When a **student** has cancer

It is heartbreaking when a student is diagnosed with cancer. Though the experience is undeniably difficult for a family or school to address, in most cases, young people with cancer are very resilient, demonstrating maturity and wisdom beyond their age.

Your school can help a student with cancer in several ways. This chapter will teach you how to support a student through all stages of their cancer, make in-school adjustments and help classmates understand what is going on.

When a student is diagnosed

When a student is diagnosed with cancer, it may come as a shock to many people in your school community.

It is difficult for families to receive this upsetting news, and 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 protocol and inform their extended family network. This can be especially difficult for single-parent families, large families or parents with demanding work schedules. At this early stage, families may not inform the school of a student's illness.

Teachers or peers may notice a student's absences and speculate about the student's behaviour. You should endeavour to minimise rumours, even if you suspect (or have confirmed, in confidence), that the student has cancer. A liaison person or member of the student welfare team may contact the family to offer support.

Helpful tips

If or when a family informs your school that their child has cancer, you (or one of your colleagues) should:

- Offer support to the family. Families may not be aware of the support that your school network can give, or they may feel uncomfortable requesting help unless approached. Your school may link the family to school counselling services.
- Inform them about the school's usual plan of action. Your school may involve the student welfare team, appoint a liaison person, or notify the principal or teacher/s. Telling the family what to expect will make the process smoother.
- Respect their wishes. A person with cancer may wish to keep their diagnosis private. The school community should respect the family's wishes and give family members time to decide what they would like to do.

> "The day in hospital when all my friends went back to school and I didn't – well, I found that very depressing. I kept thinking of my mates back at school, and it made me feel left out. I worried I was going to miss out socially."

Jeremy, secondary school student with cancer

Setting up a communication channel

Talking and communicating openly about cancer helps people understand what is happening and adjust to the news. Different schools have preferred ways of disseminating information into the community. This may depend on how urgent the message is, the content of the message or how many people need to be informed. The most important thing for your school is to inform those immediately involved and be as candid and direct as possible.

The family, school staff members and liaison person should meet to discuss the preferred way that the school should communicate about the issue. For example, some families may want you, or one of your colleagues, to discuss cancer with their child's classmates. Others may want your school to send a general letter to parents about cancer.

Communicating openly can help students to demystify health problems and let people know that it is okay to talk about cancer and ask questions. Just be sure to respect the family's privacy and ask for consent before sharing any information.

Ways to communicate

Schools can use a number of methods to communicate about cancer, such as:

- small group meetings
- parent and teacher conferences
- school/community newsletters, newspapers or magazines, either online or in print form
- teaching and learning programs or information sessions
- letters (for some sample letters, see pages 75 to 78)
- emails
- classroom discussions or guest speakers (such as a visit to the school by a member of the patient's treatment team with parental consent)
- direct phone calls.

> "His parents are so distressed, and his mum is the one who distributes the information to me. I don't want to force her to relay news to us several times, so she just talks to me and I talk to the principal. She just hates to talk about it. She hates to even say that he has cancer."

Kristin, primary school teacher of a student who has cancer

Supporting a student during treatment

Keeping in touch

Whether a young person is healthy or sick, school is an enormous part of their life. It is upsetting when a student must disrupt their routine because of cancer. Attending school is about more than just education – it establishes a familiar routine and provides a stable environment and an opportunity for socialisation.

If the student is absent for a long period of time, it may be beneficial to maintain contact with classmates. Young people with cancer find it easier to return to school if relationships with their friends have been maintained throughout their absence. Communication can make the patient feel special, as young people often look forward to hearing from friends.

Remember, not all families want to maintain close contact with the school, and the young person may not be able to reciprocate, depending on their age and prognosis.

How to maintain contact

Members of the school community could choose to:

- post letters, drawings and paintings
- record a tape/DVD of a school event, or record personal messages
- send photos or small gifts
- email notes, photos or videos
- create a website about what is happening at school
- use a computer social networking or messaging system (such as Facebook, AOL Instant Messenger or MSN Messenger) when not at school.

> All my teachers and friends were in contact via email. I was never out of touch with the group because of email.
>
> 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 over 300 people to write on. They kept me entertained for hours!

Jeremy, secondary school student with cancer

Helping with school work

Long-term patients in some bigger public hospitals may be linked to a hospital school that caters to students of all ages, from kindergarten to Year 12. The aim of a hospital school is 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.

When a young person is in hospital for several days, the hospital school may collaborate with your school to organise its curriculum. It is natural to feel anxious about how the student is going to manage the work.

