dysgraphia, Dyslexia, OWL LD, and Dyscalculia; *A Few Good Handwriting Intervention Resources* (p.66) recommending the best resources and programmes to use with students who have Dysgraphia. Ready-made templates and checklists are also available. *A Few Good Handwriting Intervention Resources* (Berninger & Alston-Abel, 2009, p.66) is a useful tool, having instant access to links which would be immediately helpful to a teacher trying to formulate interventions for the disability. It would be a good starting point for an Individual Education Plan focussing on addressing the neurocognitive late effect, Dysgraphia.

Berninger (2004) devised the PAL literacy assessment and describes it as such: “The PAL assessment intervention system is aimed at prevention and treatment of writing problems in the elementary grades.” (p. 340) The PAL Guides for Reading and Writing Intervention (Berninger, 1998b) is a manual for administering the PAL –RW test. This system of assessment is a; “research supported intervention linked to specific assessment measures and test results.” (Berninger, 2004, p. 340) The STRANDS (Survey of Teenage Readiness and Neurodevelopmental Status system) (Hooper & Levine, 2001) is aimed at adolescents with writing problems. (Berninger, 2004)

Some simple strategies which were used during research and which resulted in improved writing skills in the early years are described by Berninger (2004) as follows:

Prompting children to study numbered arrow cues for sequential pencil strokes and to write letters from memory was the most effective treatment in increasing accuracy and automaticity of letter production in first graders with poor handwriting. (p.343)

Berninger (2004) explains how writing disability related to working memory and executive function; “affects only high-level composing processes rather than low-level transcription and usually becomes evident during the middle school or high school
grades when the writing requirements of the curriculum increase.” (p.340) In summary, here Berninger (2004) outlines the three major principles associated with intervention for the disability Dysgraphia:

Instructional design principles that have emerged from our research include the following: (1) design instruction to automatize lower level transcription skills, (2) teach for transfer of low-level transcription skills to high-level composing skills, and (3) teach to all components of the functional writing system close in time within the same lesson because of temporal constraints in working memory that may interfere with connections forming among the components of the functional writing system.” (p. 343)

For teachers with a CNS cancer survivor in their class, it may be useful to provide some training for them in the identification of neurocognitive late effects including Dysgraphia. Berninger (2004) recommends the use of “neurological soft signs” (p.330) assessments with students demonstrating Dysgraphia, to give insights into the disability. Berninger provides a wide range of resources which are immediately accessible to teachers trying to construct a plan of action for their students with this disability. Askins & Moore (2008) explain how processing speed has been measured by the Stroop Word-Color Association Test.

The school psychologist would be a valuable resource person who could assist in the proper identification of learning difficulties or disability and who would be the most appropriate person to advise teachers about the course of action that should be taken to address the issues. An Individual Education Plan for students with CNS late effects neurocognitive difficulties or disability is essential, both for inclusion on the Nationally Consistent Data Collection of Data on School Students with Disability and for the successful management of the student’s educational progress.
Armstrong et al. (2005) ask the rhetorical question, Should my child be evaluated for late effects? The researchers answer by recommending that survivors at risk for neurocognitive late effects should be professionally assessed as follows:

Any child who is at risk for late effects or is having difficulty in school should have neuropsychological testing done by a licensed pediatric psychologist or neuropsychologist. Ask your medical team for a referral. The tests may be available free of charge from major medical centers or universities. You may want to tell your child that these tests are painless. (p.7)

The importance of follow up after assessments identifying neurocognitive late effects is encouraged by Armstrong et al. (2005) thus:

When testing is complete, be sure to schedule time for the neuropsychologist to explain the results and any recommendations for adjustments at school that the child may require. If needed, ask the neuropsychologist to help explain the recommendations to the school staff. Keep in mind that even if the first evaluation is normal, at some point in the future your child may experience certain late effects, such as slow processing speed and problems with visual memory. (p.7)

What about school? (Donnan et al., 2011) in its Education pathways sections, recommends relevant testing at different levels of education. For early childhood, middle childhood, late childhood/early adolescence, and adolescence they recommend; Psychometric assessment, Behavioural assessment, Neuropsychological assessment, Speech assessment and Occupational Therapy assessment. Development assessment is suggested for early childhood survivors and Academic assessment for middle childhood, late childhood/early adolescence and adolescence. In Challenges for young adults with cancer, (Donnan et al., 2011) special support is recommended for ongoing problems. Here the researchers explain the complex challenges for older children:
It can be very difficult to separate the medical and psychosocial issues at this point and all young adults need support and understanding during this time. More and more hospitals are providing Adolescent Young Adult (AYA) units for cancer treatment and follow up. Anxiety, depression and post-traumatic stress disorder may be displayed by some young adults. Formal counselling should be offered if needed or if obvious stress becomes unmanageable. (p. 92)

Martins, Lauterbach & Townes (2013) explain how “neurological subtle signs (NSS)” (p.466) can be used to differentiate children with learning disabilities from children with healthy cognitive development. In their seven year longitudinal dental study, on the safety of dental treatments with amalgam, they used NSS to screen 341 children. They used; “six neurological subtle signs directed at aspects of fine motor development, coordination and balance.” (p.470) Here they describe the six tasks:

During this exam the child is asked to perform six tasks during which 6 items are observed and scored: Tandem gait (walk a straight line heel-to-toe, keeping the balance), Motor persistence (stand still with eyes closed and keep the arms outstretched in front, for about one minute); Fine motor control tested by finger-tapping (fast index- thumb finger taps), diadochokinesia (alternating pronation-supination hand pats) and finger-thumb (fast and sequential touching each finger to the thumb, beginning with the fifth finger) (p.471)

