



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. You should use your school's existing wellbeing and communication guidelines and resources as you provide support.

Talking to someone with cancer

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. A shared silence 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.

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

Genevieve, mother of primary student with cancer

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?”

Invite them places – If you used to eat lunch in the staff common room 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.

Students may find it difficult to talk to a peer with cancer. See *Talking to a classmate with cancer* on pages 36–37 for tips on how you can guide them.



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).

Any members of the school community who are provided with personal information about a student, student's family or a staff member need 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. It is important that the student and their family feel comfortable with this person.

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.

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

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 can 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. 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.

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.

Cancer and cultural background

Cultural factors can affect whether people with cancer seek help and the level of stigma they attach to the disease.

Research shows that, compared to people from Anglo-Saxon backgrounds, people from culturally and linguistically diverse (CALD) backgrounds experience more anxiety and depression after a cancer diagnosis. They also have more unmet needs regarding emotional support and information.⁴

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 such as TIS maintains confidentiality. This can often be a better approach than using a family member or friend as an interpreter.



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.

Pages 16–19 outline 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. Key treatment or testing milestones can also prompt anxiety and behavioural changes.

Be particularly alert for changes in behaviour. For example, a young child may regress to thumb-sucking, a social student may start to withdraw from peers, a top student's grades may start to slip, 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. Call 13 11 20 for a free copy, or download it from your local Cancer Council website. Camp Quality puppet shows (see page 35) can also help primary students understand and talk about cancer.

Chapter checklist

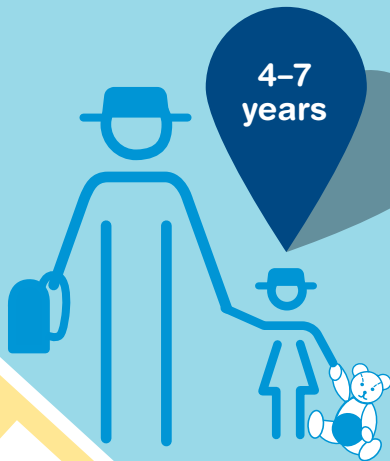
- ✓ Realise the first few weeks after diagnosis are usually stressful.
- ✓ Don't avoid the person because you feel uncomfortable.
- ✓ Listen and let the person lead the conversation.
- ✓ Offer practical support.
- ✓ Avoid giving advice.
- ✓ Respect the wishes of the individual or their family to keep the cancer diagnosis private.
- ✓ Appoint a staff member to act as the key liaison for the family.
- ✓ Pitch any explanations of cancer 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, 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 (including little things like lunch money)
- use picture books, dolls or stuffed animals to talk about the cancer
- read books together that explore anger, sadness and other feelings
- be honest
- reassure them that they will be taken care of and will be safe
- 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 (more commonly seen in girls)

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
- physical symptoms caused by stress, e.g. stomach-aches, headaches
- difficulty concentrating in class
- change in academic performance
- poor school attendance

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 (e.g. mention that you miss a teacher who is on sick leave or that you are scared too), 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, see page 50 for how to talk to parents about it