

Talking about cancer

Talking about cancer is never easy, and it can be especially difficult to talk to others in your school community. Deciding who should be told and remaining respectful of a person's privacy can be challenging.

However, your school already has an existing student welfare policy and avenues of communication which can be used to provide support for individuals affected by cancer. In this chapter, we will outline how to use your existing skills and resources to communicate with others.

Talking to someone with cancer

I waited until I could call the deputy principal without weeping. I talked to him on Saturday because I was diagnosed on a Friday and had a surgeon's appointment on Monday, so I wouldn't be in. I told him I had breast cancer and I was happy to talk about it, but I asked if he would tell the staff at the Monday morning meeting.

Shirley, secondary school teacher with cancer

It can be very difficult for someone to talk about a cancer diagnosis. Some people wish to keep their diagnosis private, while others may want to share this information. It's important to respect a person's wishes, no matter what they decide.

When you're having a conversation, avoid giving unsolicited advice or telling the person you know exactly how they feel, even if you have been in a similar situation. It is best to use phrases like, "That sounds really difficult" or "Hearing what you've gone through upsets me. Is there anything I can do to help?"

Most importantly, just be yourself and try not to worry about doing 'the right thing'.

Students sometimes find it especially difficult to talk to a peer with cancer. See *Helping students talk to a friend with cancer* on page 35 for information about how you can guide them.



Helpful conversation tips

If you talk to a person with cancer, it may be helpful to:

- Listen and let them lead the conversation. If the conversation stops, it's not always necessary to fill in the gaps. Silence can be just as important as talking.
- Offer them support. For example, a parent undergoing treatment may benefit from a carpool service.
- Enjoy a laugh. People living with cancer want to talk about other things too. Not every conversation has to revolve around illness. Students, especially, may come to school to regain a sense of normality and routine.
- Acknowledge their feelings. It is acceptable for someone to feel sad or angry about their cancer diagnosis – you shouldn't try to change their feelings.
- Tell the person if talking about cancer makes you emotional.
- Invite them places. If you used to eat lunch in the staff common room, share coffee breaks or sit together on playground duty, continue to ask the person along. If you think they are too ill, suggest another activity or join them where they are comfortable.
- Ask questions if you're confused about something.

Importance of respecting privacy

Some people wish to keep their cancer diagnosis private. There are several reasons someone may be concerned with their privacy.

Students may see school as a return to normality and their pre-cancer life. They also may fear the reactions of their peers.

Parents or family members may want to avoid gossip or probing questions. Sometimes parents need more time to talk to relatives or decide on a treatment plan.

If you have a colleague with cancer, they may want to continue working and focus on their day-to-day activities. Some teachers worry that their students are too young to understand cancer. They may wish to keep their prognosis private if they don't know how long it will be possible to continue working.

These are legitimate concerns, and people's rights should be respected unless there are overriding health and safety issues.

Appointing a school liaison person

Your school's student welfare team can support a person with cancer by appointing a willing staff member (such as a member of a student's learning support team) to liaise with them. In cases where students or family members are affected, a liaison person can provide a channel for keeping the family and the school up to date.

Though it can require a significant time commitment, families usually find it quite

helpful and convenient to have a single point of contact within the school. This ensures that one person is aware of the family's ongoing and changing needs.

Remember, the school community plays a central role in some families, but for others – often those with strong family networks – it is not as important. A family may not ask the school for support or assistance.

“I don't mind being a liaison person. I've gotten quite close to Mark's mum. It's easy to do and quite important.”

Kristin, primary school teacher of a student who has cancer

Understanding cultural differences

If your school community has a mixture of diverse cultural groups, people will probably have different attitudes regarding health care and how to communicate about it.

The word cancer can have different meanings for people from certain cultural backgrounds, and some people may not want to talk about it openly. Some cultures believe that cancer is contagious, caused by bad luck or always fatal.

It is important to be open and honest to avoid confusion. When you talk about cancer, try to be as direct as possible without

making anyone uncomfortable. 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.

For more information about how different cultures regard cancer, or to obtain information about cancer in a different language, call the Cancer Council Helpline on 13 11 20.

Balancing everyone's needs

Schools must always consider and balance the needs of students and staff members in the community. For example, if a student has cancer, the school must respect their privacy while continuing to focus on its primary purpose and obligation, which is to educate students.