The literature review identifies the challenges in obtaining complete neurological evaluations (Krull et al., 2008, p.4138) when teachers may suspect one of their students has neurocognitive late effects and demonstrates learning difficulty or disability. Teachers could do no harm using such NSS assessments to provide them with more information, which could be useful for the school psychologist to evaluate. Many kindergarten and Pre-Primary teachers have been using such tasks informally for decades, for motor coordination practice rather than assessment.
The only way to ensure this group of survivors is not left behind at school and beyond is to carefully monitor them when they return to school after remission, closely attending to any learning difficulties they demonstrate, in order to properly identify deficits and, hopefully, find ways to remediate or rehabilitate them. Teachers cannot do this alone and need the support of their school, the students’ parents, the school psychologist, hospital agencies; liaison staff and psychologists, to assess and record the students’ progress, providing Individual Education Plans, even when they are unsure of the exact learning difficulty or disability diagnosis.

6.5.5 Support from school or other agencies

Teachers with paediatric cancer survivors (particularly leukaemia or brain tumour survivors) returning to life at school once in remission need guidance, information and support in order to fully address the needs of this special group of students. Ideally, teachers could request a visit from a Hospital School Services liaison person to explain and support the situation. At the very least, an information brochure could be developed to explain what remission will mean for their student; the routine visits to hospital for blood tests and check-ups and the maintenance therapies their students may be experiencing. Such a document could touch upon potential relapse and the factors which threaten event free survival in remission, for example, contracting chicken pox. It could discuss the risk of neurocognitive late effects and the importance of formulating an Individual Education Plan for their student, even if they notice (what appear to be) mild learning difficulties.

Butler et al. (2008a) also recommend teamwork between medical, education and psychological professionals to provide a determined plan of action for these students and describe this as such:
The development of a comprehensive and collaborative team that includes the patient, therapist, caregivers, educational professionals, and other involved individuals who will marshal the necessary resources to promote commitment, involvement, and the lifetime use of skills taught during rehabilitation is essential. (p.377)

The role of the hospital school, hospital psychologist and school psychologist is vitally important for facilitating the school re-entry and ongoing monitoring of paediatric cancer survivors’ who have had CNS treatments and who may be struggling with neurocognitive deficits late effects. They may need to become actively engaged with close tracking of the survivors at school, as they progress through the phases of childhood and transitions in their education.

Butler et al. (2008b) recommend cognitive rehabilitation for CNS survivors, but recognise the practical limitations of this strategy for use in schools, which are already under-resourced to deal with students with complex special educational needs. The researchers explain this as such:

In practice, at this time, pediatric brain injury rehabilitation, not only for childhood malignancies, but for all pediatric CNS insults, has progressively shifted toward the educational system. Schools, however, lack the resources to engage in brain injury rehabilitation. They are extremely under-funded, professionals do not have expertise in brain injury rehabilitation, even within the special education arena, and few resources are committed to children whose deficits lie outside the range of typical learning disabilities. Outpatient brain injury rehabilitation needs to be brought back within the purview of physiatry, neurology, and neuropsychology. A team approach is essential and must include medical and nursing professionals, therapists, educators, and caregivers. (p.257)
Although teachers may not have the expertise, support or resources to undertake cognitive rehabilitation with their CNS cancer survivor students, Butler & Copeland’s (2002) metacognitive strategies would be a good starting point which could only lead to positive outcomes for students struggling with CNS cancer neurocognitive deficits. These strategies are simple and can be commenced immediately. Spencer (2006) summarises some examples of the specific metacognitive strategies taught in Butler & Copeland’s (2002) Cognitive Remediation Program. These strategies include; Task preparation, Warm up my brain, Magic/special words (3 student selected words to cue focus), World record (encouraging the student’s highest level of performance), Soup breath (a brief relaxation exercise), Game face, Talk to myself (self-encouraging and self-alerting), Mark my place (ticking the beginning or end of rows to keep place), Start at the top, 1 row at a time, Look for shortcuts, Time out to take a break/start over to ask for help, (to avoid becoming overwhelmed or frustrated), Look at the floor (when distracted, staring at the floor or a blank surface is helpful), asking for Hints, Post-task check your work, Ask for feedback, Reward yourself (celebrating improved performance or achievement).

Internalized metacognitive strategies allow students to manage their own learning by teaching them individualised and unique ways to overcome challenges they confront at school. Strategies that work well for the student can be recorded in Individual Education Plans for future reference by other teachers and also shared with parents for use at home, especially with homework tasks. IEPs which contain successful individualised strategies for learning would support CNS cancer survivors’ future teachers’ efforts to provide adjustments, develop individualised programmes or modify learning situations for the student.
6.6 Recommendations for future research

Wilson et al. (2009) explain that most research into late effects has mainly targeted the first decade of long term survivorship and that, in future, it will be necessary to extend this timeframe because of new treatments which will be used and also to monitor trends in new or different long term late effects. The researchers explain this as follows:

Thus, there will be an ongoing need to systematically follow survivors of childhood cancer produced by these new treatment strategies, to identify changes in the pattern of late effects, and to detect the emergence of previously unrecognised long term complications of anti-cancer therapies. (p. 1062)

This small scale, exploratory study of how teachers in Western Australian schools deal with paediatric cancer survivors returning to their classrooms after remission may serve as a precursor to further research in a comparative study of a larger scale involving many more participants. Variables could include extending the age group of the student typology being taught, increasing the purposive sampling to extend to teacher participants dealing with younger and much older students.

