

Talking about cancer

Dealing with cancer in your school community.



This resource has been designed to enable your school to better support children living with cancer or who have a family member with cancer.

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Acknowledgements

source 1

Sections of this resource have been reproduced and adapted with permission from 'Cancer in the School Community' © Cancer Council NSW 2011. To view the complete 'Cancer in the School Community' booklet, please follow this link, or visit the Cancer Council website.

Source 2

'Understanding the needs of families living with cancer in Australia'
Camp Quality Family Research Project. Conducted by ARTD Consultants, Commissioned by Camp Quality. February 2011. A snapshot of our 226-page research document is available by following this link: http://www.campquality.org.au/media/897937/researchresults_brochure2011.pdf

Source 3

'Children with a parent with cancer: Support needs and interventions' Camp Quality funded literature review
Claire E. Wakefield, Sarah J. Ellis, Genevieve Antill, Pandora Patterson



Cancer in the school community

A cancer diagnosis turns life on its head. For many children, school is a refuge. Apart from the home, it's where they spend the majority of their time. The school environment is key to the child's social, cognitive and educational development.

To maintain a sense of normalcy, some families choose to keep their cancer diagnosis private. It's important that you respect their wishes if this is the case.

If the family choose to disclose their cancer diagnosis, the school can support them by appointing a member of staff to liaise with them. Families usually find it helpful to just have one point of contact in the school. Having one liaison person ensures ease of communication and prevents families from having to repeat themselves when talking to new staff members. This liaison person is often the class teacher of the student, the school counsellor or the school principal; whoever is most appropriate for the individual family and the school.

In all cases, it is essential the person with cancer or their parent has given their consent regarding who they feel comfortable knowing about their diagnosis.

Talking to Kids about Cancer

A person's understanding of cancer depends on their age, maturity level and their experience with the disease. Many children may have heard of cancer before but often their understanding of the disease is unclear or ill-defined.

For any school affected by cancer, educating students about cancer can help prevent a variety of problems. Give the students opportunities to voice their feelings or ask questions. They might ask some difficult or sensitive questions.

Common questions classmates may have:

- How did they get sick?
- Can I catch it?
- Should I share things that are bothering me? They seem silly or trivial compared to what my friend is going through.
- What am I supposed to say or do?

For schools that have a child living with cancer, many children may ask:

- Will they miss school?
- How can I be a friend to someone with cancer?

>> Ways to Help

- **Integrate information about cancer into the core curriculum-** Encourage discussion about what cancer is, its treatments and possible side effects.
- **Be aware of the potential for cruel comments or bullying.**
- **Advise students on how to talk to a classmate with cancer**
- **Planning cancer awareness activities to teach students more about cancer.** Talking about the situation can reduce the classmates' curiosity and gossip, and may make life easier for the affected student.
- **The Camp Quality Primary School Education Program has been specifically designed for this purpose.** Information about the free program can be found at campquality.org.au or by contacting 1300 665 605

"The other kids could see something was different. They'd make games of pulling off her beanie and call her 'baldy' ... it was not fun for a kid who's gone through what she'd just gone through".

Parent of a child with cancer

Talking to someone with cancer, or who has a loved one with cancer.

Encourage teachers/school staff to:

- **Listen. Let them lead the conversation.** If the conversation stops, it's not necessary to fill the gaps. A shared silence can be just as important as talking
- **Acknowledge their feelings.** It's ok for someone to feel angry or sad about the cancer diagnosis- don't try to change their feelings.
- **Offer them practical support.** For example, a parent undergoing treatment may benefit from a car pool service.
- **Avoid giving unsolicited advice** or telling the person that you know exactly how they feel, even if you have been in a similar situation. It is best to use phrases like, "that sounds really difficult" or "You're going through so much. How can I help?"

Encourage students to:

- **Acknowledge the situation.** You might recommend that they say, "I don't know what to say, but I want you to know I care", "How are you going?" or "Is there anything I can do to help in class?"
- **Try to talk normally about day-to-day things-** you should remind students that their classmate may be tired of talking about cancer all the time. Enjoy a laugh with them and treat them the same as always.



