

Emotional care and childhood cancer

A guide for health professionals

Written by The Royal Children's Hospital Children's Cancer Centre Psycho-oncology Team.

2012



Administrative host:

The Royal Children's Hospital
1st floor, South Building
50 Flemington Road, Parkville
Victoria 3052
Telephone: +61 3 9345 4433
Fax: +61 3 9345 9163
Email: pics.admin@rch.org.au



The Paediatric Integrated Cancer Service is supported by the Victorian Government.

Disclaimer: This guide contains information for educational purposes only. The information and links to third parties presented in this guide are considered to be true and correct at the date of publication; however, changes in circumstances after the time of publication may impact on the accuracy of the information.

There is increasing demand for psychological services in the community for children who have had a diagnosis of cancer and their families. However, community based therapists may feel they have limited knowledge about childhood cancer and its treatment, which may be a barrier to uptake of referrals. This information aims to aid community health professionals who are working with children and their families whose lives have been impacted with cancer.

Childhood cancer and treatments

For a mental health professional, seeing 'cancer' within the context of a child's referral can be an unfamiliar prospect. Although you do not have to be an expert in childhood cancer in order to address a child or families emotional wellbeing, it can be helpful to have a general idea of their diagnosis and the treatment regime that they are facing or have faced. It is important to recognise that generally a family will not expect you to be an expert in the oncology field. In fact, most families end up being their own experts in their child's diagnosis and treatment, so always ask for clarification.

Cancer treatment for children differs in many ways from treatment for adults, specifically in intensity and toxicity of medications, as well as their supportive care needs. It is important to remember that children are continuing to develop, and therefore the child's developmental age will also impact on how their treatment is tolerated, and what late effects may occur.

For further information regarding the differences between adult and paediatric cancer care visit the National Cancer Institute (USA).

Stages of the illness and beyond

The cancer journey is unique for every individual within the family. Even for children that have the same diagnosis, there are a number of different pathways and responses that the child and their family can experience. Depending on the stage of cancer and other underlying conditions or issues, the symptoms and treatment may be quite different. The following information outlines the common stages and the consequent issues that may arise for a child with cancer and their family.

Diagnosis

The word 'cancer' is very prevalent in our society and although there are thousands of childhood cancer survivors, these individuals are not the images that are conjured up often when you hear the word cancer for the first time. Common reactions for parents include; shock, disbelief, feeling overwhelmed and/or confused. As such, often information may need to be repeated a number of times.

Typically in response to a crisis, mental health professionals would advise individuals to not make any life altering decisions. However, when a child is diagnosed with cancer, parents and children (depending on the age of the child) are faced with treatment decisions from the point of diagnosis, and often they do not have the luxury of waiting. Parents and children affected by the diagnosis (both the patient and/or siblings) may experience existential crises, including questioning the meaning of life and their values. This is particularly salient for the adolescent population, who are just starting to form their own values and identity. It is a time for families to adjust both practically and emotionally.

A further concern for parents is when, what, and possibly 'if' to tell their child about their diagnosis and upcoming treatment. It is important to assess the child's understanding of the illness, and whether they have been given developmentally appropriate information. As part of an assessment and intervention, it may be important to give parents guidance about communicating with their child.

Intensive phase treatment

During this stage a child can be very sick and can often spend more time in hospital. This treatment phase is when possible issues related to the effects of hospitalisation may arise.

Maintenance

Families typically view this stage as a preliminary end point. They are usually looking forward to this stage as it generally means less time visiting the hospital. However families can also feel more disconnected from the hospital, due to reduced visits and appointments. If families experience these feelings of ambivalence surrounding this phase, it can be quite confusing, and it can take some time to adjust.

It is in this phase that external referrals to community services may be more prevalent, as families are spending less time engaged with hospital services and integrating back into their local community.

Coming off treatment

Families conceptualise this as the 'end point', and are expected to feel happy and be able to get their lives back to 'normal'. However, this can be a stressful time, due to reduced contact with their treating team at the hospital, the perceived pressure of monitoring their child's health, as well as the fear of relapse.

A clinical challenge can include helping patients and their families redefine what 'normal' means. Patients and their families may get stuck on the thought or perception that things have to go back to the way they were prior to diagnosis. It is important to help families recognise that this life changing event requires a new 'normal' to be developed. This is a time for families to acknowledge their strengths and weaknesses and to incorporate that knowledge moving forward.

It is common to see increased anxiety related to the fear that the cancer might come back and parents may become increasingly hypervigilant around their child's health.

Relapse

This is the reoccurrence of the illness. The cancer may come back to the same place as the original (primary) tumour or to another place in the body. As expected this is a very difficult time, and common reactions include; a sense of uncertainty, stress, anxiety, fear, sadness, anger, guilt, and denial.

End-of-life-care

Although childhood cancer has a good cure rate, a point may be reached in a child's treatment when curative treatment is no longer possible. This phase is referred to as 'end of life care' or 'palliative care'. It is helpful to reinforce that the aim of palliative care is a focus on life enhancement or improving the child's remaining quality of life rather than on death.