Further consideration and attention should also be given to the exposition and understanding of Dysgraphia, or “fine motor” difficulty as it relates to CNS survivors, as described throughout the literature and throughout the teacher participant interviews. For this group of students, the learning difficulty may flag much more serious working memory problems, which may only become obvious in later school years when high-level thinking and writing are demanded.

One successful strategy used by the teacher of the oldest student in this study was to incorporate ICT into school tasks and projects. The benefits of this portable, independent learning are obvious for students who are often absent from school, travelling to and waiting for appointments. Remote group projects like WebQuests can help older students keep in touch with their peers and assist in maintaining continuity in
their relationships at school. The investigation of suitable WebQuest or similar online or computer software materials for use with these students warrants attention. There are many excellent apps being developed for learning in all curriculum areas and these also require exploration for use by CNS cancer survivors. It is unlikely that teachers would be able to implement cognitive rehabilitation programmes in the classroom without extra support enabling on-to-one supervision and encouragement, but ICT is an ideal medium to introduce repetitive drills and tasks in order to improve student confidence and performance in target areas where there are learning deficits. For example, the Stroop Word-Colour Association test is a good example of a repetitive task which can lead to improvement in a cognitive skill which is highly suited to practice using ICT.

The development of online cognitive rehabilitation or computer software which is appropriate for use with young CNS cancer survivors would be most useful in assisting teachers to provide support and intervention for neurocognitive deficits in CNS cancer survivors, either in the classroom or whilst the student is absent.

Tasks for such online cognitive rehabilitation could focus on developing skills in attention and concentration, memory and working memory, visual and spatial integration skills, processing speed and decision making or executive functioning skills. Like other online programmes being used in schools, online cognitive rehabilitation could be in game format with achievement rewards, and like Attention Process Training (Butler et al., 2008a), have an inbuilt mechanism for task switching if the user cannot achieve 50% on a task. As with the tasks described by Butler et al. (2008a), online or software tasks could be in timed blocks of fifteen minutes.

The cognitive behavioural approach described by Butler & Mulhern (2005) enables the student with disability to build their own repertoire of individualized strategies and is an easy strategy for teachers to use with CNS cancer survivors with neurocognitive deficits. Research into how these strategies can be successfully shared among teachers
is important. Networking to disseminate best practice for teachers dealing with these students in the classroom is essential, as the participants in this study were working in isolation. The concept of building networking platforms for these teachers needs consideration. Butler et al. (2008a) emphatically stress the need for funding to address neurocognitive late effects in childhood survivors, stating as follows:

A new standard of care in pediatric outpatient brain injury rehabilitation must be advanced. The educational system is underfunded, and there are few adequately trained faculty and staff. Medical caregivers in the area of clinical neuropsychology, psychiatry, and pediatric neurology need to become more involved and should be appropriately funded. (p.377)

6.7 Conclusion

As survival rates grow, so does the number of students who may be affected by late effects neurocognitive difficulties and whose teachers need assistance, guidance and expertise to deal with their students’ special needs. Wheeler et al. (2009) use the metaphor of a shifting finishing line to describe the journey for paediatric cancer survivors who have had CNS treatments thus:

In many pursuits, the ‘finishing line’ is not always where you think it is. For many years the ‘finishing line’ for children and adolescents with cancer was being told that they were cured – usually after four to five years of disease free survival. It is now apparent that the consequences of having had a malignancy, especially in childhood, can impact many years later. (p.192)

According to Children’s Cancer Foundation (n.d.), the average age for adults to be diagnosed with cancer in is 67; for children the average age is 6, with more than half of all child cancers diagnosed between 0-4 years of age. Askins & Moore (2008) explain how the most important life events are still ahead for young cancer survivors. This fact
is particularly relevant to children who have endured CNS treatments during cancer treatment and who suffer neurocognitive late effects. Askins & Moore (2008) comment on this point as follows:

The number of postcancer life-years is much greater for surviving children than for adults, and for children these years often include major life milestones such as education, career, and reproduction decisions. (p. 1160)

Wheeler et al. (2009) explain that long term survivors need to be given information about the potential for late effects, without giving them a negative or pessimistic view. Here they explain the dilemma:

One of the more insidious and common problems faced by cancer survivors is the lack of knowledge about the issues by both themselves and their treating medical practitioners. Clearly there needs to be a balance in informing survivors of their long-term risk and causing unnecessary concern. (p.195)

This could also be said for teachers dealing with survivors in their classrooms, parents of CNS cancer survivors as well as school psychologists who need to be aware of the risks and signs of neurocognitive late effects. Teachers of cancer survivors, especially students who have survived CNS cancer, should not hesitate to instigate referrals to specialists to assist with learning difficulties or disability, despite the student’s already crowded appointment calendar. Learning difficulties may not be at the top of the list of priorities for families of students in remission returning to school, but there is no time to lose in properly identifying and addressing them. The impact of what may appear to be a minor “fine motor difficulty” in Junior Primary may be heavily felt later on in the Secondary school, when writing competence under time constraint is a necessity of daily life in the classroom. What seem to be minor or infrequent working memory problems, such as; difficulty following a thread of instructions, trouble consistently forming correct letters or remembering sounds when writing, struggle and
confusion when trying to follow a number of comprehension questions or complete problem solving tasks, or confusion when completing multiple choice tasks may seem insignificant, but life-long decision making and executive functions are built from successful performance of such skills.

