

Cancer in the School Community

A guide for staff members



For information & support, call

13 11 20

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How this book was developed

Cancer in the School Community evolved from interviews with experts in oncology (oncologists, nurses, social workers, psychologists and counsellors), school staff, families, CanTeen, Camp Quality, NSW Department of Education representatives, hospital school staff and students. The quotations and stories in this book are authentic, but some names have been changed to protect people's privacy. The content of this edition is relevant for school systems across Australia, but some services and terminology may vary according to location. Please check with your local education authority or children's hospital for further information.

Gender-neutral language

To avoid gender-specific references, we have used third-person plural pronouns (they, their) in place of third-person singular pronouns (his or her, him or her) throughout this publication.

Note to reader

Always consult your doctor about matters that affect your health. This book is intended as a general introduction to the topic and should not be seen as a substitute for medical, legal or financial advice. You should obtain independent advice relevant to your specific situation from appropriate professionals, and you may wish to discuss issues raised in this book with them. All care is taken to ensure that the information in this book is accurate at the time of publication. Please note that information on cancer, including the diagnosis, treatment and prevention of cancer, is constantly being updated and revised by medical professionals and the research community. Cancer Council Australia and its members exclude all liability for any injury, loss or damage incurred by use of or reliance on the information provided in this booklet.

Cancer Council

Cancer Council is Australia's peak non-government cancer control organisation. Through the eight state and territory Cancer Councils, we provide a broad range of programs and services to help improve the quality of life of people living with cancer, their families and friends. Cancer Councils also invest heavily in research and prevention. To make a donation and help us beat cancer, visit cancer.org.au or call your local Cancer Council.



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Cancer in the School Community

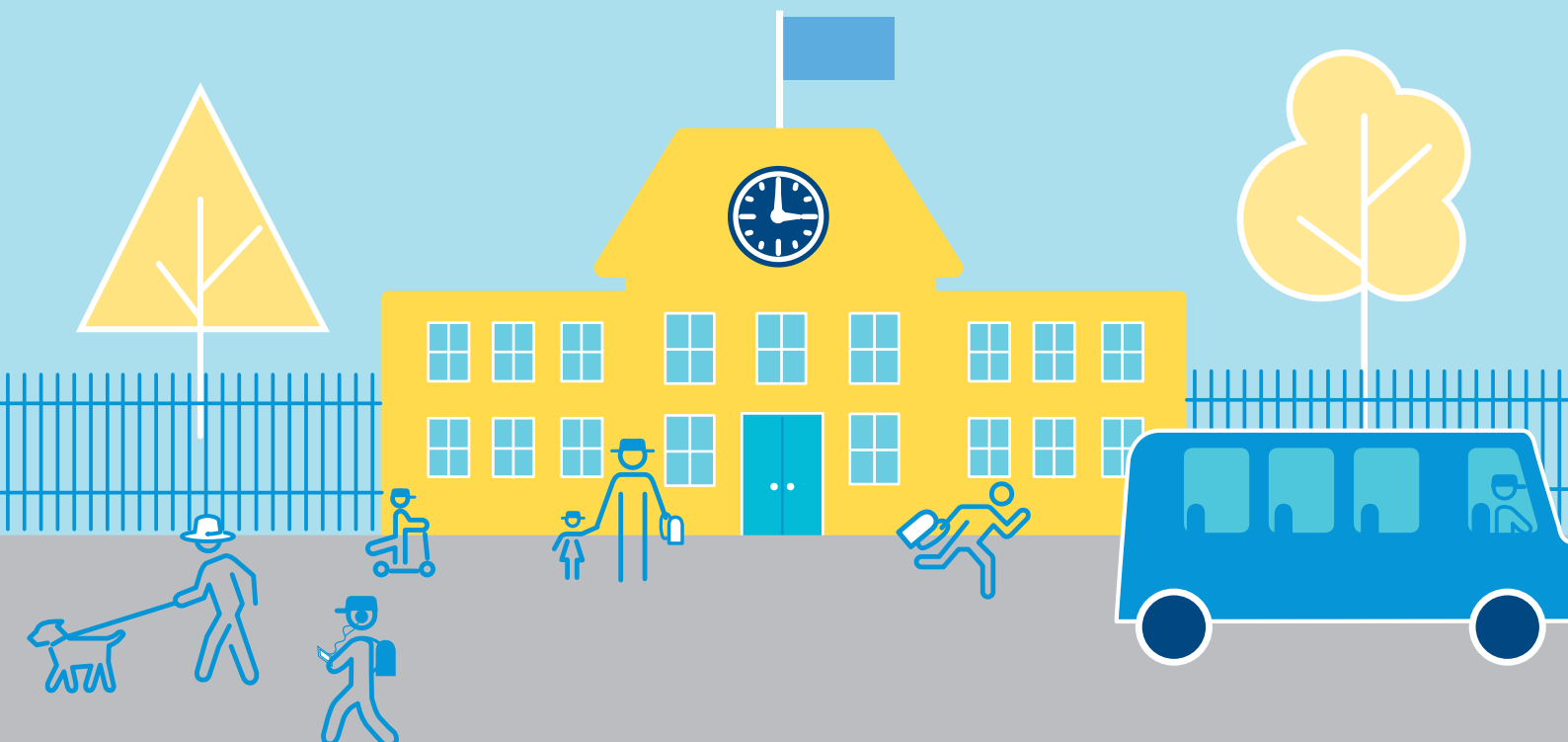
Every school is a community, a network of relationships connecting students, parents, guardians and family members with teachers, principals and other school staff. When anyone in a school community is diagnosed with cancer, people usually want to help but may not be sure where to start.

Cancer in the School Community is a guide for school staff who would like to support students, families and colleagues affected by cancer. The content is relevant for all primary and secondary school staff throughout Australia. It may also be useful for parents, guardians, students and family members.

It is important to remember that each cancer experience is different, and every individual navigates it in their own way. Some people want to deal with cancer privately, others welcome all support. Some want to talk about it, others just want to blend in. How people feel about the involvement of the school community may change at different stages.

We hope this book helps you respond effectively and sensitively to the issues that cancer may raise in your school community.

If you need extra copies of this book, call Cancer Council 13 11 20. You can also download a digital version from your local Cancer Council website.



How to use this book

Each chapter of this book explores a particular issue your school community might encounter – for example, when a member of staff has cancer. You can choose to read the entire book in one sitting, but you may only need to refer to one or two chapters at a given time. Please keep in mind that Chapter 6: *The bereaved school community* may be confronting. Many people do survive cancer, so this chapter may not be relevant to the situation your school community is facing.

Individual students, families and school staff have generously shared their experiences with us. Their perspectives appear throughout the book as quotations and personal stories. The page margins feature colour-coded boxes that highlight particular types of information:



Tips



More information



Alert



Personal story



Chapter summary

If you need help with any cancer-related issue, call Cancer Council 13 11 20 or see Chapter 7: *Finding further support* at the end of this book.

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“ Every school is different,
every person’s situation
is different. There are so
many variables at play. ”

Ruby, secondary student with cancer



1

Information about cancer

This chapter may help you answer simple questions about what cancer is and how it is treated. There are more than 200 different types of cancer and a range of treatments. Being aware of how cancer can affect people, what the treatments involve and their possible side effects can prepare you to support students, families and colleagues affected by cancer.



Individualised treatment

Cancer is increasingly seen as a genetic disease because it is caused by abnormal changes in a person's genes. An individual's cancer cells are unique. This means that different people may receive different treatments, even if their cancer type is the same. Doctors will recommend the best treatment for an individual based on the type and stage of cancer, the person's age and their general health.

What is cancer?

Cancer is a disease of the cells. Cells are the body's basic building blocks – they make up tissues and organs. The body constantly makes new cells to help us grow, replace worn-out tissue and heal injuries.

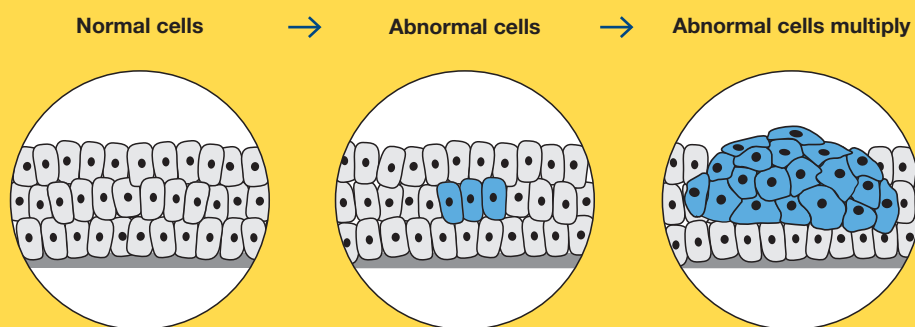
Normally, cells multiply and die in an orderly way, so that each new cell replaces one lost. Sometimes, however, cells become abnormal and keep growing. In solid cancers, such as kidney cancer, the abnormal cells form a mass or lump called a tumour. In some cancers, such as leukaemia, the abnormal cells build up in the blood and bone marrow.

Not all tumours are cancer. Benign tumours tend to grow slowly and usually don't move into other parts of the body or turn into cancer. Cancerous tumours, also known as malignant tumours, have the potential to spread. They may invade nearby tissue, destroying normal cells. The cancer cells can break away and travel through the bloodstream or lymph vessels to other parts of the body.

The cancer that first develops is called the primary cancer. It is considered localised cancer if it has not spread to other parts of the body. If the primary cancer cells grow and form another tumour at a new site, it is called a secondary cancer or metastasis. A metastasis keeps the name of the original cancer, e.g. kidney cancer that has spread to the liver is called metastatic kidney cancer, even though the main symptoms may be coming from the liver.

There are more than 200 different types of cancer, each with its own name and treatment. Most areas of the body can be affected by cancer. Some cancers are more common than others (see page 10).

How cancer starts



Treatments and side effects

Cancer and its treatment can have physical, cognitive and emotional impacts. There are a number of ways for staff to help a student or colleague manage these impacts in the school setting (see pages 30–33 and 52–53).

People with cancer may have one type of treatment or a combination of treatments. The table on the next page provides an overview of the most common cancer treatments and their side effects.

For some people treatment will cause significant side effects. However, not everyone will experience side effects. Some treatment side effects occur immediately; others appear weeks or months later. For more information, call Cancer Council 13 11 20 or visit your local Cancer Council website.

How long will treatment take?

Some cancer treatments take a few months, others take a number of years. An initial phase of intensive active treatment may be followed by a longer period of maintenance treatment.

If cancer cells and symptoms reduce or disappear after treatment, the person is said to be in remission. Remission may last for a long period of time. If the cancer comes back after a period of improvement, it is called a recurrence or relapse.

Some people experience a recurrence of cancer after a period of remission. If this happens to someone in your school community, they may need extended support from school staff.

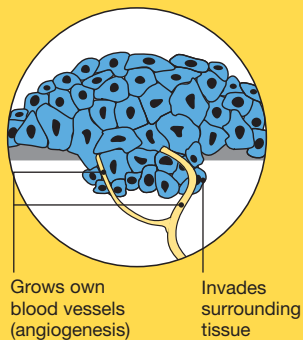


Alternative therapies

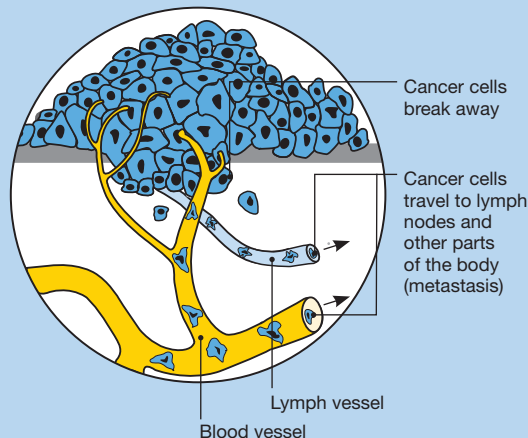
Alternative therapies are unproven therapies used instead of conventional treatment. They are often promoted as “cancer cures” without scientific testing. Examples include shark cartilage, magnet therapy and drastic diets.

Some alternative therapies may cause serious side effects or interfere with conventional cancer treatment. Cancer Council does not endorse the use of alternative therapies.

→ Malignant cancer



How cancer spreads



Common cancer treatments

	Description	Side effects
Chemotherapy	<ul style="list-style-type: none"> • Chemotherapy is the use of drugs to kill or slow the growth of cancer cells. • The drugs are most commonly given through a vein (intravenously), but can also be given as tablets (orally), as a cream, or as injections into different parts of the body. • Chemotherapy drugs circulate throughout the body. They particularly affect cells that divide rapidly, such as cancer cells or the healthy cells in a person's mouth, stomach, skin or hair. • Treatment may take several months. It is usually given in courses (cycles) over several weeks, with rest periods in-between. 	<ul style="list-style-type: none"> • Side effects of chemotherapy depend on the drugs used and vary from person to person. • They may appear rapidly (within a few hours) or later (2–4 weeks). • Short-term side effects may include nausea, vomiting, tiredness, hair loss, mouth ulcers, sun sensitivity and lowered immunity. • Long-term side effects may include problems with concentration, memory and thinking (cancer-related cognitive impairment). These can affect work or school performance for many years (see pages 32–33). Some chemotherapy drugs can cause infertility or heart problems.
Radiation therapy (also known as radiotherapy)	<ul style="list-style-type: none"> • Radiation therapy uses a controlled dose of radiation to kill or damage cancer cells so they cannot multiply. • It can be used to treat the original (primary) cancer or the symptoms of a cancer that has spread (metastasised). • The radiation is specifically targeted at the treatment site to reduce the risk of damage to healthy cells. • The radiation affects all cells in the area being treated, but cancer cells are the most affected. • Treatment may be given daily for several weeks. 	<ul style="list-style-type: none"> • Side effects may appear throughout a course of radiation therapy, but particularly near the end or even several weeks after. • Side effects will depend on the part of the body treated. • Short-term side effects may include nausea, tiredness, hair loss and reddening of the skin near the area treated. • Tiredness can persist for many weeks, especially after radiation to the head area. • Long-term side effects may include sun sensitivity, learning difficulties, growth failure, thyroid problems, hair loss, infertility and (rarely) a second cancer later in life.
Surgery	<ul style="list-style-type: none"> • Surgery involves the partial or total removal of a tumour. • Surgery for cancer sometimes requires removal of a part of the body (e.g. amputation). 	<ul style="list-style-type: none"> • The most common side effect is pain at the site of the operation. • Other possible side effects include infections and reactions to the anaesthetic. • Some kinds of surgery require prolonged rehabilitation such as physiotherapy. • An amputation can change physical appearance and ability, and may require the use of mobility aids such as a wheelchair or prosthesis. • Some surgeries cause bowel changes. Support and a private toilet may make this easier for the person to manage.

	Description	Side effects
Immunotherapy	<ul style="list-style-type: none"> Immunotherapy uses drugs to help trigger the immune system to fight cancer. 	<ul style="list-style-type: none"> Side effects vary depending on the drug. Some may become serious and treatment may need to be stopped. They may include fatigue, allergic reactions, painful joints, skin rash and diarrhoea. These can vary in severity and duration. Immunotherapy can also cause inflammation in any of the organs in the body.
Targeted therapy	<ul style="list-style-type: none"> Targeted therapy drugs attack specific particles within cells that let cancer grow. They may be used instead of or together with chemotherapy. 	<ul style="list-style-type: none"> Side effects vary depending on the drug. They may include fevers, diarrhoea, allergic reactions, rashes and blood pressure changes.
Steroid therapy	<ul style="list-style-type: none"> Steroid therapy uses corticosteroid drugs to reduce nausea or swelling. Steroids are also used to help treat some cancers and to increase the effectiveness of some chemotherapy drugs. They may be given orally or by injection. 	<ul style="list-style-type: none"> Side effects may include increased thirst and appetite, sleep problems, weight gain, behavioural changes, mood swings, stretch marks, acne, fluid retention, high blood glucose levels and muscle weakness.
Stem cell and bone marrow transplants	<ul style="list-style-type: none"> A stem cell transplant is a long, demanding process that replaces stem cells destroyed by disease, chemotherapy or radiation. (Stem cells normally live in the bone marrow and give the body a constant source of blood cells.) It may also be called a bone marrow transplant, a peripheral blood stem cell transplant or a cord blood transplant (depending on the source of the stem cells). 	<ul style="list-style-type: none"> Lowered immunity makes the person more likely to catch infections. The treatment may involve many months off school or work and prolonged isolation. The donor cells sometimes attack a patient's normal cells, a complication called graft-versus-host disease. This can occur soon after the transplant or many months later, requiring more time off school or work.
Hormone therapy	<ul style="list-style-type: none"> Certain hormones stimulate the growth of some cancers. Hormone therapy either blocks or removes hormones from the body to slow or stop the growth of cancer cells. It is mostly used for adults with breast, prostate, ovarian or thyroid cancer. 	<ul style="list-style-type: none"> Side effects for men may include tiredness, weight gain, hot flushes, breast tenderness, depression and osteoporosis. Side effects for women may include blood clots, weight gain, generalised swelling, hot flushes and irregular menstrual periods.
Complementary therapies	<ul style="list-style-type: none"> Complementary therapies are used alongside conventional treatments, and may help manage any side effects. They focus on physical and emotional wellbeing. Examples include acupuncture, yoga, massage, meditation and art therapy. 	<ul style="list-style-type: none"> Side effects depend on what type of complementary therapy is used.