This is another transition for families and obviously a very difficult phase of their child's illness. During this time the family may engage with a new team of palliative care health professionals. This can be difficult for some families who may feel it signals a 'giving up' by their trusted health care team or even by themselves. Commonly families navigate this period with a combination of hopefulness that their child may still be cured and an acceptance of the reality of the forthcoming loss. Some common themes that mental health professionals may see at this time are:

- Similar to the reaction experienced at diagnosis, anticipatory grief will most likely be present in parents of a palliative child. This may include anger responses and questioning previously held spiritual views
- Significant stress on the family unit as a whole including the unique effect on specific relationships within the family
- Stress on marital relationship and intimacy
- The impact on siblings i.e. “magical thinking” in younger siblings- feeling that they are responsible for their siblings illness or anger due to feeling that their ill sibling is getting all the attention
- Significant impact on other family members who may have played a predominant role in care-giving such as grandparents
- The role of the mental health professional is to support the family and child providing psychosocial guidance as required. Particular attention must also be given to the family’s cultural, religious and spiritual needs
- Families may also need support in decision making regarding end of life care such as whether this should occur in the hospital, at home or in a hospice
- As with any new stage or transition, the child should be incorporated in their end of life care planning. Mental health professionals can be of assistance in assessing a child’s level of understanding of their illness progression
- It is important that during this stage that children still have age appropriate needs met e.g. social interaction with peers, providing a sense of normalcy through the family’s ‘normal’ routine
- Specific issues may arise for adolescent patients relating their capacity and competency to make decisions on their palliation.

Please see below website for more information:

- [The Royal Children's Hospital: palliative care and psychosocial support](#)
- [The Centre for Palliative Care: Psychosocial and bereavement support for family caregivers of palliative care patients- A review of the empirical literature](#)
- [The Centre for Palliative Care: clinical practice guidelines](#)

Survivorship

Surviving cancer or “survivorship” can be defined in different ways. Two common definitions include:

- Having no disease after the completion of treatment
- The process of living with, through, and beyond cancer. By this definition, cancer survivorship begins at diagnosis. It includes people who continue to have treatment to either reduce risk of recurrence or to manage chronic disease.

There have been tremendous improvements in survival of children diagnosed with cancer, with the 5-year survival rate now over 80%, resulting in a growing population of childhood cancer survivors. Use of cancer therapy at an early age can produce complications that may not become apparent until years later.

- Drew, S. (2007). [Having cancer changed my life, and changed my life forever: Survival, illness legacy and service provision following cancer in childhood](#). *Chronic Illness*, 3, 278-295.

Please see websites below for more information on late effects:

- [National Cancer Institute Late Effects Information \(USA\)](#)
- [Australian Cancer Survivorship Centre](#)
- [Peter Mac Late Effects information for patients](#)
- [Memorial Sloan-Kettering Cancer Centre: late effects information](#)
- [Children's Oncology Group \(USA\): long-term follow-up guidelines](#)

Impact of hospitalisation on children and adolescents

Long term illness and hospitalisation has the potential to negatively impact a child's motor, cognitive, emotional and social development. The following section outlines the possible impacts on a child, preventative interventions and also provides external links to information on developmentally appropriate topics.

Infants / Toddlers	
Impact	Interventions
<p>Perceptual development (when a child starts to interpret and understand sensory input). Lays foundation for further cognitive and perceptual motor skill development</p> <ul style="list-style-type: none"> - Hearing and vision may be impacted by treatment - Lack of stimuli in a sterile hospital environment can negatively impact <p>Motor development – ability to control and direct voluntary muscle movement</p> <ul style="list-style-type: none"> - The influence of hospitalisation, and lacking mobility when ill, can hinder/delay the acquisition of motor skills <p>Attaining developmental milestones</p> <ul style="list-style-type: none"> - Hospitalisation may negatively impact a child's ability to reach developmental milestones e.g. toileting, autonomy etc. <p>Attachment</p> <ul style="list-style-type: none"> - Separations between a child and caregiver due to hospitalisation can be distressing and impact on developing or maintain secure attachment - Parents may use detachment from their child as a coping strategy - Changes in routine can alter sense of security - Exposure to loud noises, bright lights and sudden movements can be perceived as traumatic 	<p>Developmental impact</p> <ul style="list-style-type: none"> - Clear limits and boundaries help develop cognitive and emotional development. - Promoting socialisation with similar aged patients or family members <p>Attachment</p> <ul style="list-style-type: none"> - Encouraging parents to be central in daily care activities even while hospitalised <p>Emotional/Behavioural Issues</p> <ul style="list-style-type: none"> - Increasing a sense of control over environment e.g. allowing choices – which sticker would you like? - Emphasising the importance of home rituals transferred to the hospital environment where possible - Limit setting to prevent discipline problems
Primary school aged children	
Impact	Interventions
<ul style="list-style-type: none"> - Children in this age group are sensitive about bodily changes caused by the disease and its treatment e.g. hair loss and resulting impact on self-image and self esteem - Some children can regress in behaviour and become overly dependent on their parents - Educational and social development can suffer as a result of frequent school absences 	<ul style="list-style-type: none"> - Using age appropriate communication about illness and treatment - Encouraging expression of thoughts and feelings through different mediums e.g. art, play - School involvement where possible for cognitive, emotional and social development - Providing age appropriate choices
Adolescents	
Impact	Interventions
<ul style="list-style-type: none"> - Emotional reactivity – hormonally based versus psychologically based - A cancer diagnosis and consequent treatment may threaten an adolescent's ability to develop their identity outside of 'cancer' 	<ul style="list-style-type: none"> - Respect a young person's privacy e.g. using 'door signs' to communicate preferences- sleeping etc. - Communication that includes the adolescent as a decision making