According to Butler et al. (2008a), the neurocognitive damage suffered during CNS cancer therapies cannot now be undone; however rehabilitation should be the goal. They state as follows:

It is likely unreasonable for us to expect to be able to rehabilitate children/adolescents with a brain injury to a pre-CNS insult level of functioning. We believe, however, that it is incumbent on us to devise strategies that will ensure rehabilitation, compliance, and increased program potency. In addition, more extensive follow-up treatment and the possible benefits of adding booster sessions over time should be investigated. (p. 376)

Armstrong et al. (2005) explain how regular neurocognitive assessment should be undertaken, with special attention to it coinciding with students’ milestones like transitions from primary to secondary school, namely:

Periodic evaluations may be needed at academically challenging times, such as entry into elementary, middle, or high school or during pre-college planning.

Ask your medical team to suggest a follow-up care program that includes periodic evaluations. (p.7)

The Leukemia and Lymphoma Society of Canada. (n.d.) also recommends long-term planning for the students throughout their education: “Plans can be developed to help a child through certain situations such as transitioning from middle school to high school or going on from high school to secondary education and adult life.” (para 9)

Askins & Moore (2008) discuss the importance of early intervention for young cancer survivors with a history of CNS therapies. They believe there may be an
optimum time, or window of opportunity, when students would most benefit from diagnosis of neurocognitive deficits and intervention to assist them. They state:

Overall, these studies have shown that children start to fail to advance in their neurocognitive and academic achievement soon after the diagnosis of cancer; thus it is imperative to institute intervention programs early to attenuate these learning and academic problems. (p. 1166)

Askins & Moore (2008) explain the critical importance of timely intervention. Just as head injury rehabilitation must be commenced quickly and methodically, so CNS treatment survivors must have the benefit of similar rigorous therapy to optimize their potential for recovery. This is explained as follows:

Indeed, studies that have examined head injury rehabilitation in children suggest the importance of early intervention for restoration of impaired functions via relearning and practice. There may be an optimal or critical period during brain development and/or rehabilitation when cognitive and environmental stimulation are required for the brain to maximize its potential for recovery from the insults associated with central nervous system treatment. (p.1166)

Teachers cannot be expected to devise strategies, provide remediation and implement Individual Education Plans without any background knowledge of neurocognitive late effects in childhood cancer survivors nor the resultant learning difficulties and disabilities. They should feel confident and justified asking for assistance and support to deal with students in remission returning to school. Neurocognitive late effects can appear at any stage after treatment and can lead to declines in academic ability. In the teenage years, in secondary school settings, neurocognitive late effects can easily be mistaken for behavioural issues. Problems with attention and concentration, along with working memory deficits, in young CNS cancer survivors, can later cause; poor
reasoning and decision making, low analytical ability and deficient executive functioning when they are older students at school. (Jain & Krull, 2009)

The long-term consequences of neurocognitive difficulties or disability can have a negative effect on long-term CNS paediatric cancer survivors’ later education and life achievements. Assistance needs to be put in place as soon as possible because early intervention for these learning problems may optimise the rehabilitation opportunity. This study also highlights the need for a support network involving health and education professionals and hospital staff to assist teachers in understanding the physical and neurocognitive issues the students are facing whilst attempting to return to the normalcy of student life in a mainstream school. Teachers can have an enormous influence on optimizing survivorship but it’s essential they are equipped with knowledge and information, supported through the process of coping with paediatric cancer survivors returning to school after remission.

Despite disability discrimination protection embedded in human rights policy and legislation, CNS cancer survivors appear to be flying under the radar, not even picked up by the Nationally Consistent Collection of Data on School Students with Disability. Their teachers seem to be flying blind in unfamiliar territory, without the benefit of navigation instruments. It is essential that they receive support and assistance so that they can deal with the challenges they and their CNS cancer survivor students are facing. The Professional Development opportunity, EDMed (Ronald McDonald Learning Program, n.d.) is freely available to schools and should be utilised.

Butler et al. (2008b) stress the importance of young survivors being supported by a cooperative team of people, involving home, school, hospital and other specialist agencies. They describe this approach as such:

A team approach is essential and must include medical and nursing professionals, therapists, educators, and caregivers. All members must engage in
a cooperative, problem-solving relationship that advocates for the child rather than in adversarial struggle. (p.257)

Butler et al. (2008b) explain how hospital schools have a significant role to play in monitoring cancer survivors in the early stages after central nervous system treatments. Here they relate the reasons hospital schools need to become actively involved:

The need for comprehensive hospital-based education programs is compelling for children with cancer because of the long duration of treatment (which typically lasts from 1 to 3 years) and the risk for cognitive and academic declines experienced by those who undergo CNS therapies. (p.256)

As Moore (2005) writes here, there is more to paediatric cancer survivorship than simply survival, as: “The ultimate goal of cancer therapy today is not simply medical cure but cure that results in the survivors’ healthy, long-term neurocognitive outcome and optimum quality of life.” (p. 60)

Finally, Armstrong & Horn (1995) suggest an optimistic outcome if schools recognise the neurocognitive late effects of cancer, develop strategies to use in individualised education plans and organise appropriate monitoring and adjustment to assist learning in CNS cancer survivors. Here they describe the “solid potential payoff” (p.302) of such efforts:

Although a large number of children with cancer may need special education services many are able to complete school, enter college, and earn college degrees if provided appropriate intervention. Providing children with this possible outcome is a far better alternative than having them survive cancer and face failure because appropriate steps to intervene were not taken. (p.302)
REFERENCES


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SUPERVISORS

Chief Investigator: Professor Simon Clarke
Supervisor: Professor Tom O’Donoghue

Professor Simon Clarke  Master’s Degree Programs Course Coordinator, Graduate School of Education, Coordinating Supervisor.