Chapter summary

- ✓ Cancer is a disease of the body's cells – there are over 200 different types of cancer.
- ✓ Cancer is quite rare in children and adolescents.
- ✓ Children and adolescents are usually diagnosed with different types of cancer than adults.
- ✓ Type and length of treatment depends on the type of cancer and whether it has spread.
- ✓ Different treatments cause different side effects – short-term and long-term.
- ✓ Common side effects include fatigue, nausea, pain, loss of appetite, weight gain or loss, sun sensitivity, hair loss, swollen arm or leg (lymphoedema), diarrhoea, constipation, depression, difficulty thinking clearly, and concentration and memory issues.
- ✓ Students who have had cancer may need support throughout their schooling.

Who gets cancer?

An estimated one in two Australians will be diagnosed with cancer by the age of 85. In Australia, more than 127,000 people are diagnosed with cancer every year.¹ People over the age of 50 are the most likely to be diagnosed with cancer, and children are the least likely. Unfortunately, however, some children and young people are diagnosed with cancer.

In adult men, the most common forms of cancer are prostate cancer, bowel cancer, melanoma, and lung cancer. Adult women are most often diagnosed with breast cancer, bowel cancer, melanoma, and lung cancer.

Cancer in children and adolescents

In Australia, about 1000 children aged 0–19 develop cancer every year, which means that at any time there are thousands of school students who have had cancer.¹ Advances in diagnosis, treatment and follow-up care mean the overall five-year survival rate for children and adolescents is now more than 80%.² This can vary depending on the age of the patient and their cancer type.

Cancers affecting children generally differ from those affecting adults. Childhood cancers commonly occur in different parts of the body and are not usually linked to lifestyle or environmental factors. They tend to be more responsive to chemotherapy, and children often tolerate the treatments better.

Some side effects from treatment may not show up until many months or years later. These are called late effects. This is particularly the case for a child who was treated at a young age. Any student who has survived cancer will need appropriate support for the rest of their school years (see pages 32–33).

Childhood cancers

The most common types of childhood cancer in Australia are:³

- **leukaemia** – a cancer that affects the blood cells; the two main types are acute lymphoblastic leukaemia and acute myeloid leukaemia
- **brain tumours** – the most common types in children are gliomas (starting in the brain's glial cells) and medulloblastoma (starting in the cerebellum, the lower back part of the brain)
- **lymphoma** – a cancer that develops in the lymphatic system; the two main types are Hodgkin lymphoma and non-Hodgkin lymphoma
- **neuroblastoma** – a cancer of the nerve cells involved in the development of the nervous system
- **sarcoma** – a malignant tumour that develops in the bone, muscle or connective tissue.



2

Talking about cancer

Talking about cancer is never easy, and you may feel concerned about saying the wrong thing. It can also be challenging to balance a person's right to privacy with the need for others to know about their diagnosis. Use your school's existing wellbeing and communication guidelines and resources as you provide support.



Ways to provide practical support

- Go grocery shopping.
- Mind children or pets.
- Help with cleaning or laundry.
- Do some gardening.
- Make dinner.
- Drive to treatment.
- Meet for coffee.
- Visit your local Cancer Council website for more ideas.

People often say they don't know how to talk to someone with cancer, and they feel lost for words. The tips below can guide you, but the best advice is to just be yourself and try not to worry about whether you are saying the right thing. Saying something is often better than saying nothing because it acknowledges what is happening.

Listen and let them lead the conversation – If the conversation stops, it's not necessary to fill in the gaps. Simply being there can be just as important as talking. They may also want to talk about other things rather than having cancer dominate every conversation.

Acknowledge their feelings – It's okay for someone to feel sad or angry about their cancer diagnosis, so don't try to change their feelings and don't tell them to be positive. Let them cry or express themselves as they wish.

Avoid giving advice – Even if you have been in a similar situation, it is best not to tell the person what to do or that you know exactly how they feel. Try to use phrases like, "That sounds really difficult" or "You're going through so much."

Enjoy a laugh – People living with cancer want to talk about other things too. Not every conversation has to revolve around their diagnosis. Students, especially, see school as an opportunity for normality and routine.

Offer practical support – People overwhelmed by a cancer diagnosis often receive many open-ended offers of support (such as "How can I help?"), but may prefer specific offers, for example, "I was thinking of organising some meals for you – would that be okay?" or "If Meg's finding her bag a bit heavy, she can leave some of her books at school if she likes."

Invite them places – If you used to eat lunch in the staff common room or sit together on playground duty, continue to ask your colleague along. If you think they are too ill, suggest another activity or join them where they are comfortable.

Students may find it difficult to talk to a peer with cancer. See *Talking to a classmate with cancer* on page 37 for tips on how you can guide them.

“Simply knowing that people are thinking of you helps to ease the isolation and anxiety.”

Genevieve, mother of primary student with cancer



Respecting privacy

Some people wish to keep their cancer diagnosis private. There can be a number of reasons for this:

- Students may see school as a place to be themselves and carry on with life as normal. Because fitting in with peers can be so important, they may want to minimise anything that makes them seem different.
- Parents or family members may want to avoid gossip or probing questions. Sometimes they need more time to talk to relatives or decide on treatment.
- A colleague with cancer may want to continue working and focus on their day-to-day activities, or they may wish to keep their diagnosis private until they know how it will affect their work schedule.
- Some teachers worry that their students are too young to understand cancer.

These are legitimate concerns, and people's rights should be respected. Unless there are overriding health and safety issues, the person with cancer or their parent must give consent before anyone is told about the diagnosis.

In most cases, however, it will be easier for both the person with cancer and the school if at least key staff are aware of the diagnosis. An informed teacher can accommodate the person's needs; anticipate questions from students, colleagues or families; and help to distribute information (if consent has been given).

The reality is that even very young students have heard of cancer. Open and honest conversation about cancer reduces the risk of confusion and anxiety and helps children of all ages understand. Being open about the diagnosis can also reduce the chance of gossip and misinformation circulating around the school community, particularly if treatment leads to changes in someone's appearance (e.g. hair loss, amputation).

Any member of the school community who is provided with personal information about a student, student's family or staff member, needs to treat the information sensitively and confidentially.

Appointing a school liaison person

If a student has cancer, one of the most helpful things you can do is to appoint a particular staff member as the key point of contact in the school. It may be the student's main teacher but could also be another teacher or a member of the learning and support or wellbeing teams. To help

Keeping quiet

I didn't want to share my mum's diagnosis with everyone. Mum and I are both really private. I didn't want people to treat me differently. I had a bit of trouble with the girls in my year. I only told three friends who I trusted, but one of them told other people. I didn't want everyone to know. I didn't know what was going to happen, if Mum was going to die, and I didn't want people to gossip.

Emma, secondary student
whose mother had cancer



Cancer myths

There are many myths about cancer, which can make it difficult for people to talk openly about someone's cancer diagnosis. Cancer is not:

- contagious
- caused by something someone has said, or a punishment for bad behaviour
- caused by stress
- a death sentence.

Visit Cancer Council's iheard.com.au for more information concerning common misconceptions about cancer.

avoid further stress, it is important that the student and their family feel comfortable with and have a good rapport with this person, and that the arrangement is reviewed regularly.

The school liaison person can keep up to date with the family's changing needs and communicate with other staff on their behalf. They can also liaise with the hospital school and other education professionals. This reduces the chance of messages being misunderstood or the family having to repeat information.

Understanding differences

It can be difficult to gauge the right level of contact and how much support is needed and welcomed by a family. The school community plays a central role in the lives of some families, but for others – often those with strong family networks – it is not as important. A family may not want help from the school.

If your school community includes diverse cultural groups, people will probably have different values and beliefs about health care. This will affect how they understand cancer and the level of stigma they attach to the disease. It can also influence how information is shared.

In some cultures, cancer can have different meanings and some people may not want to talk about it openly. Some cultures believe that cancer is contagious, caused by bad luck or is always fatal. They may not want to use the word “cancer”. Others may believe the cancer has been sent to test them.

When you talk about cancer, be respectful of different ways of coping. For example, you can ask what kind of support a colleague, family or student would like, rather than assuming you know the best way to help. If the person is uncomfortable discussing cancer or has privacy concerns due to cultural reasons, they will be able to let you know.

As well as being culturally sensitive in your discussions, you can help by directing people to Cancer Council 13 11 20 for information about cancer and cancer services. If needed, they can call the Translating and Interpreting Service (TIS) on 13 14 50 and ask to speak to Cancer Council. Using a professional interpreting service maintains confidentiality. This can often be a better approach than using a family member or friend as an interpreter.

When a parent wishes to keep their own cancer diagnosis private, their children may be torn between respecting the parent's wishes, and their own need for support. Organisations such as CanTeen (see page 66) may be able to help them.



Communicating with people of all ages

A person's understanding of cancer depends on their age, maturity level and experience with the disease. When someone they know is diagnosed with cancer, they may have a range of reactions. These reactions depend on their relationship with the person, their personality and temperament, and the support they receive.

For an outline of how children, adolescents and adults without cancer may understand the disease, how they might react to someone's cancer diagnosis, and how you can talk to them about it, see pages 16–19. Key treatment or testing milestones, including finishing treatment, can also prompt anxiety.

Be particularly alert for changes in behaviour. For example, a young child may regress to thumb-sucking, a sociable student may start to withdraw from peers, a top student's grades may start to slip, or an even-tempered teacher may become moody. You can use these behavioural changes as a starting point for a supportive conversation. Provide opportunities for professional counselling if needed. Your school counsellor should be able to help.

Remember that each person is unique and these are broad guidelines. Although the experience of cancer is often challenging, many people are resilient and have positive reactions. For example, siblings of children with cancer often grow in compassion and empathy for the hardship of others.

You can refer to the glossary on pages 72–74 for a list of cancer-related words. This glossary provides two definitions for each term: one that is suitable for younger children, and one that is more appropriate for older children, adolescents and adults.

Cancer Council's book *Talking to Kids About Cancer* may help you with strategies for discussing cancer with students from different age groups. Call 13 11 20 for a free copy, or download it from your local Cancer Council website. Camp Quality offer a free educational program (see page 35), which uses puppets to help preschool and primary school students understand and talk about cancer.

Chapter summary

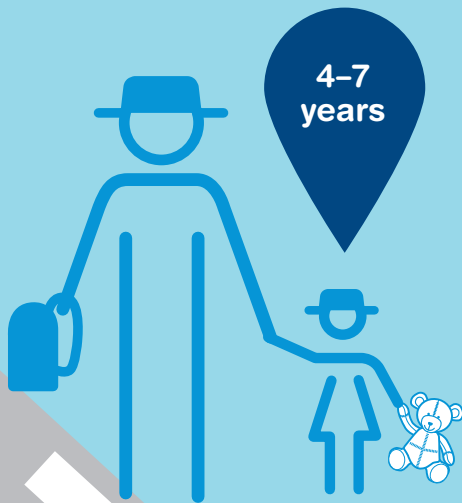
- ✓ Realise the first few weeks after diagnosis are usually stressful.
- ✓ Don't avoid the person because you feel uncomfortable.
- ✓ Listen and let the person lead the conversation.
- ✓ Offer practical support.
- ✓ Avoid giving advice.
- ✓ Respect the wishes of the individual or their family to keep the cancer diagnosis private.
- ✓ Appoint a staff member to act as the key liaison for the family.
- ✓ Explain cancer and its treatment according to the listener's age, maturity and experience.

“ I explained what would happen when he went to hospital. I didn't get too detailed, but I was open to questions. They were pleased to be told the truth. ”

John, primary schoolteacher of student with cancer

Different views of cancer

When someone in your school community is diagnosed with cancer, you are likely to encounter a range of reactions from students, families and colleagues. These general guidelines may help you pick up on signs of distress and provide age-appropriate support.



Early primary students

In the early primary years, students have a basic understanding of sickness. When someone they know has cancer, they may worry that they will catch the disease or that they caused it (e.g. by being naughty or thinking bad thoughts about the person). At this age, most children are egocentric: they often think everything is related to them and may not yet empathise with others. They tend to notice (and comment on) physical changes. Young students may be just starting to realise that people, including parents or grandparents, can die.

Possible reactions

- regression, e.g. stopping reading, starting to suck their thumb again
- comfort-seeking behaviours, e.g. using a security blanket or a special toy as a comfort object, thumb-sucking
- stuttering or baby talk
- withdrawing from conversations
- hiding behind a parent or significant adult when meeting other people
- fear of separation from others, especially at bedtime and going to school
- fear of the dark, monsters, animals, strangers and the unknown
- disturbed sleep, e.g. sleeplessness, wanting to sleep with a parent, sleepwalking or sleep talking, nightmares, bedwetting
- hyperactivity or apathy
- aggression, e.g. hitting or biting
- repeating questions about the same topic, even if it has been discussed several times
- commenting on physical changes and teasing if they don't understand them

Suggested approaches

- listen to their feelings (expressed through speech or play) and be alert to their needs
- talk about cancer using picture books, dolls or stuffed animals
- read books together that explore anger, sadness and other feelings
- be honest (to their level of understanding)
- reassure them that they will be taken care of and will be safe
- if separation anxiety is a problem, ask them to look after something special for that person, so they know they will return
- provide brief and simple explanations, but use all of the cancer terminology they may encounter (see pages 72–74); repeat your explanations if necessary
- keep routines consistent where possible, and explain any changes to their schedule
- encourage them to have fun at school and enjoy their other activities; physical activity can help to release anxiety and tension
- assure them that they have not caused the cancer by their behaviour or thoughts, nor will they catch cancer
- continue usual discipline and limit-setting



7-12
years



Later primary students

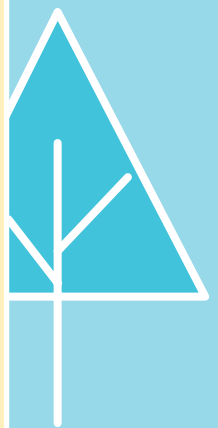
By the later primary years, most students are ready for more complex explanations of cancer and cells. Like younger children, they may feel responsible for causing the cancer of someone they know and may blame it on their own bad behaviour. Many are starting to comprehend the finality of death and its impact (especially if they have been exposed to death at a young age).

Possible reactions

- irritability, anxiety, guilt, envy
- sadness, crying
- physical complaints, e.g. headaches, stomach-aches
- school refusal
- separation anxiety when going to school or away to camp
- hostile reactions, e.g. fighting or yelling
- poor concentration or daydreaming at school, possibly with a change in academic performance
- withdrawal from friends and family
- self-consciousness, feeling like the odd one out
- difficulty adapting to changes (such as a replacement teacher or new schedule)
- fear of performance, punishment or new situations
- sensitivity to shame and embarrassment
- trying to be extra good

Suggested approaches

- listen to their feelings (expressed through speech or play) and be alert to their needs
- use books to explain disease, cancer, treatment and potential outcomes
- assure them their behaviour or thoughts did not cause the cancer
- be honest
- reassure them about their care and schedule
- maintain clear rules and expectations
- assure them that the chances of someone else getting cancer are slim
- let them know how they can help a teacher, classmate, sibling or parent with cancer
- take time to listen and let them know you care about their feelings
- appoint a teacher, staff member or buddy to watch out for them
- if the prognosis is poor, ask for help from a social worker or psychologist to gently broach the topic of a parent, teacher or classmate dying

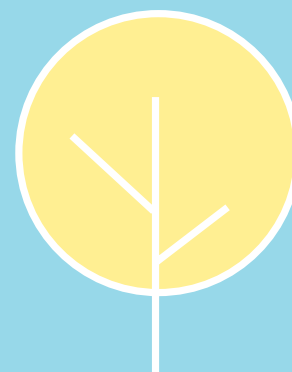




12-18
years

Secondary students

By the secondary years, students are starting to think more like adults. As their ability for abstract thought develops, they recognise relationships between events, such as cause and effect. They now appreciate that people are fragile and can imagine what it might be like to have cancer.