<ul style="list-style-type: none"> - May impact on their ability to plan for the immediate future - The demands of treatment interfere with the normal activities of adolescence, further interfering with social development and consequently this may result in depression and feelings of hopelessness - Impact of compliance and 'goog' decision making - While adolescent patients may understand all the implications of the disease and treatment, they may deny the seriousness of the diagnosis to justify poor compliance and risk-taking - 'Rebellion' as a form of identify development may be impacted 	<p>participant in their own treatment</p> <ul style="list-style-type: none"> - Linking to peer support groups e.g. Canteen - Reinforcing behavioural limits
--	---

Psychological impact of diagnosis and treatment

A diagnosis of paediatric cancer has a significant emotional impact on the children and their families; however it is important to note that many families adjust adaptively over time. Research indicates that the majority of childhood cancer patients report minimal symptoms of long-term psychological distress, with some evidence to say that some survivors also report positive psychological effects of their experience with cancer.

The Paediatric Psychology Preventative Model (Kazak, 2006) describes psychosocial risk in families conceptualised as a pyramid:

1. The majority of families (approximately 70%) fall into a 'Universal' category. These families are distressed but resilient and interventions should focus on providing general support and information
2. A smaller set of families (approximately 20%) are labelled 'Targeted'. These families experience acute distress and present with identifiable risk factors. Interventions for the 'targeted' group, would ideally focus on monitoring distress and interventions specific to symptoms/risk factors
3. The remaining families (approximately 10%) fall into the 'Clinical' category. These families experience persistent and/or escalating distress and a high number of risk factors. Interventions with the clinical families would require intervention by a mental health professional.

The evidence also shows that there is a subset of families and survivors that will continue to experience symptoms of distress following treatment. Specifically, Kazak et.al (2004) indicated that rates of posttraumatic stress disorder are often higher in parents than the child with cancer.

More information can be found through the following articles:

- Kazak, A.E, Rourke, M.T., Alderfer, M.A, Pai. A., Reilly, A.F. & Meadows, A.T. (2007). [Evidence based Assessment, Intervention and Psychosocial Care in Pediatric Oncology: A Blueprint for Comprehensive Services Across Treatment](#). Journal of Pediatric Psychology, 32(9), 1099-1110.
- Pai, A.L.H, Patino-Fernandez, A.M., McSherry, M., Beele, D., Alderfer, M.A., Reilly, A.T., Hwang, W.T. & Kazak, A.E. (2007). [The Psychosocial Assessment Tool \(PAT2.0\): Psychometric Properties of a Screener for Psychosocial Distress in Families of Children Newly Diagnosed with Cancer](#). Journal of Pediatric Psychology, 33, 1-13.
- Alderfer, M.A., Mougianis, I., Barakat, L.P., Beele, D., DiTaranto, S., Hwang, W.T., Reilly, A.T. & Kazak, A.E. (2009). [Family Psychosocial Risk, Distress, and Service Utilization in Pediatric Cancer](#). Cancer Supplement: Cancer Survivorship Research: Mapping the New Challenges, 115(8), 4339-4349.
- McCarthy, M.C., Clarke, N.E., Vance, A., Ashley, D.M., Heath, J.A. & Anderson, V.A. (2009). [Measuring Psychosocial Risk in Families Caring for a Child with Cancer: The Psychosocial Assessment Tool \(PAT2.0\)](#). Pediatric Blood Cancer, 53, 78-83.

- Kazak, A.E., Alderfer, M.A., Streisand, R., Simms, S., Rourke, M.T., Barakat, L.P., Gallagher, P. & Cnaan, A. (2004). [Treatment of Posttraumatic Stress Symptoms in Adolescents Survivors of Childhood Cancer and Their Families: A Randomised Clinical Trial](#). *Journal of Family Psychology*, 18 (3), 493-504.
- Noll, R.B & Kupst, M.J. (2007). [Commentary: The Psychological Impact of Pediatric Cancer Hardiness, the Exception or the Rule?](#) *Journal of Pediatric Psychology*, 32(9), 1089-1098.
- [Science Daily \(USA\): Most children with cancer are well adjusted](#)

Addressing psychosocial concerns

Why might a child be referred to a psychosocial/mental health professional?