When a child has cancer

At Diagnosis

The news of a student's diagnosis may come as a shock to many people in your school community. It is difficult for a family to receive the distressing news of their child's life-threatening illness, and they often describe the days and weeks after diagnosis as a whirlwind. During this time, family members not only have to come to grips with the diagnosis but they also must make difficult decisions about their treatment. While the family is coming to terms with the situation, they may not inform the school of a student's diagnosis.

>> Ways to Help

- **Make sure to offer the family support** - they may not be aware of the assistance that the school network can give, or they may feel uncomfortable asking for help unless approached.
- **Inform them about the school's usual plan of action.** Your school may involve the student welfare team, student learning support team, appoint a liaison person, or notify the principal or teacher/s.
- **Establish if and how the family would like information about the student's diagnosis and treatment to be shared with the school community.**
- **Find out how long the student may be away from school.** Often a student may be in and out of hospital for months, or even years.
- **Call the Cancer Council on 13 11 20 for further information on cancer and treatment.**
- **Book the Camp Quality Primary School Program to visit the school.**



During Treatment

Keeping in Touch

When a student is away from school it's important to maintain contact with classmates. Young people with cancer find it easier to return to school if friendships have been maintained throughout their absence. Communication can make the patient feel special, and reassure them that they've not been forgotten by their friends.

How to maintain contact:

- Post cards, letters, drawings or paintings
- Record an audio or video/DVD of a school event, or personal messages
- Send photos or small gifts
- Email notes or photos
- Create a website or blog about what is happening at school
- Use social networking or video conferencing such as Skype

Helping with School Work

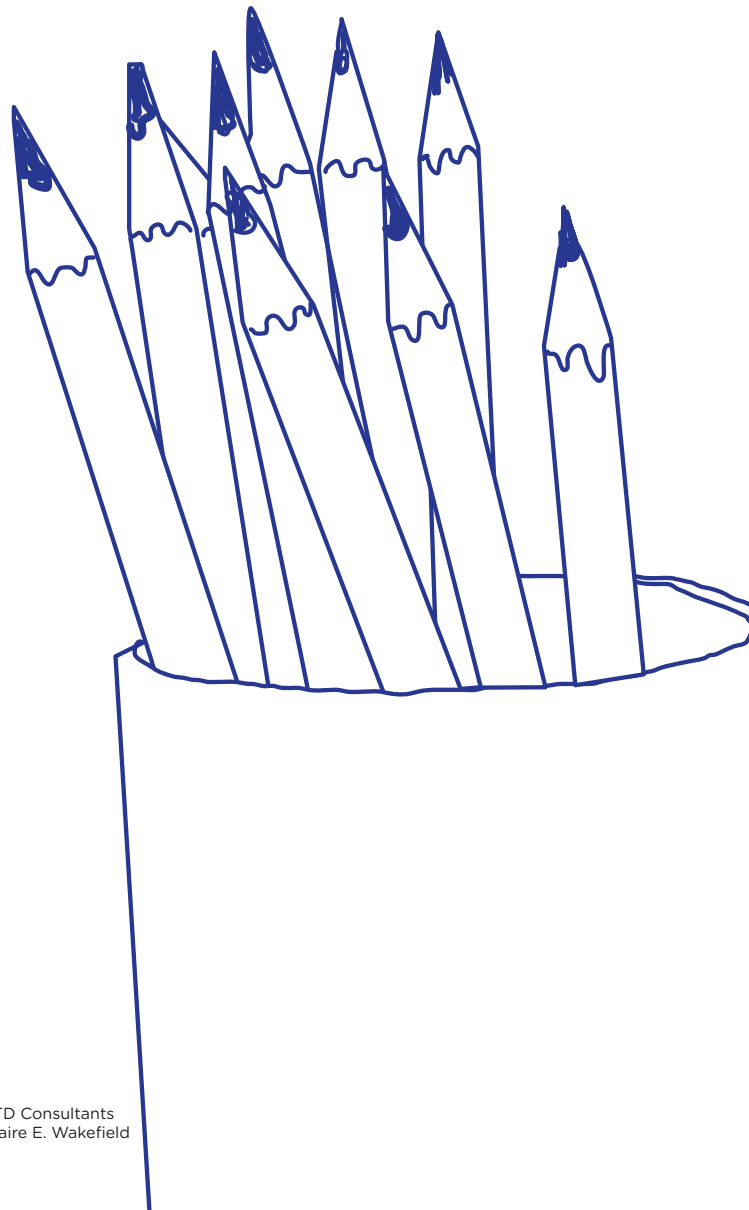
While children are in hospital, it is natural for a parent to feel anxious about how the student is going to keep up with their school work. Talk to the student's parents about their expectations, and how to arrange access to an appropriate flow of work. Long-term patients in some bigger public hospitals may be linked to a hospital school or learning program. Students in smaller, regional hospitals may require extra support from their class teachers.