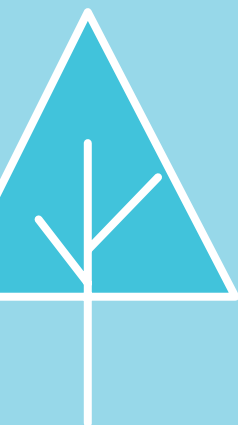


Possible reactions

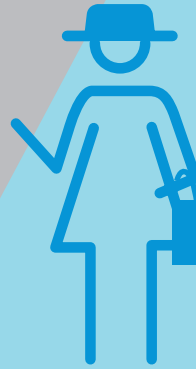
- denying fear or worry to avoid discussion
- hiding feelings – parents, teachers and friends may not see true reactions
- anger, rebellion
- withdrawal, apathy, depression, anxiety
- worry about being different and not fitting in
- becoming nervous in social situations
- wanting to be independent and treated like adults – may become more responsible
- regression, e.g. watching children's TV shows, being dependent on parents
- critical view of the support offered by adults and friends
- friendship issues
- poor judgement and risk-taking, e.g. smoking, binge drinking, unsafe sex, abuse of illicit or prescription drugs
- self-harm, e.g. cutting, restricting diet
- physical symptoms caused by stress, e.g. stomach-aches, headaches
- difficulty concentrating in class, change in academic performance
- poor school attendance
- a desire to help others and raise funds or awareness about cancer

Suggested approaches

- listen to them, don't talk at them; encourage them to discuss their feelings, but realise they might not want to talk or may prefer to confide in friends
- express your feelings so they know what they're feeling is normal (e.g. share that you are worried or miss the person), but do not burden them with the task of taking care of you
- provide privacy, as needed; highlight the importance of respecting privacy and using social media appropriately
- encourage them to maintain activities and friendships at school, if possible
- don't expect them to take on too many extra responsibilities at school
- allow them to have time with friends
- allow flexibility and special consideration with schoolwork
- provide in-school opportunities for them to learn more about cancer and receive support; don't expect them to be cancer experts
- treat them with respect as an emerging adult; let them know you are thinking about them, but be discreet and respectful



Over
18 years



Parents and staff members

Because adults and some older students can think in abstract terms, they usually empathise with the person affected by cancer. They understand complex relationships between events and are likely to recognise the impact of a cancer diagnosis and treatment on all aspects of life (such as school and personal relationships).

Possible reactions

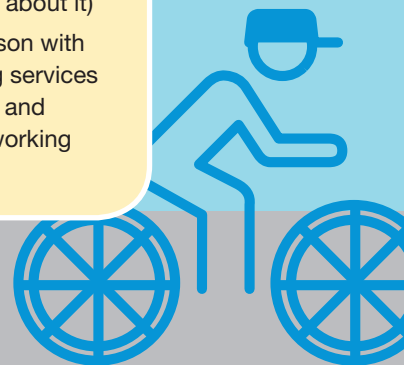
- depression, anxiety
- withdrawal
- sadness about their own experiences with cancer
- physical symptoms such as headaches
- fear about their ability to cope
- feeling overwhelmed
- needing to talk with others about how they are feeling
- putting extra energy into work or distracting activities
- fluctuation in mood, especially around significant testing and treatment dates of the person with cancer

Suggested approaches

- keep in mind that different people will feel comfortable with different approaches
- take time to listen and let them know you care about their feelings
- if a student has cancer, principals can give staff simple and factual information and encourage them to seek further information as necessary; they can discuss strategies for supporting the child and their siblings, what information may be shared with students and their families, and how to talk to children about cancer
- if a staff member has cancer, they may choose to tell parents and students (see page 49 for how to talk to parents about it)
- line managers can remind the person with cancer about any staff counselling services that they and their family can use, and discuss any requests for flexible working arrangements (see pages 49, 51)



Listen to a discussion about “Explaining cancer to kids” at cancercouncil.com.au/podcasts.





3

When a **student** has cancer

The news of a student's diagnosis may come as a shock to many people in your school community. The school can play a key role in supporting the student, their family and other students at this time. It is important to maintain connections throughout the student's treatment and to prepare for their return to school.

When a student is diagnosed

It is difficult for a family to receive the upsetting news of their child's life-threatening illness. They often describe the days and weeks after diagnosis as a whirlwind. Family members not only have to come to grips with the diagnosis, but they also have to make decisions about their child's treatment and inform their extended family network.

While the family is coming to terms with the diagnosis, they may not tell the school about it. Teachers or peers may notice a student's absence or speculate about any changes in the student's behaviour. Many families find that once the treatment has started and they have adjusted to the overwhelming situation, they feel more comfortable sharing information with the school.

Try to minimise rumours if you suspect (or have confirmed in confidence) that the student has cancer. Once the family has told you about the cancer diagnosis, you can take a number of steps to ensure the student is well supported by the school community.

Take the lead – Offer your support to the family. Explain that a school liaison person can be appointed so they only have to communicate with one person (see pages 13–14).

Ask who can be told – Establish if and how the family would like information about the student's diagnosis and treatment to be shared with teachers and the rest of the school community. You might suggest confidentially informing a small team (e.g. the year adviser, principal, vice principal, school counsellor and class teacher), who will respect the family's privacy while coordinating care and support for the student and any siblings at the school. It may also be helpful to develop a plan in case students learn about a classmate's diagnosis from the student or from social media, and need support in managing their reaction.

Respect their wishes – Allow the family time to decide what role they would like the school to play. If they want to keep the diagnosis private, staff should comply with their decision (unless there are overriding health and safety issues). If at some stage you feel that it would be in the student's interest to share the diagnosis, discuss your concerns with the family – you may want to contact the student wellbeing coordinator for advice on how to approach this conversation.

Arrange a meeting – Organise a meeting or conference call between the family and key staff such as the principal, the class teacher or year adviser, and the school counsellor. Consider meeting once per term to follow up on the student's changing needs.



Legal obligations

Under the Australian *Disability Discrimination Act 1992* and the *Disability Standards for Education 2005*, schools have responsibilities to support the ongoing education of students with cancer.

They are obliged to:

- consult so that they understand the student's needs
- make reasonable adjustments where necessary
- implement strategies to prevent harassment and victimisation.

The *Disability Standards for Education: A Practical Guide for Individuals, Families and Communities* website (resource.dse.theeducationinstitute.edu.au) provides general information about how schools can work with students and their families to support them.



Making the calls

As soon as my son Leo was diagnosed, I called my children's schools and spoke to the principals. At that point, I was still waiting for the doctor to come in and tell me he had made a big mistake. I wasn't ready to go into a lot of detail with the schools but I wanted them to know. Their initial response was it will be okay, we will be here to help you.

As time progressed, I called them all again. The main thing I wanted was for them to be kind to my kids, and they were. Everyone just wanted to know how to help and we had a really positive experience with all the schools – maybe because we were open to help.

Genevieve, mother of primary student with cancer

Work out the time frame – Consider how long the student may be away from school and how long their treatment may last. Some students with cancer are in and out of hospital for months, or even years. These students will need support throughout this time, which may involve a change of grade and teacher. Your school may be able to provide a form for the doctor to complete or ask for a letter from the doctor to explain prolonged absences or sporadic attendance. Many schools prepare an individual health care plan (or student health support plan) to outline how the school can support the student's specific health care needs (see pages 30–33).

Get professional help – Offer to link the student and family with school counselling services. With a parent's permission, staff from the hospital may be able to visit the school to discuss the student's diagnosis and treatment with staff and classmates.

Contact Cancer Council – Call 13 11 20 for further information on cancer, treatment and support services, or visit your local Cancer Council website.

Setting up a communication channel

Talking openly about the cancer diagnosis helps the school community adjust to the news, and understand what support the student needs. Ask the family what the student knows about the cancer and how the student has responded. Some families limit the information the child has about the cancer, especially if the child is young.

Schools have various ways of disseminating information to their community (e.g. newsletters, emails, websites, apps). Let the student and their family guide you about who in the school community needs to know and how much they can be told. The family, school staff members and the key liaison person can discuss the family's wishes and school policies for sharing information.

Different families may need different communication styles. For example, some may want you, or one of your colleagues, to talk to their child's classmates about cancer. Others may ask a clinical nurse consultant from the hospital to visit. Some may want the school to send a general letter to parents about cancer without mentioning the child's name. The school's parent association, such as the Parents and Citizens (P&C) or Parents and Friends (P&F), may be able to help the school communicate with families.

Be mindful of the student's close friends, as they may be deeply affected by the news. It can be very reassuring for the student if their friends find ways to show their support.



Supporting a student during treatment

Keeping in touch

School represents normal life to most students. Going to school is more than just education – it establishes a routine and provides an opportunity to socialise. A diagnosis of cancer is a major disruption for the student and leads to frequent absences from school.

Every situation is different. Not all families will want to maintain close contact with the school community, and a young child may not be able to respond to messages, depending on their age and symptoms. However, many students receiving treatment for cancer do want to maintain contact with classmates. Young people with cancer find it easier to return to school if friendships have been maintained throughout their absence. Regular communication can provide reassurance that they've not been forgotten by their friends and help to keep them engaged with their education.

The school community can keep in touch with a student in the hospital or at home by using technology such as Skype, email and the school intranet. Educational social networking portals such as Edmodo can allow you to communicate with the student and the hospital school about their schoolwork. Videoconferencing tools (such as Skype, WebEx, Google Hangouts or Adobe Connect) can also allow the student to participate in classroom lessons.

Supporting families

When a child or adolescent is diagnosed with cancer, the family may experience emotional and financial strain, which can cause anxiety. One parent may have to take time off work so they can be with the child in hospital, while siblings are often left with just one parent at home. The changing family dynamics and stress can lead to relationship issues. In single-parent or separated families, the pressures can be even greater.

Families in regional schools face extra complications. The major centres for cancer treatment are usually in large cities, away from the family's main support network. Often the student must travel great distances and stay away from home and school for long periods. One parent usually has to travel with the child, while the other parent stays home for work and to care for siblings.

School staff can link the family to school counselling services and offer support to any siblings who also attend the school (see pages 44–45). If your school has fees, the principal could consider how these can be adjusted to ease the family's financial burden. Fellow school parents often play a key role in coordinating support when a child has cancer, particularly if there isn't any extended family to help. With the family's permission, they may organise a

How to maintain contact

- Send postcards, letters, drawings or paintings.
- Make an audio or video recording of a school event, or of personal messages.
- Post a package of photos or small gifts.
- Email notes or photos.
- Consider age-appropriate programs such as Monkey in My Chair (see page 25).
- Create a website or blog about what is happening at school.
- Use social networking or videoconferencing such as Skype, FaceTime or Google Drive.
- Organise visits to the hospital by classmates, if approved by the student's parents. The student may have reduced immunity, so reschedule the visit if anyone has a cold, cough or other viral or infectious illness.



Mailbox

All my teachers and friends were in contact via email, so I was never out of touch with the group. They also sent me lots of cards and letters. Being given 25 letters at once was very overwhelming and made me feel very happy. People in my year also organised large cards, which they got more than 300 people to write on. They kept me entertained for hours!

Jeremy, secondary student with cancer

roster for meals, childminding or transport (such as taking siblings to school, sport or other activities), or set up a fundraising website. A group of parents may organise this help among themselves, or it could be coordinated by the school's parent association, such as the P&C or P&F.

Helping with schoolwork

It is natural for a parent to feel anxious about how the student is going to keep up with their schoolwork. Students may also worry about falling behind, particularly if that might mean being separated from their peer group when they do return to school. Talk to the student and the parents about their expectations, and how you can help maintain some form of ongoing learning. An Individual Education Plan (or Individual Learning Plan) can provide some direction and guidance to ensure the student doesn't fall behind.

Any school-aged student who has an extended hospital stay will be enrolled in a hospital school or hospital education service that caters for all school-aged students. A hospital school aims to provide continuity of education to make the return to school as easy as possible and to boost a young person's spirits and self-esteem. To do this, the hospital school may contact the student's regular school to discuss the educational program. This helps ensure that the learning taking place in hospital is aligned with their regular schoolwork. Students attend a classroom or, if necessary, are visited on their ward by a teacher. Some hospitals may provide other services to assist with learning needs, such as play, music or art therapy.

“My parents encouraged me to give up Year 11 and do it next year, but I didn't want to be left behind.”

Jeremy, secondary student with cancer

More children and adolescents are now receiving treatment as outpatients. This can make it difficult for them to visit the hospital school, but they may not be well enough to attend their regular school. If you know the student is spending long periods of time at home, liaise with the family and the hospital school to ensure they have educational support and peer contact. The class teacher can also work with the student and family to set up a work program they can complete at home, including opportunities for the student to connect with their class.

If the student transitions to high school or another new school, staff may share information about the student's learning needs so that the appropriate plans can be put in place.



Redkite

Redkite is a national charity that supports children and young people with cancer, and the people who care for them. They offer:

- financial assistance to help young people aged up to 24 years achieve their work and study goals, and to help young people whose education has been disrupted by a sibling's cancer treatment
- coaching assistance to help 15–24 year olds diagnosed with cancer at any age get back on track with work, study or training
- free information, support and counselling, for young people diagnosed with cancer, their families and support networks. This includes teachers and other education staff who would like advice on supporting a student.

You can help by making parents aware of Redkite's support services or by referring a student yourself. For more details, call 1800 REDKITE (1800 733 548), email support@redkite.org.au or visit redkite.org.au.

Ronald McDonald Learning Program

Provided by Ronald McDonald House Charities Australia, the Learning Program helps seriously ill children and adolescents, as well as the parents and professionals who support them. The program includes various services:

- individual tuition helps students catch up on their missed schooling
- Education Liaison Coordinators support the ongoing education of students at all children's hospitals in Australia
- EDMed, a free accredited professional development unit for teachers, helps schools meet the educational needs of children with cancer.

To find out more, visit rmhc.org.au/our-programs/learning-program, call 1300 307 642 or email rmhc@rmhc.org.au.

Hospital-based programs

Some hospitals have specialised programs to prepare students for the return to regular school. These programs liaise and collaborate with families, schools, hospital schools and oncology units to keep the child connected to their learning, their peers and their school community. Talk to your student's hospital about the educational services and programs they provide.

Monkey in My Chair

This charity supports younger children while they are absent from school by providing a large toy monkey to sit in the absent child's chair. The absent child also has a monkey. The class includes the monkey in all normal class activities and excursions, and photos are sent between children. For more information, visit monkeyinmychair.org.

Ways to support an absent student

- Provide the hospital school with curriculum outlines and a list of textbooks.
- Send copies of worksheets and projects to the student at home or at the hospital school.
- When the student returns schoolwork, acknowledge their efforts and provide them with feedback.
- Make sure the student receives school newsletters and handouts.
- Let the hospital school know if the student needs an extension or remediation program.
- Facilitate online access to assignments or websites with information about school activities.
- Find creative ways (such as Skype or video calls from class) to link the student with the school, especially if they are away from home or in isolation.
- Understand that the student may be so unwell during their treatment that they may not be able to continue with their schoolwork.



Common questions from classmates

- How did they get sick?
- Can I catch it?
- If you can't catch it, how do you get cancer?
- How many people get cancer?
- Will they miss school?
- What am I supposed to say or do?
- How can I be a friend to someone with cancer?
- Should I share things that are bothering me? They seem silly or trivial compared to what my friend is going through.
- Can people die from cancer?

Supporting the student's classmates

If you are telling students about a classmate's cancer, parents need to be aware that their children may come home upset, worried or with questions. The principal can send an email or a note home to prepare the parents.

You can expect a range of responses from students to the news. It's important to remember that everyone reacts differently to a stressful situation, and age and personality will influence this. Some students may be visibly upset. Others could be angry, confused or annoyed. Some may have no outward reaction to the news, which doesn't necessarily mean they're not listening or that they don't care. Others may look to help in any way that they can.

Give the students opportunities to share how they're feeling or ask questions. They might ask some difficult or sensitive questions, such as if they can "catch" cancer or if their classmate will die. Think about how you will respond to these questions ahead of time and approach the class in a sensitive manner (see Cancer Council's *Talking to kids about cancer* book for some suggestions).

In some cases, a member of the patient's treatment team (such as the clinical nurse consultant), a local community nurse or an organisation like CanTeen may visit the school to explain what is happening to their classmate, and how the student will look and feel when they return. Geographically isolated schools may be able to access support over the phone or internet.

Refer to pages 16–19 for strategies on how to talk to students of different ages. To prepare for potential questions about death, see *How young people understand death* on page 59.

Try to establish beforehand if some students are more likely to be upset because of their friendship with a classmate with cancer. If a student becomes very distressed, they may need to speak with a counsellor or teacher with whom they feel comfortable. Contact the parents to let them know about their child's distress.

Regularly inform classmates about the student's progress. This will help to keep the class connected and prepare them for the student's return. Events such as fundraising for cancer charities may help channel the thoughts and energies of older classmates.

Siblings of students with cancer may need particular support because of the disruption they experience. They may sometimes feel forgotten, or believe they are responsible for what is going on. For more information and ways to help, see pages 40–47.



Supporting a student after treatment

Returning to school

Getting back into a school routine is important to children and adolescents. It maintains continuity in their education and their friendships, and it reinforces the idea that life will go on and they have a future. It can be daunting for the student to return to school, however, and it is important to consider what support they will need. With the family's permission, a clinical nurse consultant or the oncology social worker may be able to visit the school to talk to staff about how the school can best support the student's return.

Encourage the student to return as soon as they feel up to it – Being accommodating and flexible to the student's needs will help the student become involved as much as possible in day-to-day lessons and school activities, rather than avoiding school. Ideally, the school will help the student by facilitating partial attendance (such as half-days) at first and reducing or modifying work, such as assessment tasks. Keep in mind that ongoing medical treatment and follow-ups may continue to affect school attendance. The family's medical team can provide documentation to support this, if required. It will be easier for the student to adjust to being back at school full-time if many short visits or half-days are kept up during active treatment. On some days, the student may just visit school at lunchtime so they can socialise with friends.