- To support families - families may experience intense distress or conflicts as a result of the stress that treatment places on them, or it may highlight pre-existing communication problems.
- Persistent and intense distress that interferes with the patient's quality of life or ability to access medical care. This may be exhibited in withdrawal, throwing tantrums, difficulty eating and/or sleeping, or refusing to comply with recommended treatment.
- Distress or pain related to treatments or procedures- in conjunction with the treating team's hospital based professionals e.g. procedural pain clinician, play therapist etc.
- Disease-related pain.
- School refusal- when a patient refuses to attend school after being medically cleared and is physically capable of going to school.
- Poor adherence to treatment and medical recommendations.
- Patient's safety - concerns about the patient's safety because of statements or behaviours.
- Mental Health Diagnosis- a patient has a known or suspected past history of mental health issues such as ADHD, anxiety or depression that may interfere or impact treatment and functioning.
- Developmental disorder- a patient who has a known or suspected past history of a developmental or communication disorder such as Down Syndrome or Autism that interferes with their quality of life or ability to access medical care.

If a child/adolescent or young adult with cancer arrived for an appointment, how would you modify your assessment procedure?

A psychosocial assessment provides information about an individual's current functioning, presenting problems, developmental history and assessment of risk. It is advised that a psychosocial assessment would incorporate a biopsychosocial framework, emphasising the impact of the biological state of the individual i.e. cancer on their psychological and social functioning.

Although it is important to carry out a thorough psychosocial assessment, it is equally important to honour the individual's 'cancer story' - when we think about a patient and/or family navigating in the traditional medical model, a mental health clinician may be the first person that a patient or family member has encountered that has the primary goal of listening rather than focusing on task completion.

The primary goal of a psychosocial assessment attempts to gather information regarding a young cancer patient and/or their family's adaptation to the disease. This adaptation is an ongoing process of adjustment.

As a general rule, markers of successful psychological adaptation to cancer include:

1. Continued active involvement in daily life
2. Ability to minimise disruptions to life roles
3. Skill at regulating emotional distress.

These markers are influenced by cancer specific and other factors.

Cancer specific factors include:

- Cancer type, site, stage and prognosis
- Clinical course of cancer and treatment
- Treatment with long term survival and cure
- Cancer as a chronic illness with possible long-term disabilities.

Other factors include:

- Disability
- Functional impairments caused by cancer treatments, side effects and or the disease itself i.e. fatigue, anorexia, self-image and pain
- Neuropsychological deficits i.e. concentration / attention, speed of information processing, working memory and organisation.

Patient specific factors:

- Past History i.e. previous mental health issues, family history, previous experience in medical/hospital environments
- Demographics i.e. socio-economic factors
- Developmental stage: As noted previously, an individual's developmental stage must be taken into account when conducting a psychosocial assessment - being mindful of regression as an impact of hospitalisation. In addition, it is important to assess a parent or caregiver's knowledge of their child's developmental stage and how that may affect how they provide information, and address developmental needs
- Coping styles i.e. assessment of age appropriate coping strategies. For example, is a young person who attends Day Oncology with their iPod permanently attached to their ears avoiding or is this a developmentally appropriate coping strategy?
- Social support i.e. assessment of both quantity (how many) versus quality of support, what type - practical assistance, emotional support etc.

Social factors:

- Culture: every individual has their own set of preconceived ideas about cancer, however a patient's and/or family's ethnic or cultural background can have a societal wide impact on how they respond to a cancer diagnosis and consequent cancer treatment.

Information about cultural competence is available on the below websites:

- [Australian Government EdCaN: The cancer experience in culturally and linguistically diverse groups](#)
- [American Psychological Association: variations for practice for culturally diverse groups](#)

Remember, the main question to ask when making a clinical judgement in the assessment of a young cancer patient's mental health: *'Is this behaviour completely out of character?'*

Reference:

Nicholas, D.R. & Veach, T.A. (2000). The Psychosocial Assessment of the Adult Cancer Patient. Professional Psychology: Research and Practice, 31(2), 206-215.

Conceptualising Somatic Symptoms in an Assessment

A clinician must be wary of the assessment of somatic symptoms such as appetite and fatigue, as to do so without consideration can result in 'false positives' in a mental health diagnosis. A child or young person with a cancer diagnosis may experience significant changes in sleep, appetite, energy, weight and appearance as

a result of their illness and/or treatment.

Comprehensive assessment of these somatic symptoms is not likely to be done solely by the psychologist, rather, the mental health professionals' role is to determine to what extent any of these somatic symptoms may be influenced by co-morbid mental health disorders or due to increased distress. Therefore the best course of action when formulating, is to talk to the child/adolescent's treating team in order to seek clarification on these issues.

Case study

Billie presents as a withdrawn and tired young person. He/she has recently lost a substantial amount of weight and reports little to no appetite. In addition, Billie reports a negative change in their self-image. He/She reports that they haven't seen their friends recently and although they report enjoying school have not been attending.

As we can see from the above case study, a number of 'red flags' of concern are evident for Billie:

- Loss of Appetite & Weight Loss
- Fatigue
- Withdrawal from previously enjoyed activities.