Ronald McDonald Learning Program is specifically designed to help seriously ill children catch up on missed school work. They also offer accredited professional development for teachers on how they can best support seriously ill children. For more information, visit <http://learningprogram.rmhc.org.au> or call 1300 307 642.

Redkite is a charity that supports children, young people and their families through cancer by providing financial assistance, educational services and emotional support. They provide tutoring support for students trying to catch up with school work and scholarships for students with a particular goal in mind. Redkite also provides telephone and email support for young people diagnosed with cancer, their families and support networks. For more details call 1300 722 644 or visit www.redkite.org.au

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1. 'Cancer in the School Community' © Cancer Council NSW 2011

2. 'Understanding the needs of families living with cancer in Australia' Camp Quality /ARTD Consultants

3. 'Children with a parent with cancer: Support needs and interventions' Camp Quality/Claire E. Wakefield

Returning to School

Encourage students to come back to school as soon as they're able. Help them be as involved as possible in day-to-day lessons and school activities, it's important the school is always accommodating. Ideally, the school will help the student by allowing partial attendance at first and modifying work until treatment is completed.

Understand that the student and their parents may feel very anxious about returning to school.

Students may feel anxious about the change in their appearance, changed social groups, keeping up with school work and no longer fitting in with their peers. It's important that you anticipate these anxieties and help to make the child's transition back to school as easy as possible. Encourage classroom discussion about what cancer is, its treatments and possible side effects. This will prepare children for physical and emotional changes in their classmate.

Infection Control

Children often return to school once they have finished their intensive cancer treatment. However, it is likely that they will continue to receive some form of treatment for months, even years. During this time, their immune system will be reduced. They should not come in contact with anyone with a cough, cold or any other viral or infectious illness such as measles or the chicken pox. It's important that this is communicated with the wider school community. It is every family's responsibility to inform the school if their child has an infectious illness.

If the child living with cancer complains of feeling unwell, particularly if their temperature is rising, their parent should be contacted immediately.

>> Ways to Help

- **Open up communication with the child's parents.** Some parents will be happy for their children to go back to school and even feel a sense of relief. Quite rightfully, others may feel very anxious and protective. If you are having difficulty managing a parent's reaction, talk to the welfare coordinator or school counsellor about the best way to handle the situation.
- **Prepare the child's peers for their arrival.** The Camp Quality Puppets are available to all schools across Australia, free of charge.
- **Arrange for help from the students welfare team if they are struggling with their schooling**
- **Unfortunately, bullying is an issue for some children returning to school after cancer treatment.** Closely monitor the reactions of other students and be aware of your schools anti-bullying plan.
- **Be aware that special adjustments may have to be made for the students to comfortably assimilate to being back at school.** For example, if a student is embarrassed by their hair loss, it is ok to let them wear a hat or head scarf inside.

"Everyone was asking 'Oh how's [your brother] going?' No one was actually asking me 'How are you?' This is really tough, how are you?' You couldn't say anything because it would sound a bit rude."