Plan for the individual needs of the student – Preparing for the student's return is essential so that any adjustments, such as modified grading procedures, can be put in place. This relies on communication between the school and the student, their family and the treatment team. The school liaison person can coordinate communication with teachers, the school counsellor and other staff.

Ask the family whether any speech, occupational or cognitive assessments were completed during treatment and, if so, whether copies of the reports can be given to the school. If not, a school counsellor can conduct an educational assessment of the student and provide recommendations on how to meet the student's individual needs. This may include further referrals, such as for occupational or speech therapy. Students may also need practical changes to accommodate their physical needs (see pages 30–31). It is important to treat the student as normally as possible, within the limits set by their condition.

Return to school plans

A return to school plan can help with the student's reintegration into school. It is prepared by the school with involvement from the student, their family and the health care team.

The plan can outline agreed expectations about attendance and schoolwork, any additional support the student requires, and what the school can do to support the student.

A return to school plan can be incorporated into the Individual Education Plan (IEP) or Individual Learning Plan (ILP) (see page 32). It is likely the student will also need practical support (see pages 30–31).

“Coming back to school after treatment takes a lot of bravery. You have been through such a traumatic experience and you look so different.”

Genevieve, mother of primary student with cancer

Anticipate anxieties about returning to school – Returning to school can be daunting for both the student and parent after a prolonged absence, especially if the student has had to be held back a year and is entering a different peer group. The school counsellor or another appropriate member of staff can arrange a meeting with the student and parents to discuss their concerns about returning to school and how the school can help. Reassure the student that while things will probably feel different for a while, they will be supported to settle back into school (see pages 29–30). Identify people they can go to if they have a problem or feel lonely, especially during lunchtimes. Discuss with the student which trusted staff member they would like assigned. Add a peer buddy if your school is equipped to provide them with appropriate support.

It is natural for parents to have a wide range of feelings about their child returning to school. Some may be overprotective or stressed about the transition, while others may be relieved or pleased. If you have difficulty managing a parent's reaction, talk to the student wellbeing coordinator or a school counsellor about how to handle the situation. With the parents' permission, you could also contact the clinical nurse consultant from their treatment team for guidance. Sometimes parents need reassurance that their child's physical and emotional needs will be supported (see pages 30–33).

Building resilience

Resilience allows children to cope with adversity – to bounce back. Although living with cancer can be undeniably difficult, in most cases young people can demonstrate maturity and wisdom beyond their age.

To help all students build resilience, teachers can:

- create a supportive environment
- value all contributions from students
- set clear expectations and rules
- encourage students to accept responsibility
- praise sustained effort and perseverance
- prompt students to think and act independently
- model and teach empathy and caring
- teach students how to resolve conflict.

For primary school students, visit **kidsmatter.edu.au** to find out more about promoting resilience and for resources you can use in class. You can also ask your local education authority if they have any resources.

For secondary students, the ReachOut Schools portal at **schools.au.reachout.com** has a *Building Resiliency in Young People* resource, which includes lesson plans. Or visit **mindmatters.edu.au** for online modules to help secondary schools promote a positive environment and build resilience.



The returning student's concerns

When students have had a lot of time off school for cancer treatment, their worries may include social, academic, psychological and physical issues. Some common concerns are listed below, along with ways that school staff may be able to provide support. Use this list to start a conversation with your student about their particular concerns and take your lead from them.

Being the centre of attention – Students may worry about being stared at or being bombarded with questions about their absence or appearance. With the student and family's permission, communicating with the school community (see page 22) before the student's return can encourage sensitive reactions from peers. Preparing the student with simple responses to typical questions can also help.

Keeping up with schoolwork – Reassure the student that their being back at school is what's important and that it will take time to catch up. Provide additional support through your school's student wellbeing team, learning and support team or liaison person, or arrange a study buddy (peer support), tutoring or special assistance. Consider modifying grading procedures and assessments if appropriate.

Being left out or rejected – Let the student know that their classmates did miss their company, and explain that their peers may be shy initially, but will eventually be more welcoming. Prepare classmates for the student's return before they arrive. Remind peers of the returning student's right to privacy and about the dangers of comments on social media.

Being bullied or teased – Your school will already have policies to deal with bullying, discrimination and harassment. Closely monitor the reactions of other students – some peers can resent what they see as special treatment, but educating students about cancer in age-appropriate ways can help (see pages 34–35). It is also important to remind them about social media etiquette. Equip the student with cancer with strategies to respond to bullying behaviour.

Fitting in with other classmates – A student who looks different (because of weight gain or loss, hair loss or a physical disability, for example) might worry about their friends' reactions. Talk with classmates honestly to help them understand the situation. Some students with hair loss may wear a head covering (cap or scarf) while their hair is regrowing. Others may have to adapt the school uniform. Ensure school staff know about any adaptations to avoid unnecessary embarrassment. If the student has to change clothes for school activities, you might be able to provide a separate changing area to give them extra privacy, especially if they are concerned about their peers' reactions.

Everyone stared

When I went back to school after chemotherapy, I had lost so much weight and was so weak that I had to use a wheelchair. I felt awkward and really nervous. Everyone looked really shocked. People stared a lot, especially the younger students. I hated it. I can't blame them because it's not every day you see someone looking so different and they were probably trying to understand what was going on. I kind of got used to it, but I still didn't like it.

Ruby, secondary student with cancer



Outside School Hours Care (OSHC)

A student with cancer may start attending before and after school care once they are well enough, particularly if both parents have returned to work. The opportunity for social interaction can be especially valuable. OSHC staff supporting a student with cancer can refer to the advice in this chapter. They may also have a special role to play in supporting a student whose sibling or parent has cancer (see pages 40–47). The parents are likely to be preoccupied with the treatment and, in some cases, it may be the first time the student has used the OSHC service.

Feeling that their classmates are immature – After the experience of having cancer, many older students feel they have less in common with their peers. The latest celebrity gossip or music news can seem unimportant. This can affect the student’s ability to fit in and socialise. Try helping the student to find new interests to share with peers. Remember that while the returning student may seem to be older in some ways, they are still very young.

Getting sick again – After treatment has finished, it is common for a student and their family to be concerned about the disease returning (cancer recurrence). This concern can arise each time they have a check-up and may last for years. For some students, the treatment leaves them with a compromised immune system and they are highly susceptible to infections. Reinforce your school’s standard infection control measures and encourage general hygiene, such as handwashing, throughout the school. You could also consider including handwashing as part of the curriculum for younger year levels.

The principal can send a letter or email to all families emphasising the importance of not sending children with infectious diseases to school and asking parents to inform the school of any cases of measles or chickenpox as soon as possible so that the parents of the child with cancer can be alerted. The letter can explain that one of your students has lowered immunity after cancer treatment but need not mention the student by name.

Making practical changes

A student with cancer will usually need some practical support related to their health care and psychological wellbeing. A written management plan prepared by the principal with the input of the student, their parents and their health care team helps to avoid misunderstandings. This individual health care plan (or student health support plan) should consider the student’s full range of learning and support needs, including treatment effects, care needs, and emergency signs and procedures. Many young people prefer not to draw attention to themselves. Talk to the student about ways they can discreetly signal their need for a break or physical assistance (e.g. by placing a white time-out card on the desk or using a hand signal).

“When I first went back to school, my friends were happy to help me, but once they thought I was better, they sort of drifted away. But you need help for longer than you look like you need help.”

Ruby, secondary student with cancer

Accessibility – Fatigue is a common side effect of cancer treatment, so when a student first returns to school, they may find it easier to manage if their classes are moved to easily accessible rooms. For secondary students, allow a window of time for movement between classes so they can avoid crowds.

In some cases, the cancer or its treatment can cause a physical disability. For example, a student may have had an amputation, they may need to use a wheelchair or they may have vision loss. School buildings may already be modified to ensure access for other students with physical disabilities, but you may need to provide permission to use more accessible toilets, access to a lift, or classrooms on the ground floor. The school may also need to organise an accessibility assessment of the school grounds.

If the student is weak and needs assistance with carrying books or pushing their wheelchair, the student's individual health care plan (or student health support plan) should set out how this will be managed. If the student has reduced or impaired fine motor function, an occupational therapist may need to recommend ways the student can be supported in their writing activities.

Sensitivity to sunlight – Students receiving cancer treatment can be very prone to sunburn. To limit sun exposure, encourage the usual SunSmart guidelines of using sunscreen, wearing hats and ensuring access to shaded areas (for more information, call 13 11 20 or visit your local Cancer Council website). On hot days, encourage indoor activities, but do so without isolating the student – for example, the student could go to the library with a few classmates.

Central venous access device – Some students will have a central venous access device (CVAD), which is a tube inserted into a vein in the neck, groin, chest or arm. It may be called a port, port-a-cath, central venous catheter, Hickman line, PICC line or central line. It allows medical staff to administer chemotherapy and other drugs, fluid or blood transfusions, or to draw blood.

All school staff, including those in charge of sports and sick bay, need to be aware of precautions and care while a student has a CVAD. Contact sports can cause the device to break or loosen, and some types should not be submerged in water because of the risk of infection. Ask the student's parents what precautions the medical team have recommended, and discuss how the student can still participate in school sports, such as by recording results.

To minimise panic and any negative effects on the child or other students, the student's individual health care plan (or student health support plan) should set out what action to take if there is a problem with the CVAD, e.g. a cap falls off, the line comes out or the site starts to bleed (see also box at right).



If the student becomes unwell

- If a student with cancer complains of feeling unwell, particularly if their temperature is rising, contact their family.
- If a student who is still receiving active treatment or has a CVAD develops a fever of 38°C or above, it might indicate a serious infection and they usually need to go to hospital immediately.
- The student's health care plan (or health support plan) should include the details of who the school should contact if the student becomes unwell and in what order. If in doubt, school staff can call 000 for guidance.
- If the student's health care plan includes arrangements for the school to monitor the student's temperature, parents may need to provide the school with a thermometer for their child.

Palliative care

Cancer in children can be unpredictable, so palliative care may be offered early in the course of the disease. Palliative care aims to optimise wellbeing by addressing the child's physical, practical, emotional, spiritual and social needs. It does not mean that their family or medical team have given up hope or that the child is dying.

Some children attend school while they are receiving palliative care. For children with cancer and their

families, school can offer a sense of connection, normality and routine throughout a time of great upheaval. Depending on their health and energy levels, the student may attend school full-time or part-time.

In some cases, the attendance may be primarily social, with the student visiting for lunch breaks or favourite classes. The school community can play an important role in supporting the student's independence, dignity and determination.

Understanding learning impacts

A student returning to school may have to manage the effects of cancer treatment on their academic performance. Parents of students with cancer have reported significant effects on writing, mathematics, handwriting, confidence, exam performance, memory, concentration and physical education.⁵ Some of these impacts may be delayed, appearing months or even years after treatment has ended.

It is important to recognise that cancer treatment can change the way the student learns and that the student may need extra educational support throughout all the years of their schooling. In particular, some students develop long-term difficulties with executive functioning. This affects the ability to plan, organise, form abstract concepts, practise self-regulation and initiate action. The student may have trouble taking notes or copying information, remembering things, concentrating, getting started on activities, or completing tasks on time. In some cases, the student's struggle to manage these challenges can lead to a lack of engagement with education or disruptive behaviour in the classroom.

In many school systems, specialist learning support staff help classroom teachers to address the additional educational needs of students. They may be part of a learning and support team (sometimes known as the program support group). This team is made up of all those involved in the student's education, including parents, the principal or other school leader, the class teacher and the school. In some cases, the team may decide to create a formal plan, which may be known as an Individual Education Plan (IEP) or Individual Learning Plan (ILP).



Sexuality, fertility and body image

The upper primary and secondary school curriculums for health and physical education, and for science, may include the topics of fertility and sexuality. Some cancer treatments can seriously affect fertility and sexual function, so these topics may need sensitive handling. Likewise, if you're planning lessons about body image, consider the impact cancer treatment may have had on your students (e.g. amputation, surgical scars), and whether you need to adapt your lesson plan.

Parents or guardians have an important role to play in discussing and planning for their child's needs. You can refer them to *Learning curve: education and socialisation after childhood cancer*, a series of booklets for different ages produced by the Victorian Paediatric Integrated Cancer Service (pics.org.au/families/survivorship).

Your school will need to work together with the parents and student to develop realistic expectations about what can be achieved academically.

Adjustments to support learning

In addition to any adjustments to accommodate physical needs (see *Making practical changes*, pages 30–31), schools may need to make temporary or permanent adjustments to manage the returning student's changes in academic performance and behaviour. These adjustments can be listed in the student's IEP, ILP or return to school plan, and may include:

- seating them towards the front of the class
- organising an in-class buddy or teacher assistant to help with note taking or recording assignment due dates
- providing catch-up work in different key learning areas
- offering extra tutoring
- adapting work so the student can manage the load
- discreetly allowing extra time for homework and assessment tasks, and increasing time limits in tests or exams
- providing a model or scaffold that shows the steps in a task
- giving verbal prompts and written reminders
- helping the student organise thoughts using graphic organisers and mind maps
- allowing the student to work without interruption as much as possible
- revising the number or types of subjects taken by the student
- encouraging rest breaks in class to help the student focus and manage fatigue.

Students may also need special consideration for physical education classes. This will be obvious if the student's treatment has involved a visible change such as an amputation, but also needs to be considered when the student is managing fatigue from chemotherapy or radiation therapy.

“Since his treatment, he's had some difficulty remembering numbers like times tables. He's having tutoring now and he's got a few tricks that the tutor has taught him.”

Rebecca, mother of secondary student with cancer

Helping young people understand cancer

Giving students factual information about cancer increases their understanding and reduces the risk of gossiping and bullying (see *Dealing with teasing and bullying* box, opposite page). Most students want to be supportive, but need the tools and knowledge to do so effectively.

Before starting a discussion with your students, consider their age and maturity and anticipate any difficult questions they might ask (see margin box, page 26). You might practise what you will say, or ask the family how they would like you to approach the class.

Planning a lesson about cancer

In some cases, a lesson or class discussion about cancer can help students understand their classmate's condition. Depending on the content, this may support the curriculum for health and physical education and/or for science – check with your local education authority (see pages 68–69).

There are a number of books about cancer (see margin box, opposite page) that you can share with your students. Staff from the student's hospital school may be able to recommend other age-appropriate resources about cancer that you can use in class. With the permission of the student's parents, you could also ask if a clinical nurse consultant or other member of the medical team can visit the school to talk to students and staff. Camp Quality offers a Primary School Education Program (see opposite page) and CanTeen runs When Cancer Comes Along, an education program for students in years 9 and 10 about cancer and its impacts (see canteen.org.au/schoolawareness).

Hosting a cancer awareness and education day

While it is important to integrate information about cancer into the core curriculum, your school may also consider hosting a cancer awareness and education day. Many awareness days include a fundraiser, such as buying ribbons or coming to school out of uniform in exchange for a gold coin donation (see page 70). However, your school does not have to collect funds.

Ask the person with cancer (or their family) if they are comfortable with the idea. While the information can be presented in a very general way, families may want to ensure certain details are kept private. Consider how best to inform all parents and students about the upcoming event.

The cancer awareness and education day could involve brief in-class discussions or lessons from teachers. Younger students could draw pictures or write stories. Older students may want to hang posters, make presentations about cancer, or set up a stall to distribute information.



Arranging a puppet show

For a cancer awareness day in a preschool or primary school, you may want to arrange a visit from the Camp Quality Primary School Education Program. This free program explains cancer to children through an interactive puppet show that addresses the challenges of living with cancer and the importance of friendship. It is a useful tool for introducing the topic of cancer in an age-appropriate way that provides the school community with a shared language for honest and open discussion.

If you are hoping to book a Camp Quality puppet show, plan well in advance. The puppets are very busy, but your State Coordinator will do their best to book you in as soon as possible. Camp Quality will provide you with a template letter so you can inform all parents of the planned visit.

Camp Quality also provides free resources that can be used in the classroom after the performance and may be useful when planning a lesson about cancer. For more details, call 1300 662 267 or visit campquality.org.au.

Dealing with teasing and bullying

A school climate that promotes respectful relationships is likely to support student wellbeing and discourage inappropriate behaviour, such as teasing and bullying.

Schools are legally obliged to develop and implement strategies to prevent harassment and victimisation of students, including those with cancer (see margin box, page 21). Schools also need to respond appropriately if an incident occurs. Consult your school's anti-bullying or anti-harassment policy for general guidelines.

The best way to prevent bullying is to be as open as possible about a student's cancer. Young people may have little understanding of what a student with cancer is going through and what treatment involves. This may make them feel frightened.

The more classmates know about cancer, the more likely they are to be supportive. Discuss the benefits of openness with the student and family and make sure you have their permission to share information about the student's situation.

It's important to be aware that some students may feel resentful when a student with cancer returns to class. They may believe their peer is receiving undue special treatment. You can explain that the student needs extra support related to their health but still has to follow the same school rules as everyone else. Try to maintain a normal classroom atmosphere.