These 'red flags' would appear to fit all the hallmarks for further exploration for a mental health diagnosis in a young person. However when a cancer diagnosis is factored in to the profile, the 'concerns' raised seem appropriate within the profile of the illness. For instance:

- withdrawal from previously enjoyed activities/friends may be due to being unable to participate in a regular sports team due to fatigue
- lack of appetite and weight loss may be a consequence of chemo treatment.

Of course, the effects of these symptoms may cause a high degree of ongoing distress for a patient and therefore require a mental health intervention; on the other hand, they may result in a period of short term distress that resolves naturally as a process of adjustment.

Assessing Post Traumatic Symptoms in Paediatric Oncology

As noted previously, the majority of patients and families who are impacted by a cancer diagnosis will adjust well over time. However there is a subset of individuals who will continue to experience distressing symptoms. A clinician should be mindful of assessing for symptoms for both a child and their parent/caregiver that may indicate post trauma symptoms.

Neuropsychological impact of cancer treatment

There is significant variability in neuropsychological and learning outcomes for children who have received treatment for childhood cancer. Treatment for cancer can include radiation, chemotherapy, and/or surgery as well as bone marrow transplant in rare cases. The use and timing of these treatments depends on the type of cancer involved and its progression over time. These treatments have different effects on the brain and its development, and therefore, the risks associated with each vary. In addition, age at treatment is an important factor with the younger the child at treatment the greater the risk of cognitive difficulties in the long-term. This is because young children have had less time to acquire knowledge and consolidate skills. Cranial radiation has been shown to affect the rate at which children learn because of the effect radiation has on key processing skills such as speed of information processing and attention. Children treated with cranial radiation make gains over time, but in general they do so at a slower rate than their peers, which impacts on their ability to attain academic skills such as reading and mathematics at the same rate as other

children their age. Some forms of chemotherapy have also been shown to affect the processing skills that are important in learning; however, these effects are generally milder than the effects of radiation to the brain. Depending on the location of the tumour, surgery can also affect important skills for learning such as sustained, selective, and divided attention, working memory, and planning and organisation.

Although the effects and risks of treatments vary depending on diagnosis, the experiences of families are similar. For example, having to attend numerous appointments, reduced developmental opportunities due to time spent at home unwell or in hospital, financial stress, missed school, and strain on relationships. These indirect effects of treatment can also have a substantial impact on a child's development. For example, missing a year of school means that a child not only misses out on learning opportunities at school, but also misses out on important social experiences of a child of that age.

Cancer can disrupt the normal processes of childhood development differently at various time points in a child's life. The types of problems that exist at the time of, and immediately after treatment, can differ from the types of issues that may arise post treatment. Difficulties with cognitive function might only become apparent as the child ages chronologically and new skills that would ordinarily develop fail to "come on line" at the same rate as their peers. A neuropsychological assessment can assist to identify current cognitive strengths and weaknesses, monitor the child's progress over time, provide recommendations about how to help compensate for cognitive difficulties and assist with educational planning.

For more information, access the article below:

- Nathan, P.C., Patel, S.K., Dilley, K., Goldsby, R., Harvey, J., Jacobsen, C., Kadan-Lottick, N., McKinley, K., Millham, A.K., Moore, I., Okcu, M.F., Woodman, C.L., Brouwers, P. & Armstrong, F.D. (2007). [Guidelines for Identification of, Advocacy for, and Intervention in Neurocognitive Problems in Survivors of Childhood Cancer; A Report From the Children's Oncology Group](#). Archives of Pediatric & Adolescent Medicine, Vol 161(8); 798-806.

Adolescent specific issues

Adolescence is a time of growth and development in all domains – physically, cognitively and psychosocially. A cancer diagnosis during adolescence, at this time of social independence and increased personal decision making, can cause significant social and emotional struggles that may impair the ability of the adolescent to make health-promoting decisions. Other age-related challenges such as forming relationships, deciding on a career path and developing a sense of self are also important to consider.

All over the world cancer treatment services and support organizations are paying attention to the issues and supports that are important for teenagers and young adults during and after treatment. This is especially true in relation to their social and emotional experiences and support needs. Please see websites that are available for adolescents and young adults to help support them through their cancer treatment and beyond for more information for adolescents.

More information related to working with adolescents with cancer can be found at the links below:

- [COSA: Psychosocial Management of AYAs diagnosed with cancer: Guidance for Health Professionals](#)
- [ONTrac at Peter Mac](#) website for more in-depth discussion regarding working with 15-25 year olds, and their developmental and survivorship issues
- Abrams, AM. Hazen, EP. and Penson, RT. (2007). [Psychosocial issues in adolescents with cancer](#). Cancer Treatment Reviews, 33, 622-630.
- Morgan, S. Davies, S. Palmer, S. and Plaster, M. (2010). [Sex, Drugs and Rock 'n' Roll: Caring for Adolescents and Young Adults with Cancer](#). Journal of Clinical Oncology, 28(32), 4825-4830.

