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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.



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

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.

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