For general information on creating a supportive school culture, you can explore the resources at studentwellbeinghub.edu.au.

Books about cancer

For younger children

Butterfly Kisses and Wishes on Wings
Ellen McVicker (author)
Nanci Hersh (illustrator)
butterflykissesbook.com

I Know Someone with Cancer series, 2014
bupa.co.uk/bupa-cancer-promise/i-know-someone-with-cancer

In the Rainbow
Tracey Newnham, 2018
intherainbow.com.au

Nowhere Hair
Sue Glader, 2010
Thousand Words Press,
nowherehair.com

Safina and the Hat Tree
Cynthia Hartman
Nomota, 2004
talesforkids.com.au

When I had Leukaemia,
Delia Crabbe
Merivale Books, 2010

For older children and adolescents

Wait... Did you say 'Cancer'? series
CanTeen, 2013
canteen.org.au/resource

*The Fault in Our Stars**
John Green
Penguin Books, 2012

The Honest Truth
Dan Gemeinhart
Scholastic Press, 2015

* Also a movie



Between friends

My daughter's friends are very caring, and they'd all have a good cry together out of the blue.

I'd ask, "What's going on?", and they'd say, "No, it's got nothing to do with you." You know, certain things they just don't tell you.

Sarah, mother of secondary student with cancer

Guiding classmates

It is not uncommon for the classmates of a student with cancer to feel helpless and unsure about what to do or say when they are with the student. Sometimes students will look to teachers or their parents for guidance on how to act, but at other times you might simply notice that the students are feeling uncomfortable. There are various ways that you can help the students to become more at ease, including:

Listening – Be prepared to listen to students' concerns.

Facilitating discussion – Encourage students to talk about what cancer is, its treatments and possible side effects. This will help prepare students for any physical or emotional changes in their classmate. See Chapter 1 (pages 6–10) for more facts about cancer.

Answering questions – Discussing the facts openly helps reduce anxieties and uncertainties. If you don't know the answer, offer to find out. Remind students of their classmate's right to privacy and the potential impact of sharing information on social media. If you're caught off guard by a question, consider responding with "That's a really good question, what makes you ask that?" This will give you some insight into why the person is asking the question.

Being prepared – When a student has cancer, it's a good bet most classmates are thinking, "Will they die?," and a few will probably ask. Balancing the truth and family wishes can be a challenge. A gentle way to respond might be: "Cancer is a very serious illness and we are all worried about your classmate, but we know that the treatment team at the hospital is working hard to help them. If we learn of any developments, we will let the class know."

Providing advice – Give students guidance on how to talk to a classmate with cancer. For some ideas, refer to the page opposite.

Encouraging emotional expression – Provide the opportunity for friends to debrief and express their feelings about cancer. For some students, activities such as painting, writing or composing music will help them work through their emotions.

Inviting an expert – You could ask a member of the student's medical team, such as a clinical nurse consultant, to speak to the class (with the consent of all parents, including the parents of the student with cancer). This will help students gain a better understanding of what their classmate is experiencing.

Talking to a classmate with cancer

Advice to give students

Like some adults, students sometimes worry about saying the wrong thing, so they may start to avoid a classmate who has cancer. Teachers can help by discussing the following tips with their students.

Try to talk about day-to-day things

Their classmate is probably tired of talking about cancer all the time. But the students also need to understand that their classmate might not be interested in trivial topics such as the latest celebrity gossip.

Acknowledge the situation

Students can say: "I don't know what to say, but I want you to know I care", "We missed you", "It's good to see you", "How are you going?" or "Is there any way I can help in class?"

Understand that their classmate might act a little differently

Their classmate may be more tired or less social than before. Students can show their support by being patient and accepting that it may take time to adjust.

Understand that their classmate might look different

Their classmate may be self-conscious about any appearance changes caused by cancer treatment. They may want to talk about these changes or they may just want to fit back in. By following the lead of their classmate, students can work out whether it's okay to talk about the changes.

Take cues from their classmate with cancer

People who have had cancer react in different ways. By observing how their classmate behaves, students might figure out how to respond.



Extra time

The school's special ed department organised someone to help me apply for special help for my senior exams. I was a slow writer and had problems writing essays within the time limits. They arranged for extra time for me, and a laptop, because I type faster than I write. I sat all the exams at the same time as the other students, but I was in an area with other kids with the same considerations. All those accommodations were fantastic.

Jeremy, secondary student with cancer

Special provisions for exams

Exams in primary school

The National Assessment Program – Literacy and Numeracy (NAPLAN) involves annual tests for students in Years 3, 5, 7 and 9.

Students with cancer may be unwell at the time of the tests, or their cancer treatment may have temporary or permanent effects such as fatigue or learning difficulties. Parents may not be aware that their child can apply for special examination provisions, so the school should raise the issue with them. The student's treatment centre can provide documentation to support a request for special provisions. For more information, school staff can visit nap.edu.au and search for “disability adjustments”, or contact their state or territory test administration authority (see pages 68–69).

Special provisions may also be available if the student is attempting placement tests for selective classes or schools. Contact your local education authority (see pages 68–69) if you know these tests are coming up.

Senior assessments

The senior assessments at the conclusion of secondary schooling are known by different names throughout Australia. In general, all students are required to meet the course requirements, but the relevant education board can adapt assessments to provide reasonable adjustments to the special needs of students with cancer.

The permitted provisions depend on the rules in your state or territory and on each student's circumstances. For example, some students may be allowed rest breaks between exams or an extension of test time. Other students may need to have physical disabilities accommodated (e.g. by using a scribe, a reader or assistive technology). In particular cases, the student's marks may be based on their scores throughout the school term/s, rather than the usual combination of in-school assessments and external exams.

If possible, it is preferred that students sit their exams, and then appeal for a different marking procedure. However, if you know a student might be eligible for special provisions for an upcoming exam, talk to the student and their parents about their options.

In most schools, applications for special provisions are made to the education board through the principal, school counsellor or learning support staff. There may be a cut-off date for applications and you may need to allow time to get supporting documentation from the student's doctor or treatment team. If possible, it is best to apply well in advance, as applications may take



several weeks or months to process. For students who become suddenly ill around the time of the exams or who have a family member with cancer, illness or misadventure provisions may be available.

If a student is finding the demands of the senior years too great, they can explore the options for extending the time frame. For information about options available in your state or territory, talk to the senior year coordinator, guidance officer or school principal, or contact your local education authority (see pages 68–69).

Access to tertiary study

In some states and territories, access schemes can help a student enter tertiary study if they have experienced long-term educational disadvantage because of a cancer diagnosis or treatment. Depending on the location, these are known as Schools Recommendation Schemes (SRS), Educational Access Schemes (EAS) or Special Entry Access Schemes (SEAS). Each university applies its own access scheme calculation to the student's final score and determines if they will be admitted into their elected program of study.

Visit the website of the universities/tertiary admission centre in your state or territory (see pages 68–69) to find out more about applying for an access scheme. You can also contact the tertiary institutions directly for information about any alternative pathways available to students. The school careers counsellor should also be able to offer guidance.

School staff could explore whether there is any extra financial assistance available for the student, for instance:

- Redkite's educational assistance includes grants to help students pursue tertiary study after cancer (see page 25)
- Ronald McDonald House Charities Australia's Charlie Bell Scholarship program provides grants to assist with the cost of vocational or tertiary studies for young people aged 15–20 years who have experienced serious illness (rmhc.org.au/our-programs/charlie-bell-scholarship).

Chapter summary

Diagnosis

- ✓ Offer support to the student and family.
- ✓ Tell the family what services are available through the school.
- ✓ Appoint a key liaison person.
- ✓ Discuss with the family what to tell others.
- ✓ Respect their privacy.

Treatment

- ✓ Use technology to keep the student connected.
- ✓ Liaise with their medical team or hospital school.
- ✓ Encourage connections with friends.
- ✓ Support siblings and classmates.
- ✓ Plan for their return.

Return to school

- ✓ Treat the student as normally as possible.
- ✓ Reassure the student and their parents.
- ✓ Ensure teachers are familiar with any medical complications detailed in the health care plan.
- ✓ Liaise with the student and their family, health care team and hospital school to plan learning and support.
- ✓ Provide ongoing support for academic, emotional and physical issues.
- ✓ Ensure good communication with all school staff and the school community.



4

When a **family member** has cancer

When a student's parent, sibling or other important family member has cancer, the impact can be profound. School attendance and performance, social relationships and behaviour can all be affected. Teachers and other school staff play a key role in maintaining a sense of stability and normality for the student during this challenging time.



When a parent has cancer

Each year in Australia, more than 127,000 people are diagnosed with cancer. About one-third of these people are under 60 and many will have a child under age 18.¹

When a parent is told they have cancer, their first concern is often for their family. How will the children react? What should they be told? How will it affect their lives? Each parent answers these questions in their own way, depending on their individual circumstances. It is common for parents to have to make many difficult personal decisions, experience financial strain, feel overwhelmed or become more protective of their children.

Children may experience a range of conflicting emotions when their parent has cancer, from sadness, fear and anxiety to anger, frustration and guilt. They may have to take on more responsibilities at home and cope with disrupted routines, changes in family dynamics and even increased conflict.

Without age-appropriate information, young people often realise their parent is ill but imagine a scenario that might be much worse than the reality. Information tailored to the age and individual needs of the child can reduce fears and help them cope with the challenges facing the family. If the family would like help finding appropriate and reliable information, you can suggest they contact Cancer Council 13 11 20.

When a sibling has cancer

Young people with a brother or sister who has cancer can experience huge disruptions in their life. The parental attention at home is suddenly shifted, daily routines are disrupted, and family roles and responsibilities change.

Healthy siblings have the highest unmet needs in families affected by childhood cancer.⁶ They may feel great sadness, fear and anxiety, as well as more complicated emotions such as guilt, jealousy, resentment and anger. Because so much focus is on their brother or sister, they may feel that their needs do not deserve to be met and that they have no right to complain. They may also feel embarrassed about their family now being different to other families.

If the child with cancer attends the same school, the sibling may be asked questions about their brother or sister's diagnosis that they find distressing or don't have the answers to. If the family agrees, it may be appropriate to include teachers and students from the sibling's class in any talks about cancer given to the sick student's class (see pages 34–35). It would also be

Shifting roles

Our routines had to change. I couldn't drive or do the shopping after the surgery. My husband did as much as he could, and my kids picked up extra responsibilities. My son got interested in cooking – he would plan out the menus. We were looking after my mother with dementia, too. It was overwhelming in many ways.

Carmen, parent with cancer



Useful resources

CanTeen produces a series of books to help older children understand how to deal with their parent's or sibling's cancer. Visit canteen.org.au/resource for more information.

Contact CanTeen for information about their other support services for children dealing with a family member's cancer (e.g. counselling, group support). Visit canteen.org.au or call **1800 226 833**.

Camp Quality's *Kids' Guide to Cancer* app helps younger children learn about cancer in an age-appropriate way. For more information, visit campquality.org.au.

supportive to nominate a trusted staff member as the sibling's "go to" person, someone they can talk to about their worries or frustrations.

Despite the many challenges of having a brother or sister with cancer, some siblings are enriched by the experience. They grow in compassion and empathy towards others, and find their own inner reliance and strength.

When another family member has cancer

Children can be greatly affected by the cancer diagnosis of family members such as grandparents, as well as of any other key figures in their life, including guardians and close family friends. They are likely to feel worried and sad about the person's illness.

If the child's parents are closely involved with the person who has cancer, life at home might be disrupted and the child may feel like they are receiving less attention.

How young people react

Children and adolescents deal with the news that a family member has cancer in different ways. How they express their feelings will depend on their age and maturity, their coping style, their relationship with the family member, and their understanding of cancer.

When any close family member has cancer, the child may feel sadness and concern for them but also react to the change in family dynamics and grieve the loss of parental attention. This can be over seemingly simple things, such as the parent not going to watch them play sport or attending school events. Younger children may feel that they are to blame for their family member getting cancer. Older students may also worry about whether the cancer runs in their family.

Respecting a family's privacy

Schools encourage all families to let them know of changes at home that may affect a student's schooling.

Although some families choose to tell the school about a cancer diagnosis, others may wish to keep it private. This is a personal decision

and your school should respect their wishes. Parents are not obliged to share information unless it is having an impact on their child's education.

If a family tells you about a cancer diagnosis, work with them to be an additional support during this time.



Delayed response

Some students may not fully appreciate that their family member is seriously ill until the symptoms worsen or the treatment changes their appearance. Because of this, any effects on their school performance or behaviour may be delayed.

A child or adolescent may not be able or willing to talk about how they feel, but might express these feelings through their behaviour. They may misbehave in the classroom, mirror their family member's symptoms or side effects, or be distracted, sad, angry or withdrawn. Changes at home may make it difficult for the young person to keep up with their schoolwork and other commitments such as sports training or music tuition. For example, they may have to go straight to the hospital after school or they may have to take on extra household responsibilities.

Because children spend so much time at school, parents usually choose to tell select members of the school community about the diagnosis. This allows school staff to create a positive school environment for the student and keep an eye out for changes in behaviour. A liaison person such as a year adviser or student wellbeing coordinator can help establish trust and confidentiality with the parents and student.

If you are aware that a student's family member is ill, try to maintain the school routine. Just like a young person with cancer, the student may view school as a safe, comfortable place. They may enjoy feeling normal, or even take pleasure in receiving attention from teachers or classmates.

Some young people ask their parents not to tell the school about the family member's cancer. They might not want their classmates or teachers to perceive them differently.

Keep in mind that some children whose family member has cancer seem able to cope, but there may be times when it gets too much. Key milestones in their family member's testing or treatment can be especially difficult and may lead to anxiety or changes in behaviour. Even when the active treatment has finished, there may still be blood tests every three or six months and the student may continue to feel distress about the possibility of the cancer coming back.

For more information on how people react to cancer, see the *Communicating with people of all ages* section on pages 15–19.

“You know the ‘look’ you get when people feel sorry for you – when I’m at school, I just want to think about school stuff and my friends, not cancer.”

Josh, secondary student whose parent has cancer

Changes in school performance

When a family member has cancer, the 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 younger siblings and taking on household duties. They may have limited time to socialise. In single-parent and separated families, the situation can become even more demanding for the student.

It is likely that the student's academic performance will be affected. It can be helpful for the school liaison person to talk to the family about adjusting their expectations. While many families will hope their child can keep up with their schoolwork, it is important to identify changes in school performance and respond appropriately, such as by offering flexible due dates or tutoring.

If students whose family members have cancer are sitting NAPLAN or senior exams, they may qualify for special provisions. They may also be eligible to be considered for an access scheme for tertiary study (see pages 38–39).

“When his little brother was having treatment, Alastair would have to study for exams in the hospital cafeteria. He said he felt like he was drifting in and out of worlds.”

Genevieve, mother of primary student with cancer

How your school can help

There are many ways your school can assist students after a family member's cancer diagnosis. With the family's consent, you might:

Keep track – Appoint the student wellbeing coordinator or year adviser to provide regular contact with the student, monitor their behaviour, and help keep track of assignments and school events. Offer the student the option of seeing the school counsellor. Special consideration may be needed for examinations and assessments. The student may also need flexibility with their attendance at compulsory sports training or music rehearsals.

Notice changes – Ask the teacher to look out for changes in the child's behaviour, social interactions and academic performance, and keep the family updated.

Connect – Put the family in touch with another family in the school community who has experienced cancer and is willing to be contacted.



Organise a parent team – A group of parent volunteers can be organised privately or by the school's parent association, such as the P&C or P&F. This group can help the family stay on top of excursions, homework, school events and after-school activities. They may also want to help by giving the student lifts to and from school and after-school activities (such as sports training), providing child care or meals. Another way to help is to arrange video recordings of school events so that the family can share them at home.

Educate – Arrange for a visit from the hospital's clinical nurse consultant or a local community nurse to conduct an education session about the treatment.

Contact Camp Quality – Camp Quality provides innovative programs and services to develop life skills and strengthen the wellbeing of children aged 0–13 growing up with cancer, and their families. They offer a free educational puppet show for primary schools across Australia (see page 35). Their *Kids Guide to Cancer* app answers common questions and is particularly aimed at children aged 8–13 who have a loved one diagnosed with cancer. Camp Quality also organises recreation programs, camps and family experiences to support children and families impacted by cancer. To find out more, call 1300 662 267 or visit campquality.org.au.

Get in touch with CanTeen – CanTeen is an organisation for young people aged 12–25 who are affected by cancer, including siblings and offspring. It offers counselling in person or by phone, email or instant messaging, and can collaborate with school wellbeing staff. CanTeen also runs camps, recreation days, seminars and workshops, produces resources for young people and provides an online community for young people impacted by cancer. It also offers support to parents, including assistance with navigating the challenges cancer brings to parenting. Call 1800 226 833 or visit canteen.org.au.

Contact Young Carers – Help the student connect with the Young Carers Program offered by the Carers Associations in each state and territory. This program offers information and support tailored for people aged under 26 who care for someone in their family with an illness or other problem. Call 1800 242 636 or visit youngcarers.net.au to find out more. You can also check out the Carer Gateway for local support services, practical information and resources for carers. Call 1800 422 737 or visit carergateway.gov.au.