- Yeo, M. & Sawyer, S. (2009). [Psychosocial assessment for adolescents and young adults with cancer](#). Forum: Cancer in Adolescents and Young Adults, 2009

Confidentiality

As with any young person, the limits of confidentiality must be discussed prior to assessment. Specifically with a child who is still actively involved in medical treatment, it is paramount to address issues such as information sharing with the young person's treating team, documentation and storage of their information.

The links below provide more information about confidentiality:

- Henkelman, JJ. and Everall, RD. (2001). [Informed Consent with Children: ethical and practical implications](#). Canadian Journal of Counselling, 35:2, p 109-121.
- [Guidelines on Confidentiality \(including when working with minors\)](#), Depression Net.

Risk Assessment

It is developmentally appropriate for an adolescent to start exploring existential questions around life and death. This of course can be heightened for a young cancer patient. Talking about death and dying is not necessarily an indicator of risk and encouraging this type of discussion with a young person will allow for risk to be comprehensively assessed, obtaining a deeper appreciation of their inner world.

Standardised assessment measures

Below are links to some useful standardised assessment measures.

Health Specific

1. Pediatric Health Related Quality of Life (HRQOL)
 - [PedsQL](#): Child report- suitable for ages 8-12 (research suggests as early as 5yrs) and parent proxy report
 - Varni, J.W., Limbers, C. & Burwinkle, T.M. (2007). [Literature Review: Health Related Quality of Life Measurement in Pediatric Oncology: Hearing the Voices of the Children](#). Journal of Pediatric Psychology. 32(9), 1151-1163.
2. [Beck Depression Inventory- Fastscreen for Medical Patients](#)
 - Assessment of the cognitive and affective symptoms of depression while excluding behavioural &/or somatic symptoms that may be related to medical problems.
 - Ages 13 +

Other Measures

1. [Beck Youth Inventories](#): 2nd Edition
 - An evaluation of a child/adolescents emotional and social impairment
 - Inventories assessing depression, anxiety, anger, disruptive behaviour & self-concept. (20 questions per inventory, 5 minutes each).
 - Ages 7-18yrs
2. [Strengths and Difficulties Questionnaire \(SDQ\)](#)
 - This is a brief behavioural screening questionnaire, assessing different domains including; emotional symptoms, conduct problems, hyperactivity/inattention, peer relationships and prosocial behaviour.
 - Validated with Australian norms.
 - Parent Report- Ages: 4 to 10 years, self-report- Ages: 11 to 17 yrs

Evidence-based therapeutic interventions

Depending on your assessment and formulation, there are a number of evidence-based interventions that are useful. This section outlines a number of these interventions, their applications and further reading.

Family-focused interventions

Family therapy works to address the relationships within families to help them better deal with a wide range of problems. A cancer diagnosis puts strain on a family and consequently in poorer functioning families this may highlight pre-existing family issues.

The articles below provide more insight into family relationships:

- Machado da Silva, F., Jacob, E. & Castanheira Nascimento, L., (2010). [Impact of Childhood Cancer on Parents' Relationships: An integrative review](#). *Journal of Nursing Scholarship*, 42 (3), 250-261.
- Alderfer, M.A., Long, K.A., Lown, E.A., Marsland, A.L., Ostrowski, N.L., Hock, J.M. & Ewing, L.J. (2010). [Psychosocial adjustment of siblings of children with cancer: a systematic review](#). *Psycho-Oncology*, 19, 789-805.

Cognitive Behavioural Therapy (CBT)

Within a paediatric oncology population, CBT can be used to treat a number of emotional or behavioural disorders including anxiety, depression and post-traumatic stress disorder.

The articles below provide more information on cognitive behavioural therapy:

- Friedberg, R.D. & Brelsford, G.M. (2011). [Core Principles in Cognitive Therapy in Youth](#). *Child and Adolescent Psychiatric Clinics of North America*, 20, 369-378.
- Thompson, R.D., Delaney, P., Flores, I. & Szigethy, E. (2011). [Cognitive Behavioural Therapy for Children with Comorbid Physical Illness](#). *Child and Adolescent Psychiatric Clinics of North America*, 20, 329-348.
- Dorsey, S., Briggs, E.C. & Woods, B.A. (2011). [Cognitive Behavioural Treatment for Posttraumatic stress disorder in children and adolescents](#). *Child and Adolescent Psychiatric Clinics of North America*, 20, 255-269.
- Kowalik, J., Weller, J., Venter, J. & Drachman, D. (2011). [Cognitive behavioural therapy for the treatment of pediatric posttraumatic stress disorder: A review and meta-analysis](#). *Journal of Behavior Therapy & Experimental Psychiatry*, 42 (3), 405-413.
- Hirschfeld-Becker, D.R., Micco, J.A., Mazursky, H., Bruett, L. & Henin, A. (2011). [Applying Cognitive Behavioural Therapy for anxiety to the younger child](#). *Child and Adolescent Psychiatric Clinics of North America*, 20, 349-368.
- Cohen, J., Mannarino, A., Berliner, L. & Deblinger, E. (2000). [Trauma-focused cognitive behavioral therapy for children and adolescents: An empirical update](#). *Journal of Interpersonal Violence*, 15(11), 1202-1223.