However, a teacher might need to know certain details about the student's illness to

accommodate their needs in the classroom and playground. If the teacher is aware of the situation, they can anticipate questions from pupils, colleagues or family members and distribute information.

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

Communicating with people of all ages

A person's understanding of cancer depends on their age, maturity level and experience with the disease.

The following tables on pages 18 to 21 provide some basic information about how some people without cancer may understand the illness, their possible reactions, and how you can talk to them about it.

Remember that each person is unique and these are broad guidelines.

You can also read the *Glossary* section on page 80 for a list of cancer-related words. This glossary provides two definitions for each term – one that is appropriate for adults, teenagers and older children, and another which is more suitable for younger children.

Often people are most disturbed by what they don't know, so I took a very up-front approach. If people are brave enough to ask questions, I don't think there should be fog and mirrors. No mystery.

Shirley, secondary school teacher with cancer

Preschool / Kindergarten-age students (3-5 years)

Understanding of illness	Possible reactions	Suggested approaches
<ul style="list-style-type: none"> • They have a beginning level of understanding about illness. • Children may believe that they caused the cancer (e.g. by being angry with their parent or thinking bad thoughts about a classmate or teacher). This is an example of magical thinking. • Preschoolers are egocentric – they consider themselves the centre of the universe. This means they cannot yet empathise with other people. • Children may think cancer is contagious. • Illness may be regarded as a punishment for naughty behaviour. 	<ul style="list-style-type: none"> • thumb-sucking • fear of the dark, monsters, animals, strangers and the unknown • nightmares • sleepwalking • sleeptalking • bed-wetting • stuttering • baby talk • hyperactivity • apathy • fear of separation from others (especially at bedtime and going to preschool) • aggression (hitting or biting, for example) • repeated questions about the same topic, even if it has been discussed several times 	<ul style="list-style-type: none"> • Listen and be alert to their feelings, which they may express through speech or play. • Talk about the illness with pictures, dolls or stuffed animals. Read a picture book about cancer. • Read a story about aggression or other reactions. • Explain what they can expect; describe changes to their school schedule. • Reassure them that they will be taken care of and will not be forgotten. • Provide brief and simple explanations. Repeat your explanations if necessary. • Encourage them to have fun at school or participate in activities. This can help them to have fun or achieve goals. • Assure them that they have not caused the illness by their behaviour or thoughts. • Continue usual discipline and limit-setting – provide outlets for aggression that are positive, such as running in the playground. Be sure they get physical activity to use up excess energy and anxiety. • Assure them they cannot catch cancer, like a cold or flu.

Adapted from *When a Parent Has Cancer: how to talk to your kids*, The Cancer Council NSW, August 2007.

Primary school-age children (6-12 years)

Understanding of illness	Possible reactions	Suggested approaches
<ul style="list-style-type: none"> • They are able to understand more complex explanations of cancer, and they can understand basic information about cancer cells. • They still may feel responsible for causing cancer because of bad behaviour. • In many cases, children in the middle of this period understand that parents, teachers or classmates can die. However, if a child has been exposed to illness or death at a young age, they may have a more mature/advanced understanding of death and dying. 	<ul style="list-style-type: none"> • irritability • sadness, crying • anxiety, guilt, envy • physical complaints such as headaches and stomach-aches • separation anxiety when going to school • hostile reactions, like fighting or yelling • poor concentration at school, daydreaming, lack of attention • poor marks • withdrawal from friends and family • difficulty adapting to changes (such as a replacement teacher or new schedule after school) • fear of performance, punishment or new situations • super-sensitivity to shame and embarrassment 	<ul style="list-style-type: none"> • Listen and be alert to their feelings, which they may express through speech or play. • Use books to explain illness, treatment and potential outcomes. • Assure them their behaviour or thoughts did not cause the cancer. • Reassure them about their care and schedule. • Assure them that though it is possible, the chances of someone else getting cancer are slim. A counsellor or social worker may help initiate this conversation. • Let them know how they can help a teacher, classmate or parent with cancer. • Take time to listen and let them know you care about their feelings. • Social workers or psychologists may help to gently broach the topic of a parent, teacher or classmate dying. • See also the ideas on how to approach preschoolers.