Link with Kids Helpline – Put students in touch with the Kids Helpline. This is a telephone, web and email counselling service with a fun, interactive website for kids, teens and young adults aged 5–25. It offers confidential counselling for anything worrying a child or young adult. Contact them on 1800 55 1800 or visit kidshelpline.com.au.

Being a young carer

My mother was diagnosed with breast cancer when I was 15. It's just me and Mum, and we didn't really have any support, so I took on the role of Mum's carer. I suddenly had to learn how to iron, cook, wash clothes, Hoover.

Because I was helping so much at home, I started struggling with school. I had high expectations of myself and didn't want to ask for help, but I couldn't always get my work done on time.

I kept up my attendance at school, but my grades dropped a lot. I couldn't focus in class and I wasn't engaged. If Mum was having a bad day, it would affect me. I had so much going on in my head and I'd stew in my thoughts.

Emma, secondary student whose mother had cancer

Helping classmates understand

Parents may be concerned about the reactions of their child's classmates to the situation. Awareness raising and education about cancer can help encourage a supportive environment, but it's important to discuss this first with the student and their family.

It's also a good idea to include the student in discussions about how to share the news about their family member's diagnosis. Young people can be particularly self-conscious and sensitive to others' reactions. Talking about the situation with their classmates can increase understanding and acceptance, and may make life easier for the affected student. Be mindful, however, that some affected students will prefer to deal with their family situation privately and their wishes should be respected.

Ways to create a supportive school environment include:

- integrating information about cancer into the curriculum
- maintaining a positive school culture of respectful relationships where bullying or cruel comments (either in person or online) are less likely to occur (see page 35)
- planning cancer awareness activities or events (see pages 34–35) to teach students more about cancer
- holding a cancer fundraising event, if the family agrees (see box below).

Cancer fundraising events

When a member of your school community is confronted by cancer, people usually ask: "How can we help?"

While the primary role of schools is to educate students, some schools allow students and staff to organise fundraising programs. These can be standalone events or may be combined with other awareness-raising activities (see page 34).

A family member's cancer often leads to considerable financial strain because income is lost and treatment-related expenses mount. However, it is important to check

with the family before any fundraising event is planned, as they may not be comfortable with the idea and their wishes should always be respected.

Your school community may choose to donate any funds raised directly to the family. Alternatively, you and the family might decide to support cancer charities (see page 70 for a list of fundraising ideas).

Cancer fundraising events not only collect money to help people with cancer. They can also empower school community members, help educate others and spread a message of support and hope.



Talking about cancer

Children and adolescents will vary in how comfortable they feel talking about cancer. A young person may want to keep school as a place where they don't have to constantly think about their family member's cancer. You should never force a student to discuss the disease.

If a student whose parent or sibling has cancer would like to talk about their situation, you may want to involve members of your school's student wellbeing team, learning and support team, or the school counsellor. If the student shows signs of prolonged distress, such as marked changes in their behaviour, refer them to professional counselling support. This can be arranged by the school counsellor.

When talking to a student about their family member's cancer, you will naturally tailor your conversation according to their age and responses (see *Different views of cancer*, pages 16–19). It is also worth keeping in mind a few general pointers:

- use words they can understand
- find out what they already know
- be honest
- offer a listening ear
- don't make promises you cannot keep
- show your own emotions.

For more information, see Cancer Council's book *Talking to Kids About Cancer*. This may help you with strategies for discussing cancer in a school setting. You can also pass it on to parents if they are interested. Call 13 11 20 for a free copy, or download it from your local Cancer Council website.

You can also listen to Cancer Council NSW's podcast episode "Explaining cancer to kids" at cancercouncil.com.au/podcasts for tips on how to talk to kids of all ages about cancer.

Chapter summary

- ✓ Respect the family's decision about whether to share a diagnosis with the school.
- ✓ Monitor the student's behaviour and academic performance – identify and respond to any changes.
- ✓ Arrange support strategies such as extra tutoring, flexible due dates, or exemption from compulsory sport or other events.
- ✓ Ask if the student would like to see the school counsellor.
- ✓ Put the student in touch with support organisations such as CanTeen, Camp Quality and Young Carers.
- ✓ Plan cancer awareness or fundraising activities (with the consent of the family).

“One friend would ask how I was going but I'd snap at her because I didn't want to talk about it. I didn't want to think about it, I didn't want to know about it.”

Emma, secondary student whose mother had cancer



5

When a **staff member** has cancer

If a staff member in your school has been diagnosed with cancer, it can affect every aspect of their life, including their employment. The staff member may have to take extended leave from work, and could need support from the school community during and after treatment.



How cancer affects the staff member

Work is an important part of life for most people – besides income, working at school may provide satisfaction, enjoyable challenges, and a chance to mix with people from different age groups and backgrounds.

When one of your colleagues is diagnosed with cancer, they have to make many decisions:

Who to tell – Some people may decide they want to keep their diagnosis private. Their wishes should be respected (see *Respecting privacy*, page 13). Others are happy for students and parents to know, or they may wish to tell only a few people such as the principal, a staff support officer or colleagues they are close to. You cannot share information about a colleague's health without their consent.

How to say it – A person with cancer may choose to make a personal announcement, but they might prefer to use another method, such as writing an email or asking the principal to tell colleagues.

Plan of action – While some people may continue working, others may take time off or retire. Flexible working arrangements, such as altered work hours or location, can sometimes help staff to accommodate the side effects of cancer treatment (see pages 8–9).

Many school staff are also parents, and this adds to their stress when they have cancer. They will probably be preoccupied with managing changes at home and may need particular understanding from their workplace.

Choosing to tell parents and students

Although a staff member is not obligated to tell parents and students about their diagnosis, they may choose to share some information. This can be particularly helpful in smaller communities, where the staff member may be confronted with questions about their absence if they run into students and parents at the shops or other local places.

The staff member could discuss how to tell the school community with appropriate colleagues, such as the school principal, counsellor, student wellbeing team and/or staff wellbeing officer.

Most parents will appreciate a straightforward approach. Parents can be contacted by letter, email or phone; a parent group such as the P&C or P&F could be asked to relay the news; or parents can be invited to a meeting.

Help with making decisions

If your colleague has been diagnosed with cancer, they may feel overwhelmed and ask for help with the many decisions they must make. You can remind them of any professional counselling services, such as an Employee Assistance Program (EAP), that are available to staff through the school.

Your colleague can also call Cancer Council **13 11 20** for a free copy of the *Cancer, Work & You* booklet, or download it from their local Cancer Council website.



Keeping in touch with the teacher

Students may like to:

- prepare get well cards
- draw pictures
- write a story
- send a letter or email describing what they've been doing in class
- make a video of get well messages from students
- start a blog to keep the teacher up to date with news from the classroom.

It's a good idea to let the parents know if the teacher plans to be away and for how long. The principal can also explain how the school plans to manage the teacher's work.

Telling students requires a sensitive approach. Remember, students come from all types of backgrounds, so some of them may not know much about cancer and others may have a personal experience with it. A young person's age and maturity also affect their level of understanding.

Plan what to say to students in advance (see page 47) and prepare answers to any likely questions. It is wise to send a letter or email home to parents so they know that their children might want to talk about their teacher's cancer. Any letter should include contact details for appropriate support services and resources (see pages 66–67).

How people may react

When people in your school community learn about a colleague's cancer, there will be a variety of reactions. Many people wish to be supportive but are unsure what to say or do. Some people will ask questions or be extremely helpful; others will pretend they don't know or will go out of their way to avoid the person with cancer.

On rare occasions, there may be parents who will make it clear they don't want their child in the class of a teacher who has cancer because they believe their child's schooling will be disrupted. In this case, the principal can explain how the school plans to maintain the student's schedules.

If any member of your school community reacts in an insensitive manner to the news of the diagnosis, or how the school plans to manage the absence, speak to the principal or staff wellbeing officer.

The principal can assist students and parents who want to find out more about cancer or would like to access counselling services. See pages 66–67 for a list of reliable organisations and websites.

“Some of my colleagues were so uncomfortable they didn't even talk about it. I don't think they had a lack of concern, I just think they had no idea what to say.”

Shirley, secondary schoolteacher with cancer



How parents can help

If parents are aware of your colleague's cancer, they might offer to help in various ways. The school could appoint a contact person to manage these offers. The contact person can check what sort of help, if any, the colleague would like from parents and then coordinate the support.

Depending on school policy, a parent's assistance in the classroom may be helpful at this time. The principal can clarify whether this is allowed and what clearances (e.g. Working with Children Check) are needed, and the teacher can decide if it would be welcome.

Many teachers have their own personal support network outside the school community and may prefer to keep their professional and personal lives separate. However, others gratefully accept offers such as a meal roster or help with their own children.

If a teacher with cancer does not want direct support, you can check whether they would be happy for your school to host a general cancer awareness or fundraising event (see pages 34 and 46).

Cancer in the workplace

Many employees continue to work while undergoing cancer treatment. Whether a person is able to work depends on the kind of work they do, the type and stage of cancer, the type of cancer treatment and any side effects from treatment. It also depends on personal factors such as their other commitments and whether they want people to know about the diagnosis.

If a staff member continues to work during treatment, they may need flexible working arrangements or to have their role modified. For example, some employees having chemotherapy may need to arrange a non-contact role with students to reduce their risk of catching an infection.

As more people are diagnosed in early stages – and as survival rates and treatments improve – it is increasingly likely that an employee will return to work after treatment or continue to work during treatment in some capacity. Cancer survivors are more likely to return to their job if they have a supportive work environment.

Returning to work after treatment can be difficult. School staff returning to work are often anxious about how they will manage cancer-related fatigue, employer expectations, and changes in their appearance, workload, productivity and relationships with colleagues and students.

Rights at work

Cancer Council's online Workplace Fact Sheets assist employers and workplaces to provide a supportive and fair work environment for people affected by cancer.

Fact sheets can be downloaded from your local Cancer Council website. The fact sheets cover topics such as *Managing the effects of treatment*, *Creating cancer-friendly workplaces* and *Supporting a colleague with cancer*.

For more information about employees' rights at work, you can:

- contact your local education authority (see pages 68–69)
- visit the Australian Government workplace and employee relations website, fairwork.gov.au
- visit the Australian Human Rights Commission, humanrights.gov.au
- call Cancer Council **13 11 20** or visit your local Cancer Council website.



Taking a break

The hardest part is going for tests. I had constant tests – three-month tests, different scans, doctors' appointments. It takes it out of you. I would try to do it all in one day, so I didn't have to take too much time off school, but it was exhausting. I ended up deciding to take six months off. The administration was supportive of my decision.

Susan, primary schoolteacher with cancer

Dealing with side effects

People diagnosed with cancer or undergoing treatment often experience side effects such as nausea, vomiting, hair loss and fatigue. Long-term physical changes might be visible, such as the loss of a limb, but they can also be less obvious, such as loss of strength or diminished vision.

Cancer treatment sometimes causes temporary cognitive impairment, such as short-term memory loss or difficulty concentrating. People can usually manage these cognitive difficulties by getting extra sleep, making to-do lists and avoiding situations where quick thinking might be required.

The school community can help by being patient and understanding. A person who has had cancer treatment may not be as efficient as they once were for some time, but can usually make a successful transition back to work if the environment is supportive.

The role of the principal

Initial support

When a staff member informs the principal that they have cancer, they need a sensitive and sympathetic response. Aside from worrying about work, the person may be making difficult personal decisions. It can be helpful to remind them of any staff counselling services, such as the Employee Assistance Program (EAP), that they and their family members can use.

If the person is newly diagnosed, they may feel like they are being bombarded with information. Rather than adding to this “information overload” in the initial conversation, the principal might want to set up a meeting at a later time and come prepared with relevant material, such as detailed information about working arrangements and leave entitlements. Download a copy of our *Talking to your employee about cancer* factsheet for more suggestions.

It is important for the principal to respect a staff member's preferences about how much they would like to disclose about their cancer, and who they would like to tell.

Many people with cancer find it helpful to talk to someone in a similar situation. If there is another staff member with cancer, the principal could put the employees in touch with one another (with their permission). Another option is for the staff member to contact someone with a similar experience through Cancer Council. They can call 13 11 20 and ask about Cancer Connect, the telephone peer support service, or explore the Cancer Council Online Community at cancercouncil.com.au/OC.

The principal can provide advice and guidance regarding changes to a staff member's work schedule. The staff member may consider taking a break, adjusting their workload or arranging a flexible work schedule. The principal can help the staff member make these decisions in line with leave and relief staffing procedures.

Return to work

By law, employers must make reasonable adjustments for an employee affected by cancer or its treatment. These may involve physical adjustments, such as access to disabled bathroom facilities, or adjustments to workload.

When a staff member returns to work after a long absence, organising a return to work meeting can make the situation clear for all involved and help prevent misunderstanding among colleagues. It is helpful to develop a written return to work plan with input from the staff member's health care team. Tailored to the staff member's specific situation, the plan outlines any agreed adjustments and establishes a timeline.

There are several ways to reduce an employee's anxiety and help them during their transition back to work. These can include:

- specifying regular meetings in the return to work plan to help the person manage their workload and talk about any concerns they may have (such as job security)
- adjusting their work schedule and load as agreed in the return to work plan
- making any necessary physical adjustments
- liaising with other staff (being a contact person or coordinating offers of help)
- proactively liaising with parents and students, if appropriate
- offering counselling/EAP support for the person and their family
- supporting the employee's decisions and offering reassurance.

When a family member has cancer

The information in this chapter may also be helpful if a colleague's partner, child or parent is diagnosed with cancer. The colleague is likely to need time off work to care for their family member. If the treatment hospital is a long way from home, they may require particular flexibility.

Working carers must juggle many demands alongside their workplace responsibilities. A supportive work environment can help them manage. For more information, download a copy of our *Supporting working carers* fact sheet from your local Cancer Council website.



Chapter summary

- ✓ The staff member with cancer decides who to tell – there is no legal obligation to share their diagnosis.
- ✓ Before telling students, discuss with the principal and other key staff, and possibly send an email or note home to parents.
- ✓ Explain to parents how the school will maintain continuity for students.
- ✓ Teachers with cancer may need a lighter load and flexible working arrangements.
- ✓ The principal's role involves creating a cancer-friendly workplace while minimising any impact on student learning programs and on the broader school community.

Supporting other colleagues

When an employee is diagnosed with cancer, the principal can help to address any concerns that other staff may have. The staff member with cancer may ask the principal to liaise with colleagues on their behalf. Support should be offered to employees who are upset. If your school offers an EAP, staff can be referred to this service.

If an employee has to take a leave of absence, the principal can work with colleagues to organise substitutes for the absent employee. Most colleagues are likely to be flexible and accommodating, but a temporary substitute or permanent replacement may need to be arranged.

Supporting students and families

A staff member may wish to inform parents or students about their cancer diagnosis, but may be uncomfortable standing up in front of the class or calling parents to relay the news. The principal can offer support by coordinating how the information is shared. They can also liaise with any parents who are concerned and explain how the school will maintain the students' continuity of education during the staff member's absence.

It is important for the principal to talk to students regularly to assure them that the school is supporting their teacher and to let them know if their teacher will be taking time off. Principals can also remind students that school staff are available to support them.

The Thing About Cancer podcast

For more information about all things cancer, listen to Cancer Council NSW's audio podcast series, *The Thing About Cancer*. The episodes cover a wide range of topics, including:

- Coping with a cancer diagnosis
- Managing cancer fatigue
- How to help someone with cancer
- Explaining cancer to kids
- Making treatment decisions
- Appetite loss and nausea
- New cancer treatments – immunotherapy and targeted therapy
- Genetic tests and cancer
- Cancer affects the carer too



To listen, go to cancercouncil.com.au/podcasts.



6

The **bereaved** school community

This chapter introduces a very difficult issue – one that hopefully never affects your school community. Although many people diagnosed with cancer will be successfully treated and live for many years, not everyone will recover and some people with cancer do die. There are ways to prepare if you know the prognosis is poor. The school can also support people who are bereaved.



Saying goodbye

We were told to say our goodbyes, but I wasn't ready to say it. Friends and family always said that at least I had the opportunity to say goodbye because his death didn't happen suddenly in an accident. The truth is, it is just as bad either way, and you are not prepared for it even if you are expecting it. From the day my father was diagnosed to the last day was the hardest eight months I will ever face.

Daniel, student whose parent had cancer

How to prepare for a cancer death

When a person with cancer has a poor prognosis and may not survive, your school community can plan ahead to prepare people for what might happen. This might include:

- staff and students visiting the person, if desired by their family – it may be advisable for students to go with parents or other supportive adults, and to avoid going in class time or as a class group. This can help minimise disruption to familiar routine and avoid pairing the death and the class too closely in students' minds
- students, staff and parents continuing to communicate with the person in other ways (via emails and letters, for example)
- the principal arranging for key community members to be told of the situation and kept up to date
- staff having discussions with students about death, loss and grief.

Keep in mind that after the person dies, the school may also want to host a service, arrange a memorial prize, offer counselling and/or fundraise.