Acceptance and Commitment Therapy (ACT)

A mindfulness based behavioural therapy that uses metaphor, paradox, mindfulness skills, experiential exercises and values-guided behavioural interventions. The aim of Acceptance and Commitment Therapy is to accept problematic thoughts or emotions rather than trying to change or eliminate them. There is a role for using ACT in treatment of depression, anxiety and pain etc. This type of therapeutic approach can be beneficial in both individual work or as a parenting intervention.

The articles below provide more information about ACT:

- Coyne, LW. McHugh, L. Martinez, E.R. (2011). Acceptance and Commitment Therapy (ACT): Advances and Applications with children, adolescents and families. *Child and Adolescent Psychiatric Clinics of North America*, 20, 379-399.
- Masuda, A., Cohen, L.L., Wicksell, R.K., Kemani, M.K., Johnson, A., (2011). [A Case Study: Acceptance and Commitment Therapy for Pediatric Sickle Cell Disease](#). *Journal of Pediatric Psychology*, 36(4), 398-408.
- Hassirs, R. (2006). [Embracing Your Demons: An overview of Acceptance and Commitment Therapy](#). *Psychotherapy in Australia*, 12:4, p 1-7.

Social Skills Training (SST)

SST is a form of behaviour therapy that focuses on teaching the verbal and nonverbal behaviors involved in social interactions. SST helps individuals learn to interpret social signals, so that they can determine how to act appropriately in the company of other people in a variety of different situations.

Social Skills Training in a paediatric oncology environment: As indicated previously, prolonged hospitalisation may impact a child's development, specifically their social development, therefore social skills training may help aid children in acquiring developmental skills missed due to lack of socialisation as a result of hospitalisation.

More information on SST is available in the articles below:

- Dieluweit, U., Debatin, K.M., Grabow, D., Kaatsch, P., Peter, R., Seitz, D.C.M. & Goldbeck, L. (2010). [Social outcomes of long-term survivors of adolescent cancer](#). *Psycho-Oncology*, 19, 1277-1284.
- Forsbach, T. (2003). [The impact of childhood cancer on adult survivors' interpersonal relationships](#). *Child Care in Practice*. 9(2), 117-128.

Grief and Loss Counselling

The grieving process has an enormous impact on children and families who have been affected by cancer. Grief is the normal and natural reaction to loss of any kind and does not necessarily refer exclusively to the process of death and dying.

Children and families may grieve over the loss of:

- Independence - Due to hospitalisation or as a result of fatigue which may impact ability to independently self-care.
- Self-image - Physically as a side effect of treatment e.g. hair loss, weight loss, nasogastric tubes
- Identity - Separation from school, friends, sporting or other extracurricular activities, home environment.

Additional information on grief and loss counselling can be found in the below resources:

- DeCinque, N., Monterosso, L., Dadd, G., Sidhu, R. & Lucas, R. (2004). [Bereavement support for families following the death of a child from cancer: Practice characteristics of Australian and New Zealand pediatric oncology units](#). *Journal of Pediatric Child Health*, 40, 131-135.
- The Australian National University: [Australian Child & Adolescent Trauma, Loss & Grief Network](#)
- Counselling Connection: [Play Therapy Activities to Engage Children](#)
- [Australian Centre for Grief and Bereavement](#)
- The Grief Recovery Handbook- 20th Anniversary Addition. James & Friedman (specifically the 'Loss of Health' section).

Problem Solving Skills Training

Problem Solving Skills Training (PSST) is designed to teach the skills involved in effective problem-solving, including skills that address practical problems faced by caregivers.

A cancer diagnosis requires an immediate reorganisation of life and relationships. Such reorganisation can lead to new roles being taken on by family members and new strains on resources. Problem Solving Skills Training aims to provide a preventative intervention by teaching practical skills for families to reduce the stress experienced.

The below resources offer more information on PSST:

1. Outcomes Research References

- Sahler, O., Fairclough, D., Phipps, S., Mulhern, R., Dolgin, M., Noll, R., Katz, E., Varni, J.W., Copeland, D., & Butler, D. (2005). [Using problem-solving skills training to reduce negative affectivity in mothers of children with newly diagnosed cancer: report of a multisite randomized trial](#). *Journal of Consulting and Clinical Psychology*, 73, 272–283.
- Varni, J. W., Sahler, O. J., Katz, E. R., Mulhern, R. K., Copeland, D. R., Noll, R. B., et al. (1999). [Maternal problem-solving therapy in pediatric cancer](#). *Journal of Psychosocial Oncology*, 16, 41–71.

2. Clinical Approach References

- Iobst, E.A., Alderfer, M.A., Sahler, O.J., Askins, M.A., Fairclough, D.L., Katz, E.R., Butler, R.W., Dolgin, M.J. & Noll R.B. (2009). [Problem solving and maternal distress at the time of a child's diagnosis of cancer in two-parent versus lone-parent households](#). *Journal of Pediatric Psychology*, 34, 817-821.