(Sibling of child with cancer, 8-12 years old)

When a Sibling of a Student has Cancer

Support

Children who have a brother or sister with cancer experience huge disruptions in their life. Their home life is suddenly changed and daily routines are disrupted. Loss of parental attention as the family focus on the sick child can leave siblings feeling isolated, left out and even angry or resentful of the child who is sick. Siblings of children living with cancer have very high unmet needs; many studies suggest that siblings have higher unmet needs than their sick brother or sister.

Your school community can provide a strong support system for a sibling of a cancer patient.

Just like a child with cancer, a sibling may view school as a safe, comfortable place. They may enjoy just feeling normal, or they may even take pleasure in receiving attention from teachers or classmates. Communication with the child and their parents is important at this time to find out the individual needs of that child.

Siblings of cancer patients are often asked questions about their brother or sister's diagnosis that they find distressing or don't have the answers to. It's important that the sibling and their class or year group are included in any cancer education that takes place at the school- The Camp Quality puppets, clinical nurse visits etc.

During Treatment

Siblings of children with cancer may need special consideration during their siblings' treatment. They may struggle with their studies due to distractions or changes at home. Their class teacher or the families' staff liaison should look out for changes in the child's behaviours, social interactions and academic performances. It's recommended to keep the parent updated on those changes.

Families based in regional and remote areas sometime relocate temporarily during treatment. If this is the case, make sure to keep in touch with the siblings as you would the child having treatment. The class can send cards, have Skype sessions etc. Ensure that the sibling feels just as valued as the patient.

>> Ways to Help

- **With parental consent, it may be necessary and appropriate in some circumstances to offer counselling support to a student who has a sibling with cancer.**
- **Siblings of children with cancer need to express themselves emotionally.** A school counsellor can give them strategies of managing their feelings and behaviour to better cope with their situation.
- **Children need to feel just as valued and important as their sick sibling.** Don't just ask how their sick sibling is going, it's important to ask them how they are going as well.



When a Parent has Cancer

Privacy

When a parent has cancer, it has a profound impact on their children. Although some families choose to share information about their health with school staff, others may wish to keep the diagnosis private. This is a personal decision and your school should respect a parent's wishes. (Buchbinder, Longhofer et al. 2009).

If your school is aware that a student's parent has cancer, you may note changes in a student's attendance, school performance, social relationships and behaviour. While maintaining a sense of normality is important for many children, you might consider making a few special adjustments for the student.

During Treatment

From diagnosis, children who have a parent with cancer face substantial changes to their family routine and role functioning. In an instant, a child may be acting as carer, visiting the hospital, looking after siblings and taking on household duties. As well as taking on additional responsibilities while their parent is undergoing treatment, they may receive less emotional and practical support from both parents during this time. Understandably, studying and completing homework may not always be their main priority.

When a parent has cancer, their child will probably be preoccupied with what is going on at home. Studying and completing homework may not always be their main priority. Away from school, a young person may be acting as a carer, visiting the hospital, looking after their siblings and taking on household duties. This can also limit the amount of time they have to socialise. The situation becomes more demanding for the student if the parent with cancer is a sole parent.

The student's class teacher, or a school liaison person, may need to prepare for changes in the student's academic performance. You should also talk to the student's family about adjusting their expectations.

Research indicates that children who have a parent with cancer benefit from age appropriate education and information about cancer and its treatments. The Camp Quality Primary School Education program offers age appropriate cancer education to Primary Schools specifically to fulfil this need. As research indicates, children who have a parent with cancer may feel isolated from their peers, who have little to no understanding of the challenges a family faces with a cancer diagnosis. The Camp Quality puppets aim to help create supportive school communities by bridging this gap.

Talking about a parent's cancer

Children will vary in how comfortable they feel talking about their parents cancer. You should never force a student to discuss their situation if they do not feel comfortable doing so. However, if a student would like to talk about their situation research indicates that children benefit from having a 'safe space' in which they could express their concerns, without needing to filter their anxieties to protect their family members from distress.