Talk to the student's parents about their expectations about keeping up with school work. A patient may not be able to manage a full workload due to their treatment regime.

Ways to support a student who is absent

You (and/or the school liaison person) can help by:

- providing the hospital school with outlines of the curriculum
- providing the hospital school with a list of necessary textbooks
- sending copies of worksheets and projects to the hospital school
- making sure the student receives school emails and any handouts
- letting the hospital know if the student needs extension activities or a remediation program
- facilitating online access to assignments or applicable websites with information about school activities, if possible
- organising visits to the hospital by classmates, if approved by the student's parents.

The Back on Track program

The Back on Track program, funded by the Fight Cancer Foundation, aims to support students whose educational progress has been compromised by school absences and periods of hospitalisation. This program helps patients by keeping them educationally and socially connected.

Back on Track provides a variety of services, including tutoring and access to technology, to link the student with their NSW school. When a student is enrolled in the program, an Education Program Coordinator (who is a trained school teacher) liaises with the student's school, family and hospital staff to create and implement an individualised plan. This plan may facilitate a smooth transition for students returning to school or entering a tertiary institution on completion of their treatment.

At the time of print, Back on Track is only available for young people receiving treatment at The Children's Hospital at Westmead, however there are plans to expand the program throughout NSW. For more information, call (02) 9845 0423.

Redkite

Redkite is a charity that supports children, young people and their families through cancer by providing financial assistance, educational services and emotional support. It provides professional tutoring grants for students trying to catch up with school work and scholarships for students with a particular goal in mind.

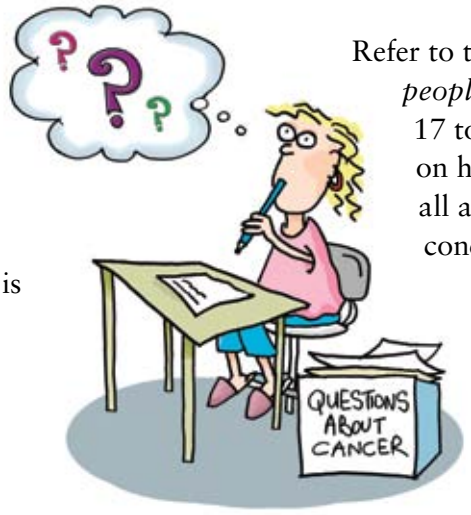
While Redkite's educational assistance is usually coordinated by hospital social workers, you can play an important role by making parents aware of Redkite's support services or directly referring a student. Patients or family members as old as 21 years old can receive educational assistance from Redkite.

Redkite also provides telephone and email support for young people diagnosed with cancer, their families and support networks. For more details call 1800 334 771 or visit www.redkite.org.au.

> "The Children's Hospital at Westmead has a hospital school. They have a Years 9 to 12 group that meets around 9am to noon some days, but I was immunosuppressed and couldn't be around other kids. The teachers came around to our bedsides to tutor us in the afternoons."
>
> *Jeremy, secondary school student with cancer*

Supporting the student's classmates

School fosters close relationships between students, so you can expect a range of reactions when you talk to students about their classmate's cancer. It's important to remember that everyone reacts differently to a stressful situation. You might notice that students are visibly upset. Others may be angry, confused or annoyed. Some may have no outward reaction to the news.



No matter how close a student is to their classmate with cancer, they will have feelings about it. The best thing you can do is communicate as openly and honestly as possible with the students and their parents (considering any confidentiality requirements).

Give the students opportunities to voice their feelings or ask questions. They might ask some difficult or sensitive questions, like if they can 'catch' cancer or if their classmate will die. You should approach the class in a sensitive manner. In some cases, a member of the patient's treatment team (such as the community nurse) may be present to help you to answer the students' questions.

Refer to the *Communicating with people of all ages* section (page 17 to 21) for some strategies on how to talk to children of all ages. If you are particularly concerned with fielding questions about death, see *What young people understand about death* on page 61.

It is wise to establish beforehand if some students will be particularly susceptible to being upset because of a close association with a person with cancer. If a student becomes very distressed they may need time out with a counsellor or teacher with whom they feel comfortable.

> "The hardest thing is speaking to her classmates. We can't ignore the physical side effects. The class is very aware that something is going on, and they're worried about her."

John, primary school teacher of a student with cancer

Supporting a student after treatment

Returning to school

Getting back into a school routine is very important to children and young adults – it maintains continuity in their education and their social relationships, and it is also reassuring because it reinforces the idea that life will go on and they have a future.