Adapted from *When a Parent Has Cancer: how to talk to your kids*, The Cancer Council NSW, August 2007.

Secondary school-age children/teenagers (13-18 years)

Understanding of illness	Possible reactions	Suggested approaches
<ul style="list-style-type: none"> • They are capable of abstract thinking: they can think about things they have not experienced themselves and feel sympathetic to others. • They are able to begin thinking more like adults. • They are able to understand that people are fragile. • They are able to understand complex relationships between events. • They are able to recognise prevention measures and symptoms. • They are more likely to deny fear or worry in order to avoid a discussion. 	<ul style="list-style-type: none"> • worry about being different and not fitting in • desire to be more independent and to be treated like adults • angry and rebellious • critical of how parents, teachers or classmates handle the situation • depression • anxiety • poor judgment and risky behaviour such as smoking, binge drinking or unsafe sex • withdrawal • apathy • physical symptoms: stomach-aches, headaches, rashes • more likely to turn feelings inward (so parents, teachers and friends are less likely to see reactions) • regression: tendency to lapse into previous habits or behaviours, such as watching children's TV shows or being especially dependent on parents 	<ul style="list-style-type: none"> • Encourage them to talk about their feelings, but realise it may be hard for them to confide in you. They may find it easier to confide in their parents or closest friends. • Listen to them, don't just talk to them. • Express your feelings (for example, mention that you miss a teacher who is on sick leave). • Provide privacy as needed. • Encourage them to maintain activities and friendships at school, if possible. • If they have severe reactions, provide opportunities for counselling. • Don't rely on the student to take on too many extra responsibilities. • Take advantage of in-school opportunities for them to learn more about cancer and receive support. • See also the ideas on how to approach primary school-age children.

Adapted from *When a Parent Has Cancer: how to talk to your kids*, The Cancer Council NSW, August 2007.

Adults (such as parents and staff members)

Understanding of illness	Possible reactions	Suggested approaches
<ul style="list-style-type: none"> • They are capable of abstract thinking: they may have close friends or family members with cancer, so they can imagine what it may be like. This can sometimes bring up feelings of sadness about their own experiences with cancer. • They feel sympathetic to others. • They are able to understand the impact of diagnosis and treatment on all aspects of life (for instance, school and personal relationships). • They understand complex relationships between events. • They are able to recognise symptoms and understand prevention measures. 	<ul style="list-style-type: none"> • depression • anxiety • withdrawal • physical symptoms such as headaches • for some, the need to talk about how they are feeling with others • putting extra energy into work or distracting activities 	<ul style="list-style-type: none"> • When it comes to talking about cancer, different people will feel comfortable with different approaches. For ways a school can talk to parents about a staff member's cancer, see the <i>Choosing to tell parents</i> section on page 49. • Adults should be provided with simple and factual information if a student has cancer. This will alert them to the student's potential needs and encourage them to seek further information as necessary. You should discuss and agree on the information that may be shared with the students and their families.

Adapted from *When a Parent Has Cancer: how to talk to your kids*, The Cancer Council NSW, August 2007.

“My 15-year-old daughter is in class with a student who has cancer, and I have cancer, too. My daughter is very empathetic and now knows how to talk about cancer.

My younger children have reacted differently. My three-year-old understands what is going on – he says, ‘Mummy’s boob is sick.’ But he does act very naughty the weeks I receive chemo.”

Janet, primary school canteen manager with cancer

Where to get information or assistance

Talking about cancer in your school community can be very difficult, and there are many reasons you might seek the support of experts. The Cancer Council offers a free and confidential telephone information service (called the Cancer Council Helpline) where you can discuss questions you may have. Calling the Helpline costs the same as making a local call.

The Helpline is staffed by experienced cancer health professionals, including oncology nurses and counsellors. They are available Monday to Friday, from 9am to 5pm, and can provide detailed information

about the best ways to communicate about cancer and deal with a diagnosis. They can also send you written information, direct you to resources in your area or provide you with reliable Internet links.

You can reach the Cancer Council Helpline on 13 11 20. If you are calling outside business hours, leave a message on the answering machine and your call will be returned the next business day.

You can also visit the Cancer Council's website, www.cancercouncil.com.au.