Professor Clarke provided guidance and advice in qualitative research methodology and in school-based research approaches exploring systemic initiatives and change.

Professor Tom O’Donoghue  Professor, Graduate School of Education

Professor O’ Donoghue’s knowledge of interpretivist research, constructing and completing a thesis, research experience in students with disabilities and inclusion in school systems was invaluable.
APPENDIX A

Note. From

<table>
<thead>
<tr>
<th>Questions from the Brief-A Used in the Second Follow-Up Survey</th>
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<tr>
<td>Below is a list of statements that describe problems that people can have. We would like to know if you have had any of these problems over the past six months</td>
</tr>
<tr>
<td>1. I get upset easily</td>
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<tr>
<td>2. I don’t think of consequences before acting</td>
</tr>
<tr>
<td>3. I am disorganized</td>
</tr>
<tr>
<td>4. I forget instructions easily</td>
</tr>
<tr>
<td>5. I have problems completing my work</td>
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<tr>
<td>6. My mood changes frequently</td>
</tr>
<tr>
<td>7. I am impulsive</td>
</tr>
<tr>
<td>8. I have trouble finding things in my bedroom, closet or desk</td>
</tr>
<tr>
<td>9. I forget what I am doing in the middle of things</td>
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<tr>
<td>10. I have problems getting started on my own</td>
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<tr>
<td>11. I am easily overwhelmed</td>
</tr>
<tr>
<td>12. I have trouble doing more than one thing at a time</td>
</tr>
<tr>
<td>13. My desk/workspace is a mess</td>
</tr>
<tr>
<td>14. I have trouble remembering things, even for a few minutes (such as directions, phone numbers, etc.)</td>
</tr>
<tr>
<td>15. I have trouble prioritizing my activities</td>
</tr>
</tbody>
</table>
APPENDIX B

Note Adapted from

Neurocognitive Deficits and Risk Factors Among Children Treated for Acute Lymphoblastic Leukemia (ALL) and Malignant Brain Tumors

Neurocognitive deficits
Core symptoms Attention
Working memory
Processing speed
Secondary symptoms IQ loss
Academic failure
Vocational & social problems
Risk factors for deficits
ALL Young age at treatment
Cranial radiation therapy
Intrathecal and IV methotrexate
Corticosteroids
Female gender
Brain tumors Young age at treatment
Cranial radiation therapy
Tumor invasion of normal brain
Trauma from surgical resection
Hydrocephalus
Seizures Sensory and motor impairments
Female gender
APPENDIX C

Note. Adapted from


DEFICITS FOLLOWING TREATMENT FOR CHILDHOOD CANCER

<table>
<thead>
<tr>
<th>DOMAIN</th>
<th>STATUS FOLLOWING TREATMENT</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cognition</td>
<td>Not impaired initially but gradually declines</td>
</tr>
<tr>
<td></td>
<td>Non-verbal reasoning may be affected</td>
</tr>
<tr>
<td>Auditory-linguistic/Language</td>
<td>Generally vocabulary and comprehension spared</td>
</tr>
<tr>
<td>Functions</td>
<td>Naming fluency/retrieval impaired</td>
</tr>
<tr>
<td>Auditory-linguistic/Language</td>
<td>Visual perception ability impaired, visual-motor integration impaired</td>
</tr>
<tr>
<td>Constructional Praxis</td>
<td>Perceptual motor skills impaired</td>
</tr>
<tr>
<td></td>
<td>Visual-motor constructional skills impaired</td>
</tr>
<tr>
<td>Processing Speed</td>
<td>Information processing speed/ sluggish cognitive tempo</td>
</tr>
<tr>
<td>Learning and Memory</td>
<td>Short–term memory impaired</td>
</tr>
<tr>
<td></td>
<td>Verbal memory impaired</td>
</tr>
<tr>
<td></td>
<td>Nonverbal memory/Visual memory impaired</td>
</tr>
<tr>
<td></td>
<td>Working memory impaired</td>
</tr>
<tr>
<td></td>
<td>Recognition skills tend to be spared</td>
</tr>
<tr>
<td>Attention/Concentration</td>
<td>Attention: focused, selective, and sustained tend to be impaired</td>
</tr>
<tr>
<td></td>
<td>Attentional flexibility also impaired</td>
</tr>
<tr>
<td>Executive Function</td>
<td>Sequencing impaired</td>
</tr>
<tr>
<td></td>
<td>Fluid abilities and problem solving impaired</td>
</tr>
<tr>
<td>Achievement/Academic Skills</td>
<td>Arithmetic achievement affected negatively</td>
</tr>
<tr>
<td></td>
<td>Learning in general slowed</td>
</tr>
<tr>
<td>Emotional/Behavioral</td>
<td>Difficulty with coping and emotional regulation</td>
</tr>
<tr>
<td>functioning</td>
<td>evident in conjunction with executive function deficits</td>
</tr>
</tbody>
</table>
### Guiding Question Matrix