It is normal for parents to have a wide range of responses to 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 dealing with a parent's reaction, talk to the student welfare coordinator, a school counsellor or a clinical nurse consultant about how best to handle the situation. Sometimes parents need reassurance that the school will adequately monitor their child.

"When a child is just off treatment, the school really needs to know about keeping them away from chickenpox and measles – for the first six months if they've had chemotherapy, 12 months if they've had a bone marrow transplant."

Kylie, clinical nurse consultant to young people with cancer

"I worried about leaving my parents and returning to school – but I didn't tell anyone. They'd been there for me throughout my entire treatment and I was scared to leave them behind and to be doing something without their help – even though I was 17."

Jeremy, secondary school student with cancer

A student who has been absent will also have concerns when they return to school. They might worry about:

- **Being left out or rejected.** You can assure the student that their classmates missed their company, and though peers may be shy initially, they will eventually be more welcoming. You should prime classmates for the student's return before they arrive.
- **Keeping up with work.** You can enlist the help of your school's student welfare team or liaison person, or you can arrange tutoring or special assistance to help the student catch up. Assure the student that they won't be expected to be immediately up to date.
- **Being bullied or teased.** Your school will have policies to counter bullying, discrimination and harassment. Closely monitor the reactions of other students and be aware of your school's strategies to identify, report and address bullying behaviour (see page 34). Resentment on the part of other students can play a part in this type of behaviour. You should equip the student with cancer with strategies to respond to any bullying behaviour.
- **Fitting in with other classmates.** A student who looks different (due to weight gain or loss, hair loss, a physical disability or a swollen face, for example) might worry about their peers' reactions. Again, talking with classmates honestly may alleviate the stress.
- **Relapsing or returning to hospital.** Some students have a compromised immune system due to treatment (immunosuppression). This means they are highly susceptible to contracting infectious diseases. Implementing standard infection control measures and encouraging general hygiene such as hand washing can help prevent a student's exposure to common germs. A school counsellor or parent can also assure the student about their health. See page 75 for a suggested letter to parents about infection control.

The school liaison person may also be able to assist by obtaining relevant information about the young person's medical condition, adjusting grading procedures or adapting sporting events and physical education. This will ease the worries of parents and the student with cancer.

Helping the student settle back in

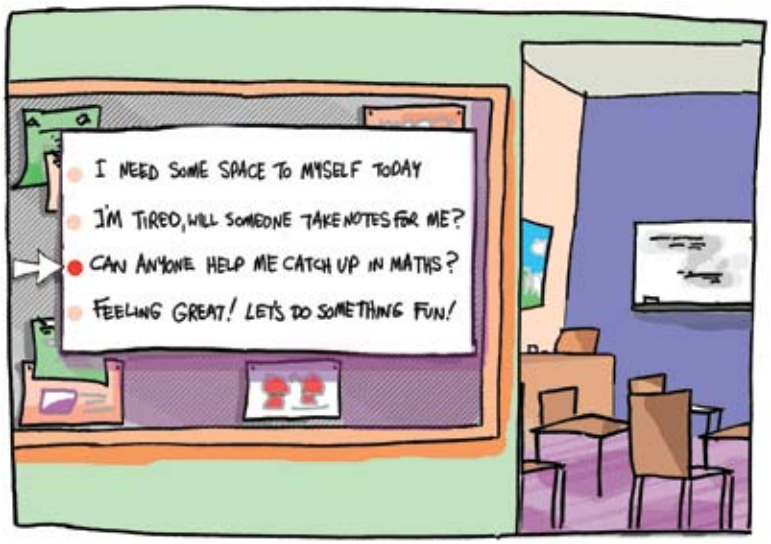
A student returning to school may have to manage side effects and delayed effects of treatment, which can appear months or even years after treatment has ended. They might have difficulties with spelling and writing, reading comprehension or mathematics. A student might also have difficulties taking notes or copying information, remembering things, organising and planning, or completing tasks on time.

Your school may need to make accommodations for students with cancer. This may include providing catch-up work in different key learning areas, organising an in-class buddy (who can help with note taking or recording assignment due dates) or adjusting homework assignments and deadlines. You (and your school's learning support team) should work with the student's family to arrange a suitable routine.

In addition to concerns about academic performance, a young person might worry about how to communicate their feelings to staff or peers.

One way to alleviate these concerns in a primary school classroom is to use an emotions thermometer, a simple device that allows the student to show how they're feeling each day.