Symptom Management: Procedural Pain

The articles below provide information on procedural pain:

- Young, K.D. (2005). [Pediatric Procedural Pain](#). *Annals of Emergency Medicine*. 45(2), 160-171.
- Rheingans, J.I. (2007). [A systematic review of nonpharmacologic adjunctive therapies for symptom management in children with cancer](#). *Journal of Pediatric Oncology Nursing*, 24 (2), 81-94.
- LaMontagne, L., Wells, N., Hepworth, J.T., Johnson, B.D. & Manes, R. (1999). [Parent coping and child distress behaviours during invasive procedures for childhood cancer](#). *Journal of Pediatric Oncology Nursing*, 16 (1), 3-12.
- Uman, L.S., Chambers, C.T., McGrath, P.J., Kisley, S., Matthews, D. & Hayton, K. (2010). [Assessing the quality of randomised controlled trials examining Psychological Interventions for Pediatric Procedural Pain: Recommendations for Quality Improvement](#). *Journal of Pediatric Psychology*, 35(7), 693-703.
- McMurty, C.M., Chambers, C.T., McGrath, P.J. & Asp, E. (2010). [When “don't worry” communicates fear: Children's perceptions of parental reassurance and distraction during a painful medical procedure](#). *Pain*, 150, 52-58.

Expressive Therapies

Expressive therapy is the use of the creative arts as a form of therapy. Unlike traditional art expression, the process of creation is emphasized rather than the final product. Some common types of expressive therapy include art therapy, dance therapy, drama therapy, music therapy and writing therapy.

The articles below provide additional information on expressive therapies:

- Angstrom-Brannstrom, C., Norberg, A & Jansson, L. (2008). [Narratives of Children with Chronic Illness about being comforted](#). *Journal of Pediatric Nursing*, 23(4), 310-316.

- Baerg, S. (2003). 'Sometimes there just aren't any words': Using expressive therapy with adolescents living with cancer. Canadian Journal of Counselling. 37(1), 65-74.

In addition to the evidence based therapeutic treatments listed above, The National Child Traumatic Stress Network (US) suggests the following [evidence based trauma treatment programs](#).

Further education and training

There is limited specific training regarding childhood cancer, however there are a number of other ways to increase your clinical skills to help work with individuals and families that have been diagnosed with childhood cancer. Below is a list of organisations that hold training and education:

- [Australian Centre for Grief and Bereavement](#)
- [The Bouverie Centre](#)
- [Alma Family Therapy Centre](#)
- [Victorian Cancer Council](#)
- [Acceptance and Commitment Therapy](#)

Online Learning:

- [Cognitive Behavioural Therapy with Child Traumatic Grief](#)
- [Learning Centre for Child and Adolescent Trauma](#)
- [Psycho-oncology \(UK\) Education](#)

Professional Psychosocial Oncology Associations:

- [Association of Paediatric Social Workers](#): topics on this website include coping with the new diagnosis, sibling issues, school and school re-entry, end of treatment and beyond, relapse, grief and loss and resources
- [Canadian Association of Psychosocial Oncology: The Emotional Facts of Life with Cancer](#)
- [Australian Psychological Society](#)
- [Interest Group for Psychologists in Oncology](#)

Other useful websites for Health Professionals

- [St Jude's Child Life Fact Sheets](#): including preparing for procedures, preparing for radiation, dealing with body changes
- [Trauma informed care](#): specifically section include what providers need to know- including developmental issues, understanding the family's experience
- [Cancer Care for the Whole Patient \(Full PDF Book Available\)](#)

Clinical Practice Guidelines

- [The Royal Children's Hospital Clinical Practice Guidelines](#)
- [Australian Posttraumatic Stress Disorder Guidelines for health professionals \(adult based\)](#)
- [Treating Depression: the beyondblue guidelines for treating depression in primary care \(2002\)](#)

Self-care for health professionals

As with most mental health fields, working with children and families whose lives have been affected by cancer can be an emotionally draining task and therefore it is important for health professionals to consider their own self-care in order to prevent professional burn-out.

Self-care can be thought of as anything that contributes to emotional, spiritual, physical and/or social rejuvenation, in order to create balance in our lives (specifically balance between work and personal life).

The following websites provide information that encourages a professional's self-care and gives tips on how to achieve self-care:

- The American Psychological Association: [self-care for Psychologists](#)
- Australian Institute of Professional Counsellors: [burnout and self-care strategies](#)
- Centre for Clinical Interventions: [Fun Activities Catalogue](#).

Contacts

Both The Royal Children's Hospital Cancer Services and Monash Children's Hospital Children's Cancer Centre have dedicated professionals including art, music and play therapists, mental health clinicians, procedural pain clinicians, psychologists and social workers.

If you have been referred a client within Victoria and would like to consult with a member of staff, please contact these services on the details below:

- [The Royal Children's Hospital Cancer Services](#): 03 9345 4614
- [Monash Children's Hospital Cancer Centre](#): 03 9594 7660