<table>
<thead>
<tr>
<th></th>
<th>Have any learning difficulties been observed in these areas?</th>
<th>Have new strategies been introduced or trialled in addressing difficulties?</th>
<th>Have adaptations been made to learning programmes to accommodate learning difficulty?</th>
<th>What are the main issues believed to be affecting the student's performance?</th>
<th>Has there been any intervention by support staff or agencies for learning difficulty?</th>
</tr>
</thead>
<tbody>
<tr>
<td>Reading speed and comprehension</td>
<td>B D</td>
<td>B</td>
<td>B</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Sequential memory</td>
<td>A B</td>
<td>B</td>
<td>B</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Processing speed when learning new concepts</td>
<td>A B</td>
<td>B</td>
<td>B</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Organisation: Daily tasks, assignments and locating materials</td>
<td>B C</td>
<td>A</td>
<td>B</td>
<td>B</td>
<td></td>
</tr>
<tr>
<td>Understanding maths concepts/remembering math facts</td>
<td>B C</td>
<td>B</td>
<td>B</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Visual memory for new things: decoding letters, numbers and music</td>
<td>A B</td>
<td>B</td>
<td>B</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Auditory Memory: Following instructions</td>
<td>B</td>
<td>B</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Fine-motor coordination Visual-motor integration</td>
<td>A B C D</td>
<td>A C</td>
<td>B</td>
<td>A B C D</td>
<td></td>
</tr>
<tr>
<td>Attention and concentration</td>
<td>A B C</td>
<td>B</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
APPENDIX E

Research Support
Ronald McDonald Learning Program
& The University of Western Australia Master's Student - Anne Christie

Project Title: How teachers deal with paediatric cancer survivors returning to their classrooms after remission.

Student: ANNE CHRISTIE (ID 20453519)
THE UNIVERSITY OF WESTERN AUSTRALIA
GRADUATE SCHOOL OF EDUCATION
Masters in Education Thesis Proposal
Project Number: RA/4/1/4703

Background: (NAME) was contacted by Anne Christie about support for her research project in mid 2011. Anne is currently teaching at Nedlands Primary School and pursuing Masters studies at the University of Western Australia. Approval for (NAME) to work with Anne was given by (NAME). (NAME) communicated with Anne and her UWA Supervisor, Simon Clarke, to ascertain RMLP involvement and to refine her research proposal. Her aim was to develop theory about Western Australian government school teachers’ beliefs, feelings, ideas and observations about teaching students who have been treated for cancer and who are returning to their classrooms. (NAME) met with Anne whilst in WA to discuss the research project further in November 2011. All communication was passed on to (NAME) with the proposal to recruit families from the WA RMLP database. The only requirement for RMLP family contact was to ask the parents to pass on a participation letter to the school where there was a class teacher who had taught their child. (See process steps below).

Anne undertook the lengthy ethics approval process during 2011 and 2012. This included (NAME) reviewing all participant and consent letters as they may apply to anyone contacted through the RMLP. This study has been approved by The University of Western Australia Ethics Committee and the Department of Education and Training Ethics Committee. All Ethics Approval documents and final approved participation and consent letters have been received by (NAME) and remain on file. Anne is aiming to commence recruitment in Term 1, 2013.

Research Statement of Purpose:
The aim of this research is to generate substantive theory about a new and rapidly growing special needs area in education. The survival rate of paediatric cancer patients has risen dramatically in the last four decades because of new protocols and drugs used in treatment. Although the survivor rate steadily increases, there is a serious survivorship issue of educational equity for those left with neurocognitive disability related to treatment therapies. This research aims to shed light on the current situation in Western Australian schools.

Research Questions:
The central research question for the study is; How do classroom teachers deal with paediatric and adolescent oncology survivors who have endured treatments affecting the central nervous system and who are returning to their classrooms after remission? The guiding questions for the initial collection of data are:
• What are teacher perspectives of learning difficulties in children who return to school after remission?
• What strategies or adjustments are being used by teachers in response to perceived learning difficulties in students in remission?
• What do teachers perceive as the main issues when dealing with children who return to school after remission?

The research questions would be asked during focus groups with participating teachers and/or phone interviews.

RMLP Involvement - steps
• WA RMLP Parents who are currently receiving or have within the last 12 months received RMLP tutoring would be identified from the Exceed database.
• Parents would be mailed out a package of information. Within the package is:
  o A cover letter from the RMLP.
  o A research participation letter to the parent.
  o An envelope to pass on to their child's School Principal and within that envelope is the letter to teacher participant(s). (DET have required the school site to fill out a consent form prior to issuing a letter to teachers.)
• Parents either agree to pass on the package to the principal - consent - or do nothing. No further contact is made with the RMLP parents.
• Anne would be requested to prepare the packages and take them to RMH Perth for (NAME) to place mailing labels on the packages to parents.
• At no time would Anne have access to any RMLP names or addresses.
• A RMLP cover letter within the Principal and Teacher package would also be included.
• Principals and teachers send consent forms back to Anne Christie
• Teacher research focus groups and interviews are then arranged by Anne Christie.
• Teacher Focus Groups would take place at The University of WA Graduate School of Education group interview rooms.