A student can decide on the feelings that should be included on the thermometer and make a pointer that can move between the feelings. Some examples of statements might be, "I need some space to myself today", or "I would appreciate some help taking notes today". The young person's teacher or a classroom aide will need to help the student manage the thermometer.



> The principal introduced Sean to all the staff and they put a picture of him on the teachers' noticeboard so any relief teachers would know who he was.
>
> *Jim, father of primary school student with cancer*

Making practical modifications for students

Accessibility

In some cases, students with cancer can become physically disabled as a result of treatment. For example, a student may have had an amputation, or they may need access to a wheelchair. School buildings may already be modified to meet the needs of students with physical disabilities. However, additional adjustments, such as access to a lift or timetable changes, may be necessary to ensure the young person has physical access around the school.

Cognitive impairment

One possible side effect of cancer or its treatments may be cognitive impairment. Some young people with cancer may need more time to process information, or they may have to deal with short-term memory loss. Some students have particular trouble solving maths problems or remembering lists of facts.

You should make accommodations for students who struggle to keep up, such as providing extra tutoring, allowing more time for homework or assigning an in-class buddy to take notes or record assignment information.

Sensitivity to sunlight

Some students who receive treatment must stay out of the sunlight. Your school may have to ensure there are shaded areas or indoor activities available.

Central venous access devices

Some students will have a central venous access device (line), which is a tube inserted into a vein in the neck, groin or chest. This line allows doctors to easily administer intravenous drugs or draw blood.

If knocked or jarred, a central venous line may bleed. Ask the student's parents whether they can participate in contact sports, and don't allow peers to use rough physical contact. Also, some types of central lines should not be submerged in water. Relevant school staff should be aware if the student is not allowed to swim.

The central line should not require regular maintenance from school staff unless it bleeds. In this case, the area between the line and the bleeding site should be pinched or compressed while medical assistance is sought. If a cap has fallen off, it may have become dirty, so it should not be inserted back into the end of the line without medical assistance.

Dealing with teasing and bullying

Unfortunately, young people can be cruel to each other. Most teasing and bullying occurs when a young person wants attention, feels resentful or hurt, or doesn't understand something.

If you work at a public school, you will be familiar with the NSW Department of Education and Training's *Student Discipline in Government Schools Policy*, and you should implement strategies to prevent bullying in your school community. Private schools also have relevant anti-harassment policies.

The best way to prevent bullying is to be as open as possible about a student's cancer. Cancer is frightening to young people – the more students know about cancer, the more likely they are to be supportive.

You should also realise 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 why the student requires extra attention, then endeavour to maintain a normal classroom atmosphere.

Supporting the student's parents

When a family has a child with cancer, communication with the school can provide significant support. If your school has a liaison person, a buddy system, a welcoming network or parent contact lists, you are already set up to provide support. A support network can help in many ways, such as taking children to after-school activities, providing meals or helping with household chores.

Remember, the school community plays a central role in some families, but for others it does not. Be sure to consider the privacy concerns of the family before taking action.

> "We're working with his parents to help him make the transition to secondary school. We help all the kids, but we need to take special care with Jason. Because he's ill, he must really balance education with the happiness and contentment he feels being around friends."
>
> *Kristin, primary school teacher to student with cancer*

Helping young people understand cancer

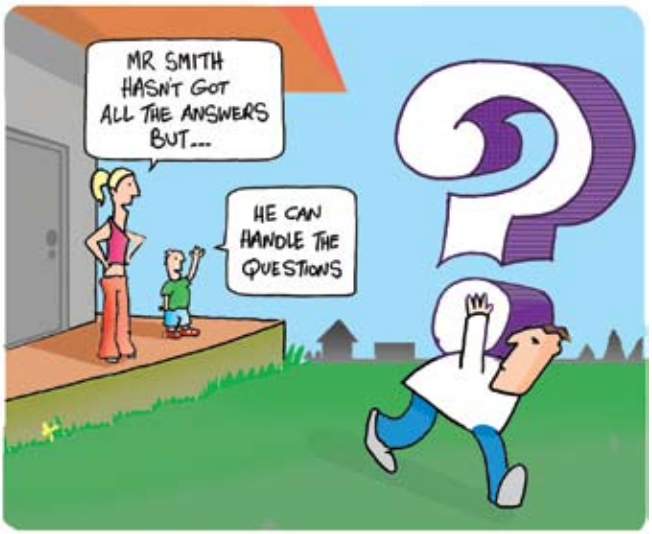
It can be extremely difficult to talk to children and young adults about cancer. If you talk to students, you should consider how old they are – and anticipate difficult questions they might ask – before starting the discussion. You might practise what you will say, or ask the family how they would like you to approach the class. See page 17 for specific ways you can talk about cancer with young people.