Action to take when someone dies

When someone in your school community dies – particularly a student or colleague – your school's guidelines for managing critical (serious) incidents may apply.

The school must decide, with the family's permission, how to inform people. It is usually better to tell students in their normal class groups or in small groups, rather than holding an all-school assembly. It is important that students are told in an honest and sensitive way, without overloading them with too much emotion from the person giving them the information. Often the principal will work with other executive staff and/or the school counsellor to draft a short script or guideline for teachers to tell their classes what happened. Teachers are often very grateful for this as it relieves them of the pressure of deciding what to say while they are still processing their own initial grief. The school counsellor may be able to offer further guidance and support.

Staff can be briefed with the following information:

- an outline of key points that clearly explains the circumstances of the death
- some positive words of reminiscence
- details of how the school will honour the person who has died, if appropriate
- details of the funeral service and arrangements for attendance, if known and if the family wishes the school community to participate
- the best way to send condolences from the school and individuals
- details of support and counselling services (see page 63).

Staff should be asked to speak to classes only if they feel able to manage students' reactions and questions. Some staff may like a member of the school executive team or the school counsellor to be with them when the class is told. In some schools, or for some individuals, faith or religious tradition plays a central role in dealing with loss. If your school has a chaplain or spiritual adviser, they may be able to help tell people about the death and provide support.

The purpose of telling students is to draw the school community together and facilitate the grieving process. Students who are experiencing or have previously experienced other forms of loss (e.g. sick parent, family separation or divorce) may need extra support. The cultural diversity of your school community may also influence what you say and how you say it. Some cultures have particular customs around death and bereavement.

Be aware that older students may have already found out about the death through social media such as Facebook. Social media can help members of the school community share their sorrow, record memories and send condolences. However, remind students about the family's right to privacy and the importance of not spreading rumours or adding to the family's grief.

Not everyone in the school community will hear the news through class meetings, so you may need to use other means. For example, you can send a letter or email to parents, put a note in the school's newsletter or meet separately with colleagues. Remember to tell all the people who need to know, such as canteen staff, Outside School Hours Care staff, and relief teachers.



Indigenous families

If an Indigenous member of your school community dies, any information should be handled in a culturally sensitive manner. In some cases, it may be offensive for the school to mention the person's name or to use the image, voice or video recording of the person. School staff should be aware of this possibility and check with the person's family or community.

Funerals in Indigenous communities often take up to five days, so affected students and staff may need to be away from school for a week or more.

When death is sudden

While members of your school community will usually be aware if someone is near death, in some cases, a person's death will be sudden or unexpected. As with other deaths, you should follow your school's critical incident procedures.

It can be hard for some people to grieve – and react to a crisis – if they feel unprepared. Students might be angry that they weren't told the person's prognosis in advance. Others might feel hurt that they could not say goodbye.

For suggestions about how to help people who are bereaved, see the next page. You and your colleagues will have to be particularly sensitive if the death was sudden. You should be prepared for strong emotional reactions, and be ready to offer support (such as counselling) to those who need it.

Additionally, the school needs to inform others who may be affected or who might need to support the students (for example, by sending a letter or email to parents).



Understanding grief

Grief is a natural response to losing someone. Depending on their relationship with the person who died, members of the school community may experience a range of emotions, including sadness, numbness, disbelief, loneliness, guilt, anger, relief and acceptance.

People express grief differently. Some people openly display their emotions, while others may show no visible signs of grief. There's no right or wrong way to grieve or set amount of time it lasts. It is important that people respect each other's way of grieving. For more information, call Cancer Council **13 11 20** for a copy of our booklet on *Understanding Grief*.

Helping people who are bereaved

If someone in your school community dies, each person's reaction and grieving process will be unique. Responses to grief depend on the individual's personality, how close they were to the person who has died, their own experiences with death and their access to support services. Bear in mind that it is normal for someone to feel out of control, overwhelmed or even disbelieving.

Be mindful that the staff who are trying to support grieving students may also be dealing with their own grief and loss. Staff should not feel that they need to hide their grief. It is important for students to see the adults around them modelling a range of healthy grieving processes. For people who are bereaved, you can:

Listen – Encourage the bereaved person to talk about the person who has died. If you have a conversation, be attentive and non-judgemental. Allow the person to silently reflect on their loss. Don't try to talk about other things if they aren't interested. Let the person cry, act angrily or talk about something else.

Find outlets – Explore different ways that the students can express their emotions. Primary students may want to make cards to send to the family, while adolescents may want to be with close friends in a supported setting. With the family's permission, an online tribute or remembrance page may be a good way for the school community to share memories and send condolences. If it seems appropriate and the family agrees, a school memorial service (see page 62) can also help grieving students, staff and parents. Other options include creating an area of remembrance or raising money for a cancer charity.

Show support – If you can, offer support to the family or closest friends. Sending a note of sympathy is a simple but caring gesture.

Be patient – Accept that it may take some time for the intense feelings of grief to abate. As time goes on, it can become easier to recognise birthdays and anniversaries, although life has changed forever.

Stick to school routines – Some consistency can be helpful for students as long as teachers are flexible about how much schoolwork they can cope with.

Teach about cancer – Include discussion of cancer research and treatment in the curriculum where appropriate, particularly if students raise the topic.

Seek further support – Bereavement support services (see page 63) may help you or someone you know who is going through a difficult time.

How young people understand death

Children and adolescents understand loss in different ways, depending on their age and maturity level. To find out more, consult your school counsellor or the hospital social worker.

4-7
years

Early primary students

- may think death is temporary
- might realise that death means someone isn't around anymore, but may not understand the cause of death
- sometimes believe their behaviour caused the death
- might wonder who will look after them or teach them
- might worry that cancer is contagious or that they will die too
- may be very open and ask confronting questions

7-12
years

Late primary students

- understand death is permanent
- know some reasons why death happens (e.g. illness, old age)
- are less likely to blame themselves for the loss, but might blame someone else
- want to know the facts about death, including what happens after death
- are better able to articulate their feelings and act sympathetically

12-18
years

Secondary students

- usually understand the facts of death
- might respond in a self-centred way to the loss
- may struggle with their own mortality
- may express feelings in positive ways (e.g. listening to music, playing sports, writing in a journal)
- usually want to spend more time with friends after a loss
- may express their distress through risk-taking behaviours (e.g. skipping classes, experimenting with drugs or alcohol, acting recklessly)
- need to know that support and counselling are available
- might find it especially helpful to participate in a private or public memorial service (see page 62)





Memory book

When my husband died, it was after his cancer metastasised and he had a sudden stroke on our son's seventh birthday. That was so hard. When my son returned to school, the teacher and all the kids had made a book about Joey's dad. It was so thoughtful, and it means a lot to have a tangible keepsake like that.

Patricia, parent whose husband had cancer

When a student dies

The survival rates for children and young adults with cancer have improved substantially over the past 20 years. Today, the five-year survival rate for young people with cancer is over 80%, and this rate is expected to increase because of improvements in treatments.² However, some children and young adults do die from cancer.

The death of a young person is an enormous tragedy, and it can be difficult to accept. It is important that your school community responds in a compassionate manner. The principal or the student wellbeing coordinator should ask the family of the deceased student what the school can do to help, how the parents would like to inform staff and students (if they don't already know), and if a memorial can be organised.

If you and your colleagues worked closely with the student, you are likely to feel saddened and will need to take time to deal with your own feelings before talking to students. It may be helpful to attend the funeral service.

The student's classmates will react in different ways, depending on how old they are (see previous page). Their reactions will depend on their relationship with the student and their own coping mechanisms. Classmates should be able to turn to school staff for guidance and support.

Remember that a child who dies may have siblings at the school, so parents will still be part of the school community, and this may be difficult at first for other parents who are not sure what to say.

“I was devastated when Lisa died. I didn't think it would happen. She was my best friend and school just wasn't the same without her.”

Melissa, classmate of secondary student who had cancer

When a parent dies

When a parent in the school community dies, the reactions of community members can vary. If the parent was a well-known community member, people may outwardly grieve the loss. If the parent was not particularly well known in the school community, many people may be unaware of their death.

Students who know a classmate's parent has died will probably worry about their own family. They might want to express sympathetic sentiments,



and wonder how to support their friend and what to say. With the family's permission, some students may attend the funeral service to support their classmate, as may staff and other parents.

Other parents may also reach out to help the family in the weeks and months afterwards. Parents can help make meals, keep track of the child's homework, or provide transport to school and after-school activities.

You and other school staff members will probably be aware of the death, and you should explain the situation to students, if necessary. You will need to grieve the death in your own way and provide in-class support (such as more flexible homework deadlines) to a student who has lost a parent.

When a student's sibling dies

The loss of a student's sibling is extremely traumatic. No matter how close the young person was to their sibling, they will need time to mourn the loss. The student may have to take time away from school, and their parents will likely be occupied with making funeral and other arrangements.

Schools can be supportive when the student is away from school, and try to help them manage their schoolwork on their return. It is understandable that a student may be more focused on their family than on schoolwork for a time. Sometimes it is helpful to refer a grieving child or young adult to school or other counselling services, in consultation with their family.

The sibling's treatment team can also support the bereaved student, especially by answering any questions about the illness and explaining the medical aspects leading up to the death. A hospital or school chaplain may be another source of support. You can check that the family is aware of the bereavement services offered by CanTeen and Redkite (see page 63).

When a staff member dies

When a teacher or other prominent member of the school community dies, there is a far-reaching impact. You and your colleagues will need to deal with your own grief, as well as comfort students who may also be grieving.

If you are grieving, find out about all available employee support services and take time to deal with your own feelings. If you worked closely with the person, you may wish to attend the funeral. The school may organise a memorial service to honour your colleague and to allow staff, parents and students to pay their respects.

How to support grieving children

- Understand that each child will react to loss in their own way.
- Do not underestimate the impact of a bereavement, even if a child is very young or does not seem sad. Their grief may be expressed through play or other behaviour.
- Realise that children often work through their feelings slowly, facing them in bearable doses.
- Explain the death in concrete terms. Avoid euphemisms such as "passed away", "lost" or "gone to sleep".
- Answer questions in an open, honest and age-appropriate way. Accept that children may need to ask the same questions many times.
- Allow children space to grieve – you do not need to "fix" their sorrow. It is natural for people to express sadness in various ways, just as they express other emotions.
- Maintain routines and boundaries. School can offer a reassuring sense of predictability.



Lasting tributes

If the person who has died was well known in the school community, your school might want to establish an ongoing way to honour them. Options include:

- planting a tree or garden
- placing a memorial plaque somewhere in the school grounds
- establishing an annual award named after the person
- acknowledging anniversaries.

Students can take the death of a teacher particularly hard. They will mourn in individual ways. It is okay for students to know that you are sad, too – they rely on adults to model healthy grief. Reassure students that grief is a natural reaction, and that counselling is available. The principal or a counsellor can talk to students about grief and ways to remember their teacher (see box at left).

Planning a memorial

In addition to any funeral or other formal service organised by the family, your school might hold a memorial service to honour the life of a student, parent or colleague. Participation in a memorial service allows the community to share their grief and honour the loss of the school member. Community members can collaborate with the family to organise the event.

When planning a service, you might consider:

- **The setting** – Will the service be held at the school? How formal will it be? Is there any special music that could be played or performed?
- **Who will attend** – Will you make a public or school-wide announcement to let people know about the service? Would the family like you to ask everyone to wear a particular colour as a gesture of support?
- **Who will lead the service** – Are there school staff, friends, students or family who would like to be involved?
- **Sharing memories** – How can people share favourite memories or thoughts? Will there be a program or a slide show?
- **Flowers, donations and cards** – Should people bring flowers, or would the family prefer donations to a charity? Where can people leave sympathy cards?

Appoint a staff member (school counsellor, chaplain or teacher) for children to talk to if they become upset before, during or after the memorial service.

Seeking professional support

It is important to understand that bereavement is a process, not a single event, and can take many months or even years. A student or staff member should be referred to professional help if they simply need someone to talk to, but especially if they demonstrate significant changes in behaviour, such as:

- saying they want to die too or becoming extremely preoccupied with dying
- suffering academically or at work for an extended period after the death
- acting sad and withdrawn for an extended period
- increased risk-taking or self-harm
- having trouble socialising.



Talk with your school principal and colleagues about ways to support bereaved members of your school community. If you think that a student needs professional support, consult your school counsellor. Staff who need counselling for themselves may be able to access it through an Employee Assistance Program (EAP) if this is available at your school. Some people may need ongoing support for many months.

You could also contact one of the organisations listed in the table below. These can be good starting points for general advice or for referrals to bereavement counselling.

Bereavement support services	
Australian Centre for Grief and Bereavement offers online information for people experiencing grief and bereavement	1800 642 066 grief.org.au
Cancer Council 13 11 20 can refer callers to local services or recommend a telephone support group	13 11 20 For your local Cancer Council website, see back cover
CanTeen offers online information and bereavement support tailored for young people aged 12–25 years	1800 226 833 canteen.org.au
GriefLine provides community and family services to support all Australians who have encountered a loss	1300 845 745 griefline.org.au
Redkite offers bereavement support for families and friends of children and young people aged 0–24 years	1800 733 548 redkite.org.au
The Compassionate Friends has member organisations across Australia that offer support to any family that has lost a child	1300 064 068 tcfaustralia.org.au/contact
The National Centre for Childhood Grief offers counselling for bereaved children aged 3–18	1300 654 556 childhoodgrief.org.au

Chapter summary

- ✓ If a prognosis is poor, take time to plan how best to communicate with students, families and staff.
- ✓ In the event of a person's death, ask the family for consent to tell the school community.
- ✓ Tell students in small groups.
- ✓ Send an email or letter home to all families, if appropriate.
- ✓ Create opportunities for students to talk about the death and ask questions.
- ✓ Encourage students to express grief and sympathy in ways that feel comfortable to them.
- ✓ Model healthy grief.
- ✓ Be sensitive to cultural differences.
- ✓ Consider holding a memorial service.
- ✓ Explore ways to honour the memory of the person in an ongoing way.



7

Finding further **support**

If you are supporting students, parents or colleagues affected by cancer, you are not alone. Cancer Council can provide information and support, and can point you in the right direction for more specialised assistance. This chapter lists many different organisations that can help your school community.



Support from Cancer Council

Cancer Council offers a range of services to support people affected by cancer, their families and friends.

Cancer Council 13 11 20 – This is many people’s first point of contact if they have a cancer-related question. Trained professionals will answer any questions you have about the situation in your school community. For more information, see the inside back cover.

Practical help – Your local Cancer Council can help people access services or advice to manage the practical impact of a cancer diagnosis. This may include access to transport and accommodation, practical assistance in the home (short-term cleaning, gardening, childminding), or legal and financial support. Call 13 11 20 to find out what is available in your state or territory.

Support services – It can be helpful to share experiences with other people affected by cancer. Some people join a support group. Others prefer to talk to a trained volunteer who has had a similar cancer experience. Cancer Council can link people together by phone, in person (Cancer Connect) or through the Cancer Council Online Community at cancercouncil.com.au/OC. Call 13 11 20 to find out what services are available in your area.

Life after cancer – It’s natural to feel a bit lost after finishing treatment. Cancer Council can provide support and information to people adjusting to life after cancer – call 13 11 20 for details.

Printed, online and audiovisual resources – Cancer Council produces easy-to-read booklets and fact sheets on more than 20 types of cancer, as well as treatment, emotional issues and recovery. All publications are developed in consultation with health professionals and consumers, and content is reviewed regularly.

School support services

Schools can access support from several different areas, including:

- student wellbeing teams
- learning and support teams
- school psychologists or counsellors
- pastoral care teams
- learning and engagement officers or special education teams
- staff wellbeing officers
- health resources from your school’s education authority (see pages 68–69)
- local support networks through your school’s education authority.

Related publications

You might also find the following free Cancer Council publications and resources* useful:

- *Talking to Kids About Cancer*
- *How Can I Help? Supporting Someone with Cancer* (brochure)
- *Cancer, Work & You*
- *Workplace Fact Sheets* (online only)
- *Cancer Care and Your Rights*
- *Caring for Someone with Cancer*
- *Emotions and Cancer*
- *Understanding Complementary Therapies*
- *Living with Advanced Cancer*
- *Understanding Palliative Care*
- *Facing End of Life*
- *Understanding Grief*
- *Living Well After Cancer*
- Relaxation and meditation CDs

Call Cancer Council **13 11 20** or download copies from your local Cancer Council website.

* May not be available in all states and territories.