If a student would like to talk about their situation, you should involve members of your school's student welfare team. If approved by their parent or guardian, it may be necessary and appropriate to offer counselling support to a student who has a parent with cancer.

Particularly for single parent families, it is important for you to ensure that daily living needs are being met.

- **Ensure they have lunch available**
- **Ensure they have all of their usual school equipment and supplies**
- **In some cases it may be necessary to make exceptions around school uniform and school arrival times**

Information about Cancer

The following document is not intended to provide detailed information on specific types of cancer. For more information about cancer, please call Cancer Council 13 11 20 or visit the Cancer Council Website. Cancer is a disease of the body's cells, which are the body's basic building blocks.

Our bodies constantly make new cells to help us grow, to replace worn out cells, or to heal damaged cells after an injury.

Normally cells grow, divide and multiply in an orderly way, but sometimes something goes wrong with this process and the cells grow in an uncontrolled way. This uncontrolled growth may result in abnormal blood cells or may develop into a lump called a tumour. Some tumours are benign, some are malignant.

There are over 200 different types of cancer in adults while for children, there are 12 major types of cancer; Leukaemia being the most common, followed by brain cancer.

The most common cancers affecting children are:

- **acute leukaemia**- a cancer that affects the blood cells. The two main types are acute myeloid leukaemia and acute lymphoblastic leukaemia
- **brain tumours**- the most common type in children or gliomas and medulloblastoma
- **neuroblastoma**- a cancer of the nerve cells involved in the development of the nervous system
- **lymphoma**- a cancer that develops in the lymphatic system. The two main types are Hodgkin's lymphoma and non-Hodgkin's lymphoma.
- **sarcoma**- a tumour that develops in the bone, muscle or connective tissue

Treatment

Treatment for cancer includes one or more of the following:

- Chemotherapy
- Radiotherapy
- Surgery
- Stem Cell Transplant

The most common treatment for children with leukaemia is chemotherapy, a mixture of many different drugs that target and destroy rapidly growing cancer cells. Children with solid tumours may require surgery and most will also have chemotherapy and/or radiotherapy.

Chemotherapy often extends over many months while radiotherapy is usually completed within 2 to 6 weeks. When the cancer is no longer detectable, the person is said to be in remission.

Side Effects

- Nausea/Vomiting
- Fatigue
- Hair loss
- Weight loss/gain
- Facial swelling
- Mouth ulcers
- Dry skin/eyes
- Lowered immunity
- Abnormal hormonal function (can affect growth and puberty)
- Continual cognitive difficulties (memory, learning, attention)



Support Services

Alongside the Camp Quality Education Program, there are other organisations that can help meet the specific needs of your school.

Cancer Council

For any questions related to a specific type of cancer or cancer in general, contact Cancer Council 13 11 20. Here you can talk openly about any concerns confidentially with oncology health professionals. Cancer Council NSW also produces more than 50 resources for people affected by cancer. The series includes easy-to-read information about specific types of cancer, treatments, and emotional and practical issues. For a list of Cancer Council publications visit www.cancercouncil.com.au/publications. Included in these publications is the full document 'Cancer in the School Community'. This document will be very valuable for your school if you would prefer more detail than provided in this resource.

Ronald McDonald House Charities

Ronald McDonald Learning Program (RMLP) - Funded by Ronald McDonald House Charities, RMLP provide one-on-one tutoring for young people whose education has been disrupted by a serious illness.

EDMed

EDMed is a one hour session provided free to schools and all staff. Each participant will receive an EDMed reference book and teacher handout. Their program aims to help teachers understand the effects of chronic illness and treatments on a students learning. Go to <http://learningprogram@rmhc.org.au> or call 1300 307 642

Redkite

Redkite offers a range of services for children diagnosed with cancer, their families and support networks including:
Education grants (which can be used to help children catch up on their return to school e.g. tutoring), financial assistance, information and emotional support, professional counselling, Book Club (a range of books to help children understand about cancer, that families can borrow for free), Parent support groups (via telephone and on select Camp Quality family camps) Go to www.redkite.org.au or call 1800 REDKITE (1800 733 548)