Anne's goal is to get 12 participants for the focus groups. Initially she was seeking students over the age of eleven but this is perhaps not so important now, because proximity to the UWA for the teacher participants will be more critical to the success of the study.
Anne would interview 6 teachers in a focus group to clarify the major issues, and then follow up with the other 6 teachers for one-to-one interviews. Again, the availability of teachers to meet after school hours in the middle of the city is going to be a major factor in the interviews.
Initial letter distribution to RMLP families who have had a child treated for cancer would be to as many as possible in order to account for research retention rates of 30-50%.
(NAME) would request a review of Anne's master's thesis draft in order to ensure that the RMLP has been appropriately and correctly represented within her research write up.
Dear Parent,

On behalf of Anne Christie I am writing to invite you to participate in a Masters Thesis study. Anne is currently teaching at Nedlands Primary School and pursuing her M.Ed at the University of Western Australia. This year she is conducting research focusing on teachers currently or previously educating students who have been treated for cancer with chemotherapy or radiotherapy protocols. Your participation would simply involve passing on an invitation to your child’s school principal who, in turn, may pass on an invitation to your child’s teacher/s.

Her research topic is entitled “How teachers deal with paediatric cancer survivors returning to their classrooms after remission.” Her aim is to develop theory about Western Australian government school teachers’ beliefs, feelings, ideas and observations about teaching students who have been treated for cancer and who are returning to their classrooms.

This study has been approved by The University of Western Australia Ethics Committee and the Department of Education Ethics Committee.

Individual teachers’ participation will require some commitment of time throughout this year but this will not affect your child in any way. Twelve teacher participants will be interviewed on two separate occasions during the study. Your child will not be involved in the interview process in any way. The only written information relating to your child which may be viewed for the purpose of the research would be any (if any) data associated with the teacher developing strategies in the learning programme for your child, for example an Individual Education Plan. No other student documents would be viewed by the researcher. **Names would be removed from any such documents.**

Should you agree to your child’s teacher’s participation in this study, confidentiality will be maintained. Neither teachers, students, administrators nor their schools will be identified at any stage during the conduct of the research or in any publications or discussions that may result from this study in the future. The complete privacy of you, your child, your child’s teacher, principal and school is completely assured. You may
also withdraw, without prejudice, from the study at any time. If that is the case, any data that may have been collected from your participation will be destroyed.

If you would like to know any more information about this study, please do not hesitate to contact Anne on 0414384929 or email her at 20453519@student.uwa.edu.au. She is very happy to answer your questions. If you have any concerns about the organisation or running of this study, you can contact the Secretary, Human Research Ethics Committee, Registrar’s Office, University of Western Australia, 35 Stirling Highway, Crawley, WA, 6009. (Telephone number 6488 3703).

An extensive search has uncovered very little research in Australia focusing on teachers involved with teaching students who have had treatment for cancer when they return to school. Your contribution to this valuable study will be important in helping to inform policy makers, system administrators and practitioners about the work and needs of teachers dealing with such students in their classrooms now and in the future.

**If you would like your child’s teacher(s) to participate, we ask that you:**

- Pass on the enclosed invitation to your child’s school principal, who will then pass on an invitation to your child’s teacher(s)/education professional(s) (this may include multiple teachers in the case of high school students, past teachers if they have changed grades or swapped schools in the last 18 months).
- If you do not wish to involve your child’s teacher(s) in this study, or would prefer we do not discuss your child’s progress with their teachers,
- Please feel free to not pass on the teacher’s invitation to them.

Thank you for your time.

Yours sincerely,

Anne Christie

Masters Thesis Student

Professor Simon Clarke

Masters Supervisor
Dear Principal,

*How teachers deal with paediatric cancer survivors returning to their classrooms after remission.*

On behalf of Anne Christie I would like to invite [Department site] to participate in a Masters Thesis study. Her research focuses on those teachers who are currently educating students in remission from cancer after surviving chemotherapy or radiotherapy protocols involving the central nervous system; leukaemia survivors or students who have received radiotherapy to the head. These survivors are at most risk of demonstrating learning difficulties at any stage post-remission. [Department site] is one of twelve schools in Western Australia being approached for its participation. The aim of this research is to develop theory about Western Australian government school teachers’ perspectives about teaching students who are in remission and returning to their classrooms.

It would be much appreciated if one teacher from your school is able to participate in the study. This teacher has been identified by Ronald McDonald Learning Programme as currently or previously teaching a child who has survived cancer treatment for leukaemia or cancer in the head area. These students are most at risk of their past therapies interfering with their normal academic progress and their day to day success at school.

The teacher will be invited to participate in a focus group interview with five other teachers of between forty five minutes and an hour’s duration at the University of Western Australia Graduate School of Education. If the teacher is willing, he/she will be invited to participate in an extra one-to-one follow up interview. The individual interviews will be between forty five minutes and an hour’s duration.

Participation in this research project is entirely voluntary. If any member of a participant group decides to participate and then later changes their mind, they are able to withdraw their participation at any time. If that is the case, any data that may have been collected from your participation will be destroyed. There will be no consequences relating to any decision by an individual or the [Department site] regarding participation, other than those already described in this letter. Decisions made will not affect the relationship with the research team or The University of Western Australia.
Should you choose to participate in this study, confidentiality will be assured. Neither teachers, students, administrators nor their schools will be identified at any stage during the conduct of the research or in any publications that may result from this study. If you would like to discuss any aspect of this study with a member of the research team, please contact Anne on 0414384929 or email her at 20453519@student.uwa.edu.au. If you wish to speak with an independent person about the conduct of the project, please contact Bev Vickers Bev.Vickers@education.wa.edu.au who represents the DoE Ethics Committee monitoring the study.