Helping students talk to a friend with cancer

It is not uncommon for the classmates of a student with cancer to feel helpless and unsure about what to do or say around them. Sometimes students will look to teachers or their parents for guidance on how to act, but at other times you might notice that the students are uncomfortable.

You can help by:

- Listening to students' concerns.
- Encouraging discussion and talking openly about what cancer is, its treatments and possible side effects. This will help prepare students for physical and emotional changes in their classmate. See *Chapter 1* for more facts about cancer.
- Answering questions, or finding out the answers if you don't know. When you discuss the facts openly and honestly, anxieties and uncertainties will diminish.
- Advising the students on how to act around a classmate with cancer. For some examples on how to guide students, refer to the following section, *Advising students on how to act*.
- Encouraging emotional expression. Painting, writing, composing music or participating in other activities may help the student with cancer feel at ease.
- Inviting a member of the student's medical team to speak to the class, with the written consent of all students' parents, including the student with cancer. This will help mature students gain a better understanding of what their classmate is experiencing.



Advising students on how to act

You might want to help students talk to a friend with cancer. You can advise them to:

- Acknowledge the situation. You might recommend that they say, "I don't know what to say, but I want you to know I care", "We missed you", "How are you going?" or "Is there anything I can do to help in class?".
- Take cues from their friend with cancer. By observing how their friend acts, students might learn how to respond.
- Try to talk normally about day-to-day things. You should remind students that their classmate is probably tired of talking about cancer all the time.
- Understand that the student might act a little differently. You can point out to students that aside from health-related modifications to their routine, their classmate will follow the same school rules as everyone else.

Planning a lesson about cancer

In some cases, a lesson or class discussion about cancer can help students understand what is going on with their classmate. The NSW Board of Studies, which serves government and non-government schools, may provide some guidance on how to incorporate information about cancer into the core curriculum. For more information call (02) 9367 8111 or visit www.curriculumsupport.education.nsw.gov.au.

"I explained what would happen when he went to hospital. I didn't get too detailed, but I was open to questions. The students just wanted to know basic information – they're very interested and bright. I think my approach worked. They were pleased to be told the truth."

John, primary school teacher of a student with cancer

Special provisions for the HSC

Although all students are required to meet course requirements, the NSW Board of Studies (BoS) can adapt HSC assessments to accommodate special needs of secondary school students with cancer. Illness/misadventure provisions may also be available for students who have family members with cancer.

The permitted HSC modifications depend on each student's circumstances. For example, some students may be allowed time to rest between examinations. Other students may need to have physical disabilities accommodated. The NSW BoS may also consider marking the student based on their scores throughout the school term/s, rather than the usual combination of in-school assessments and external exams.

If possible, the NSW BoS prefers that students sit their exams, then appeal for a different marking procedure. However, if you know a student might be eligible for special provisions for an upcoming exam, you should talk to the student about their options. You can contact the NSW BoS Special Provisions Section on (02) 9367 8111 or www.boardofstudies.nsw.edu.au and help the student apply. Applications may take two weeks to two months to process.

> "The school's special ed department organised someone to help me apply for special help for the HSC. 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 school student with cancer

Gaining access to tertiary study

The Universities Admission Centre (UAC) has a variety of Educational Access Schemes (EAS) that may help a student gain access to tertiary study if they have experienced educational disadvantage due to circumstances such as a cancer diagnosis or treatment.

If a student's Universities Admission Index score (UAI) has not already been adjusted considering their medical circumstances, an EAS may help the student gain admission. A student would apply to both the selected university and the UAC. Each university applies its own EAS to calculate the student's score and determine if they will be admitted into their elected program of study.

For more information about how you can help a student apply for an EAS, see www.uac.edu.au/equity/eas.html.

"I applied for the Broadway Scheme, which allowed the University of Sydney to give me extra marks because of my special circumstances. If my UAI was 95 and I received two extra points from admissions, I could enrol in a course that requires a 97 minimum.

It's easy to apply for, and it's fair. In the end, I didn't use the Scheme because I got good enough marks. But it helps if you're disadvantaged. It makes you feel like your uni plans won't be ruined just because you had cancer."

Jeremy, secondary school student with cancer