Support and information directory

Not-for-profit support organisations

<p>Camp Quality provides programs and services to develop life skills and strengthen the wellbeing of children aged 0–13 growing up with cancer, and their families</p>	<p>1300 662 267 campquality.org.au</p>
<p>Cancer Council provides a wide range of support and information services for people affected by cancer (see previous page for more details)</p>	<p>13 11 20 For your local Cancer Council website, see back cover</p>
<p>CanTeen supports young people aged 12–25 living with cancer, their parents, siblings and friends</p>	<p>1800 226 833 canteen.org.au</p>
<p>Carer Gateway national service providing practical information and resources for carers and links with local support services</p>	<p>1800 422 737 carergateway.gov.au</p>
<p>Leukaemia Foundation offers free services and information to support people with leukaemia, lymphoma, myeloma and related blood disorders, and their families</p>	<p>1800 620 420 leukaemia.org.au</p>
<p>Make-A-Wish Australia grants wishes to young people with a life-threatening illness</p>	<p>1800 032 260 www.makeawish.org.au</p>
<p>Redkite offers financial, emotional and educational support for children and young people aged 0–24 with cancer, as well as their families and networks</p>	<p>1800 REDKITE (1800 733 548) redkite.org.au</p>
<p>Ronald McDonald House Charities Australia provides a learning program for young people whose education has been disrupted by a serious illness, professional development for teachers, and accommodation services</p>	<p>1300 307 642 rmhc.org.au</p>
<p>Starlight Children's Foundation Australia supports seriously ill children by providing in-hospital programs, granting wishes and organising family escapes</p>	<p>1300 727 827 starlight.org.au</p>
<p>Work After Cancer provides information about working during cancer treatment and returning to work after treatment</p>	<p>workaftercancer.com.au</p>
<p>Young Carers works with the carers association in each state and territory to provide information, support and counselling for people under 26 who care for a family member with a serious illness</p>	<p>1800 242 636 youngcarers.net.au</p>

Support and information directory**Online cancer information**

Cancer Council clinically reviewed information about cancer by topic and by type; PDFs and ebooks of <i>Understanding Cancer</i> booklets and fact sheets; links to local support groups, programs and services	For your local Cancer Council website, see back cover
Cancer Australia Children's Cancer information about children's cancer by type, how to find clinical trials, and guidance about what to expect once treatment is finished from the Australian Government's cancer control agency	childrenscancer.canceraustralia.gov.au
Cancer Advisor moderated by Redkite, provides links to reliable information resources about children's cancer, support services and a place for people to share their experiences	canceradvisor.org.au
Victorian Paediatric Integrated Cancer Service (PICS) information about diagnosis and treatment of childhood cancer, finishing treatment, and survivorship	pics.org.au
Youth Cancer Services information about cancer, hospital-based cancer treatment and support services for young people aged 15–25	canteen.org.au/youth-cancer
Macmillan Cancer Support information about many aspects of cancer prevention, diagnosis and treatment from the leading United Kingdom cancer charity	macmillan.org.uk
American Cancer Society detailed information about cancer types and topics from the largest voluntary health organisation in the United States	cancer.org

Support and information directory**Workplace relations**

Fair Work Ombudsman information and advice about Australia's workplace rights and rules, including awards, entitlements and national employment standards	13 13 94 fairwork.gov.au
Australian Human Rights Commission information and advice about Australia's discrimination legislation and disability standards; investigates complaints about discrimination	1300 656 419 humanrights.gov.au
Cancer Council articles, fact sheets and booklets about cancer and work for workplaces, employers and employees	13 11 20 For your local Cancer Council website, see back cover

National

Australian Curriculum, Assessment and Reporting Authority (ACARA)	acara.edu.au
Bullying. No Way!	bullyingnoway.gov.au
Independent Schools Council of Australia	isca.edu.au
National Catholic Education Commission	ncec.catholic.edu.au

Australian Capital Territory

ACT Board of Senior Secondary Studies	bsss.act.edu.au
ACT Education Directorate	education.act.gov.au
Association of Independent Schools of the ACT (AISACT)	ais.act.edu.au
Catholic Education Archdiocese of Canberra and Goulburn	cg.catholic.edu.au
Universities Admissions Centre	uac.edu.au

New South Wales

Association of Independent Schools of NSW (AISNSW)	aisnsw.edu.au
Catholic Schools NSW	www.csnsw.catholic.edu.au
NSW Department of Education	education.nsw.gov.au
NSW Education Standards Authority (NESA)	educationstandards.nsw.edu.au
Universities Admissions Centre	uac.edu.au

Northern Territory

Association of Independent Schools Northern Territory (AISNT)	aisnt.asn.au
Catholic Education Northern Territory Diocese of Darwin	ceont.catholic.edu.au
Northern Territory Board of Studies	education.nt.gov.au/education/committees,-regulators-and-advisory-groups
Northern Territory Department of Education	education.nt.gov.au
South Australian Tertiary Admissions Centre (SATAC)	satac.edu.au

Queensland

Department of Education and Training Queensland	education.qld.gov.au
Independent Schools Queensland	isq.qld.edu.au
Queensland Catholic Education Commission (QCEC)	qcec.catholic.edu.au
Queensland Curriculum and Assessment Authority (QCAA)	qcaa.qld.edu.au
Queensland Tertiary Admissions Centre (QTAC)	qtac.edu.au

South Australia

Association of Independent Schools of SA (AISSA)	ais.sa.edu.au
Catholic Education South Australia	cesa.catholic.edu.au
South Australia Department for Education	dec.d.sa.gov.au
South Australian Certificate of Education	sace.sa.edu.au
South Australian Tertiary Admissions Centre (SATAC)	satac.edu.au

Tasmania

Department of Education Tasmania	education.tas.gov.au
Independent Schools Tasmania (IST)	independentschools.tas.edu.au
Office of Tasmanian Assessment, Standards and Certification (TASC)	tasc.tas.gov.au
Tasmanian Catholic Education Office	catholic.tas.edu.au
University of Tasmania Admissions	utas.edu.au/admissions

Victoria

Catholic Education Commission of Victoria (CECV)	www.cecv.catholic.edu.au
Department of Education and Training Victoria	education.vic.gov.au
Independent Schools Victoria	is.vic.edu.au
Victorian Curriculum and Assessment Authority (VCAA)	vcaa.vic.edu.au
Victorian Tertiary Admissions Centre (VTAC)	vtac.edu.au

Western Australia

Association of Independent Schools of Western Australia (AISWA)	ais.wa.edu.au
Catholic Education Western Australia	ceo.wa.edu.au
Department of Education WA	education.wa.edu.au
School Curriculum and Standards Authority	scsa.wa.edu.au
Tertiary Institutions Service Centre (TISC)	tisc.edu.au

Australia's Biggest Morning Tea

Every May, more than a million Australians come together at school, work, home and in their community to donate money for cups of tea and coffee. Cancer Council uses this money for cancer research and to support those affected by cancer.

1300 65 65 85
biggestmorningtea.com.au

Daffodil Day

The daffodil is a sign of hope, and Daffodil Day is a day to remember people touched by cancer, celebrate survivorship, hope for a brighter future and raise money to fight cancer. Daffodil Day is held by Cancer Council every August.

1300 65 65 85
daffodilday.com.au

Hospital fundraisers

Many hospitals coordinate fundraising events that support them directly.

Contact your local children's hospital (or general hospital providing cancer treatment)

National Bandanna Day

Organised by CanTeen, this event sells bandannas as a symbol of cancer's impact on young people. It is held each year in October.

1800 226 833
canteen.org.au/bandanna-day

Girls' Night In

Girls' Night In is a fun, simple way for women to raise funds and awareness for women's cancer research, prevention programs and support services while getting together with friends.

1300 65 65 85
girlsnightin.com.au

Relay For Life

Relay For Life is a fun, outdoor community event where teams of 10–15 people take turns walking or running around a local oval or school campus to raise funds for Cancer Council.

1300 65 65 85
relayforlife.org.au

Starlight Day

Each May, the Starlight Children's Foundation Australia holds a fundraiser for children and families who live with a serious disease and need to stay in hospital.

1300 727 827
starlight.org.au

Glossary and **index**

The glossary in this chapter will help you define and explain common cancer-related words. For each word, there is a simple definition suitable for young children, as well as a plain English definition suitable for older children, adolescents and adults. An index for this book can be found after the glossary.

Glossary

Word	For younger children	For older children, adolescents and adults
benign	Not cancer.	Cells that are not malignant (cancerous).
biopsy	When the doctor looks at cells in the body to see if they're healthy or not.	A test to diagnose cancer. The doctor takes small bits of tissue from the body and looks at them under a microscope to see if the cells have changed.
blood count	A test that checks how healthy the blood is.	A test that counts the number of red blood cells, white blood cells and platelets in the blood.
bone marrow	The soft, spongy kind of jelly inside bones where different blood cells are made.	The soft, spongy material inside bones, which produces red blood cells, white blood cells and platelets.
cancer	Cancer is a disease that happens when some cells in the body stop working properly. These cells can grow into a lump and can spread to other parts of the body.	Cancer is the name for over 200 diseases in which abnormal cells grow and rapidly divide. This uncontrolled growth may result in abnormal blood cells or grow into a lump called a tumour. The abnormal cells may spread to other parts of the body.
cells	The body is made up of billions of tiny things called cells, and each has a job to make your body work and stay healthy.	Cells are the basic building blocks of the body. Our bodies constantly make new cells to help us grow, to replace worn-out cells, or to heal damaged cells after an injury.
central line	When a person has a tube in their body so they don't have to have needles.	A small tube that is used to get direct access to a vein so blood or chemotherapy can be given.
chemotherapy	Special medicine that kills the bad cancer cells.	A cancer treatment that uses drugs to kill cancer cells or slow their growth.
CT scan	A test that makes pictures so doctors can see what's happening inside the body.	A procedure that uses x-rays to create detailed, cross-sectional pictures of the body that show if cancer is present.
diagnosis	When the doctor works out what is making someone sick.	Working out what kind of disease someone has.
donor	A person who gives someone else some of their blood or another part of their body.	The person who gives blood, tissue or an organ to another person for transplantation.
haematologist	A doctor who treats people whose blood makes them unwell.	A specialist doctor who diagnoses and treats diseases of the bone marrow, blood and lymphatic system.
immune system	The part of the body that helps someone stay well by getting rid of germs inside the body. It fights illness if somebody does get sick.	A network of cells and organs that defends the body against attacks by foreign invaders, such as bacteria and viruses, which can make people sick.
immunocompromised	When someone gets sick very easily.	Weakening of the immune system, often caused by disease or treatment.
intravenous (IV)	Putting a needle into a vein (where blood is in the body).	Injected into a vein.

Word	For younger children	For older children, adolescents and adults
lymph nodes	Lymph nodes are like filters that remove germs that could harm you. Sometimes, the germs can make some of the lymph nodes swell.	Small, bean-shaped structures that form part of the lymphatic system and help fight infection.
maintenance treatment	When someone is given medicine for a long time to help keep the cancer away.	Treatment given for months or years as part of the treatment plan.
malignant	Another word for cancer.	Cancerous. Cells that are malignant can spread to other parts of the body.
medical oncologist	A special doctor who uses strong medicine to treat people.	A specialist doctor who treats cancer with drug therapies such as chemotherapy, targeted therapy and immunotherapy (systemic treatment).
metastasis (advanced cancer)	When the cells that aren't working properly have travelled to another part of the body.	When cancer has spread from one part of the body to another.
MRI scan	A way to take pictures of the inside of a person's body to see if they are sick.	A medical scan that uses magnetism and radio waves to take detailed, cross-sectional pictures of the body.
nausea	Feeling sick in the tummy.	Feeling as if you're going to vomit.
palliative care	Sometimes the doctors and nurses can't stop the cancer from growing, and they will give someone medicine to make them feel better and get rid of any pain.	Treatment that focuses on relieving symptoms and improving people's quality of life without trying to cure the cancer.
prognosis	What the doctors think might happen after treatment, and someone's chances of getting better.	The expected outcome of a person's disease. This helps doctors decide on treatment options.
radiation oncologist	A special doctor who uses x-rays that go into the body to kill cancer cells and make the cancer smaller.	A specialist doctor who treats cancer by prescribing and coordinating a course of radiation therapy.
radiation therapy	Invisible beams called x-rays that go into the body to kill cancer cells and make the cancer smaller.	The use of targeted radiation to kill or damage cancer cells so they cannot grow, multiply or spread. The radiation is usually in the form of x-ray beams. This is different to when you get x-rayed to see inside you (e.g. for a broken leg).
recurrence/relapse	When cancer comes back and the person feels sick again.	When cancer comes back after a period of improvement.
remission	When cancer goes away after treatment.	When cancer cells and symptoms reduce or disappear because of treatment. Remission may not mean that the cancer is cured, but that it is now under control.

Word	For younger children	For older children, adolescents and adults
side effects	Problems that can make someone feel sick or tired or lose their hair after treatment. Someone might gain or lose weight, or experience other changes. Most side effects go away after some time.	The unwanted effects of treatment, such as nausea, fatigue and hair loss. This is because treatment damages some healthy cells as well as the cancer cells. The healthy cells usually recover after a while (e.g. hair grows back again).
stage	When the doctor tells the person how sick they are.	The extent of the cancer and whether it has spread from an original site to other parts of the body.
surgery	When someone has an operation and a doctor called a surgeon cuts out the cancer.	An operation to remove the cancer. Sometimes large parts of the body will be removed with the cancer, such as a breast or the bladder.
symptoms	What people feel (e.g. sore, itchy) or see (e.g. redness, a lump) when something's not right in the body.	Changes in the body caused by an illness, such as pain, tiredness, stomach-ache or rash. These help the doctor work out what is wrong.
tumour	A lump in the body that shouldn't be there.	A new or abnormal growth of tissue on or in the body. Tumours can be benign (not cancer) or malignant (cancer).
ultrasound	A test that allows doctors to look inside the body so they can work out if anything is wrong.	A scan that uses soundwaves to create a picture of part of the body. It helps show where and how big a tumour is.

References

1. Australian Institute of Health and Welfare (AIHW), *Australian Cancer Incidence and Mortality (ACIM) books: all cancers combined*, AIHW, Canberra, December 2017.
2. Australian Institute of Health and Welfare (AIHW), *Cancer in Australia 2017, Supplementary tables: Chapter 5 Survival and survivorship after a cancer diagnosis*, AIHW, Canberra, 2017.
3. Cancer Council Queensland, *A summary of childhood cancer statistics in Australia, 1983–2014*, cancerqld.org.au/research/cancer-registries/australian-childhood-cancer-registry/ <accessed 28 March 2018>.
4. P Butow, *Immigrants with cancer: What are their unmet needs?* Presentation on Psycho-Oncology Co-operative Research Group (PoCoG) study, PoCoG, Sydney, 2013.
5. BM Donnan et al., "What about school? Educational challenges for children and adolescents with cancer", *The Educational and Developmental Psychologist*, vol. 32, issue 1, 2015, pp. 23–40.
6. ARTD Consultants/Camp Quality, *Understanding the needs of families living with cancer in Australia* (Camp Quality Family Research Project), Camp Quality, 2011.

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Cancer Council 13 11 20

Being diagnosed with cancer can be overwhelming. At Cancer Council, we understand it isn't just about the treatment or prognosis. Having cancer affects the way you live, work and think. It can also affect our most important relationships.

When disruption and change happen in our lives, talking to someone who understands can make a big difference. Cancer Council has been providing information and support to people affected by cancer for over 50 years.

Calling 13 11 20 gives you access to trustworthy information that is relevant to you. Our cancer nurses are available to answer your questions and link you to services in your area, such as transport, accommodation and home help. We can also help with other matters, such as legal and financial advice.

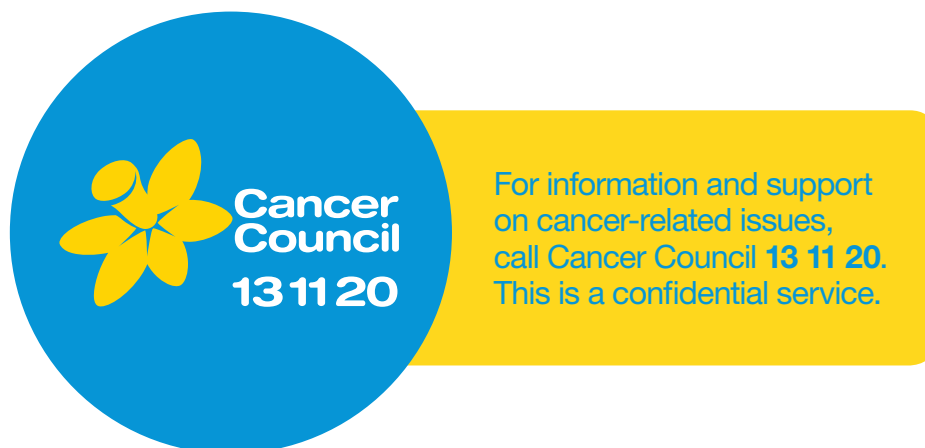
If you are finding it hard to navigate through the health care system, or just need someone to listen to your immediate concerns, call 13 11 20 and find out how we can support you, your family and friends.

Cancer Council services and programs vary in each area.
13 11 20 is charged at a local call rate throughout Australia (except from mobiles).



If you need information in a language other than English, an interpreting service is available. Call 13 14 50.

If you are deaf, or have a hearing or speech impairment, you can contact us through the National Relay Service. www.relayservice.gov.au



Visit your local Cancer Council website

Cancer Council ACT
actcancer.org

Cancer Council NSW
cancercouncil.com.au

Cancer Council NT
nt.cancer.org.au

Cancer Council Queensland
cancerqld.org.au

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