Approval to conduct this research has been provided by The University of Western Australia and the Department of Education, in accordance with their ethics review and approval procedures. Any person considering participation in this research project, or agreeing to participate, may raise any questions or issues with the researchers at any time. In addition, any person not satisfied with the response of researchers may contact the Human Research Ethics Office at The University of Western Australia on (08) 6488 3703 or by emailing to hreo-research@uwa.edu.au. All research participants are entitled to retain a copy of any Participant Information Form and/or Participant Consent Form relating to this research project.

If you have had all questions about the project answered to your satisfaction, and are willing for the [Department site] to participate, please complete and return the Consent Form on the following page in the stamped, self-addressed envelope provided and also forward the Teacher Participant Information Sheet and Consent Form to the identified teacher.

Thank you for your interest in this research project.

Yours sincerely,

Anne Christie          Professor Simon Clarke
Masters Thesis Student  Masters Supervisor
CONSENT TO PARTICIPATE IN A RESEARCH PROJECT

How teachers deal with paediatric cancer survivors returning to their classrooms after remission.

I, ____________________________, have read the information provided and any questions I have asked have been answered to my satisfaction. I agree to participate in this activity, realising that I may withdraw at any time without reason and without prejudice.

I understand that all information provided is treated as strictly confidential and will not be released by the investigator unless required to by law. I have been advised as to what data is being collected, what the purpose is, and what will be done with the data upon completion of the research.

I agree that research data gathered for the study may be published provided my name or other identifying information is not used.

__________________________  ______________________
(Participant)                     (Date)

Approval to conduct this research has been provided by The University of Western Australia, in accordance with its ethics review and approval procedures. Any person considering participation in this research project, or agreeing to participate, may raise any questions or issues with the researchers at any time. In addition, any person not satisfied with the response of researchers may raise ethics issues or concerns, and may make any complaints about this research project by contacting the Human Research Ethics Office at The University of Western Australia on (08) 6488 3703 or by emailing to hreo-research@uwa.edu.au. All research participants are entitled to retain a copy of any Participant Information Form and/or Participant Consent Form relating to this research project.
How teachers deal with paediatric cancer survivors returning to their classrooms after remission

Dear Teacher,

On behalf of Anne Christie I would like to invite you to participate in a Masters research project. Her research focuses on those teachers who are currently educating students who have had treatment for cancer and who have endured chemotherapy or radiotherapy protocols involving the central nervous system; leukaemia patients or students who have received radiotherapy to the head. These students are at most risk of demonstrating learning difficulties at any stage post-remission. You are one of twelve teachers in Western Australia being approached for their participation. The aim of this research is to develop theory about Western Australian government school teachers’ perspectives about teaching these students returning to their classrooms.

You have been identified by Ronald McDonald Learning Program as currently teaching or previously teaching a child who has endured treatment for leukaemia or cancer in the head area. These students are most at risk of their past therapies interfering with their normal academic progress and their day to day success at school.

You will be invited to participate in a focus group interview with five other teachers. This interview will be for about an hour and will be held at the University of Western Australia Graduate School of Education. If you are willing, you will also be invited to participate in a one-to-one follow up interview. The individual interviews will be between forty five minutes and an hour’s duration, either face to face or by phone, according to participants’ preferences.

Participation in this research project is entirely voluntary. If any member of a participant group decides to participate and then later changes their mind, they are able to withdraw their participation at any time. If that is the case, any data that may have been collected from your participation will be destroyed. There will be no consequences relating to any decision by an individual regarding participation, other than those already described in this letter. Decisions made will not affect the relationship with the research team or The University of Western Australia.

Should you choose to participate in this study, confidentiality will be assured. Neither teachers, students, administrators nor their schools will be identified at any stage during the conduct of the research or in any publications that may result from this study. If you would like to discuss any aspect of this study with a member of the research team, please contact Anne on 0414384929 or email her at 20453519@student.uwa.edu.au.

If you are willing to participate, please call or email Anne. It would also be appreciated if consent forms are signed and returned in the stamped, self-addressed envelope before focus group interviews. If you wish to speak with an independent person about the
conducted of the project, please contact Bev Vickers Bev.Vickers@education.wa.edu.au who represents the DoE Ethics Committee monitoring the study.

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If you have had all questions about the project answered to your satisfaction, and are willing to participate, please call or email Anne and complete and send the Consent Form on the following page.
Thank you for your interest in this research project.

Yours sincerely,

Anne Christie Professor Simon Clarke
Masters Thesis Student Masters Supervisor
CONSENT TO PARTICIPATE IN A RESEARCH PROJECT

How teachers deal with paediatric cancer survivors returning to their classrooms after remission.

I, ______________________________________________________, have read the information provided and any questions I have asked have been answered to my satisfaction. I agree to participate in this activity, realising that I may withdraw at any time without reason and without prejudice.

I understand that all information provided is treated as strictly confidential and will not be released by the investigator unless required to by law. I have been advised as to what data is being collected, what the purpose is, and what will be done with the data upon completion of the research.

I agree that research data gathered for the study may be published provided my name or other identifying information is not used.

_________________________________________________  ______________
(Participant)                                          (Date)

Approval to conduct this research has been provided by The University of Western Australia, in accordance with its ethics review and approval procedures. Any person considering participation in this research project, or agreeing to participate, may raise any questions or issues with the researchers at any time. In addition, any person not satisfied with the response of researchers may raise ethics issues or concerns, and may make any complaints about this research project by contacting the Human Research Ethics Office at The University of Western Australia on (08) 6488 3703 or by emailing to hreo-research@uwa.edu.au All research participants are entitled to retain a copy of any Participant Information Form and/or Participant Consent Form relating to this research project.

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