WHEN A STUDENT IS IMPACTED BY CANCER IN THE FAMILY

a guide to CanTeen

FOR SCHOOLS
CanTeen is a national organisation that has been supporting young people living with cancer for more than thirty years.

Through CanTeen, young people develop skills to cope with the impact cancer has on their life and connect with others their age who are in the same boat.

CanTeen conducts leading research into the emotional and social impacts of cancer to ensure that we truly understand how cancer is different in a young person’s world. Evidence informs everything that we do – our research underpins and supports the services we provide to young people affected by cancer.
WE WORK WITH 12-25 YEAR-OLDS WHO...

+ Are dealing with a parent’s cancer
+ Have/had cancer
+ Are dealing with a sibling’s cancer
+ Are coping with the death of a parent or sibling
Every year, another **23,000** young Australians have to face the challenge of cancer.

- **21,000** find out their mum or dad has cancer
- **1,000** are diagnosed with cancer
- **1,000** find out their brother or sister has cancer

**Young People Who Have a Parent With Cancer**

One in three adult cancer patients will have a child or children under the age of 26.

Our evidence shows that young people dealing with a parent's cancer are **three to six times more likely to experience high or very high levels of psychological distress than their peers**.
Whether they’re dealing with a close family member’s cancer or their own, our studies show that young people experience high or very high levels of psychological distress, which in turn can significantly affect their educational outcomes as well as their behaviour at school.

Young people often internalise their anxiety to try and ‘stay strong’ for their family or in an attempt to appear normal to their peers.

In reality, their cancer experience frequently means they struggle with:

- Poor attention and irritability during class
- Completing homework on time (they may for example be visiting a parent or sibling in hospital or taking on more duties at home while a parent is absent)
- Maintaining friendships within the school community

When Mum was diagnosed I didn’t know how to react because all I knew about cancer was that people died from it. I was scared for her and didn’t want to lose her. These were the only things going through my head, all day, every day. Canteen helped me cope. If it wasn’t for Canteen I don’t think I’d be the person I am today.

Olly, Age 17
Adolescence is a critical developmental period, and one in which independence and identity are key factors. Both neurologically and socially, the experiences faced shape who they are and resonate into adult life.

The services we offer aim to provide experiences whether they be with professionals or peers that promote resilience and emotional wellbeing.

Our research shows that after 6 months of support from CanTeen, almost two thirds of young people affected by cancer report improvements in their mental health and overall wellbeing.

The CanTeen Psychosocial model provides a strong framework of stepped care and effective, evidence-based intervention for all young people.

The model has five core stages completed with each young person (see opposite).
1. **PSYCHOSOCIAL ASSESSMENT**
   - Each young person participates in an assessment of their wellbeing and cancer-related needs.
   - The assessment includes standardised psychological distress and cancer-related unmet needs questionnaires and a semi-structured interview (modified HEADSS assessment).
   - Questionnaire results are reviewed with the young person and key needs are identified. Possible support options are discussed and young people contribute ideas and priorities for their individual support plan.

2. **TRIAGE**
   - Assessment results and the proposed individual support plan for each young person are presented for psychosocial multidisciplinary team review.
   - Each young person is allocated to a psychosocial service stream based on their level of distress, cancer-related need, and required level of support (see below).
   - Each young person is allocated a key support worker.

3. **SERVICE PROVISION**
   - Young people access CanTeen’s range of programs and services as per their support plan.

4. **PSYCHOSOCIAL REVIEW**
   - Support needs are reviewed after an initial six months and then reviewed annually.
   - Standardised measures are completed. The key support worker discusses changes in needs and goals with the young person.
   - The psychosocial multidisciplinary team reviews the assessment results and service stream. The young person is allocated to a new service stream if needed and their individual support plan is updated.
   - The updated plan can recommend ongoing service provision or service closure.

5. **SERVICE CLOSURE**
   - Service provision ends if support is no longer required by the young person.

**LEVEL OF CLINICAL NEED**
- **SPECIALIST**
  - Significant mental health co-morbidities; high risk of self-harm; multiple unmet needs beyond cancer experience, e.g., youth homelessness. Support offered: Referral to specialist external agency
- **THERAPEUTIC**
  - High cancer-related distress and unmet need; mild to moderate mental health co-morbidities; moderate risk of self-harm; emotional support needs, including isolation, bereavement or palliative support. Support offered: Counselling; therapeutic intervention
- **COORDINATED**
  - Moderate cancer-related distress and unmet need; at risk of mental health co-morbidities; low-moderate risk of self-harm; information or practical support needs. Support offered: Coordinated care across therapeutic and recreational services
- **UNIVERSAL**
  - Low cancer-related distress and unmet need; no mental health co-morbidities; low risk of self-harm; peer support or respite/recreational needs. Support offered: Recreation, peer support, or leadership development programs
support
options

I found online counselling really helpful. The kind of online platform where you can connect to someone when you need support the most. I usually don't have much business hours, but there are online platforms that connect people with someone whenever they need it.

Alix, Age 22
All of the support options CanTeen provides are free. We offer a range of services and programs that are tailored to a young person’s specific cancer experience.

**ONLINE SUPPORT**

CanTeen Connect is a secure, online community available 24/7 where young people can connect with others in a similar situation, check out events around the country and chat to a counsellor 7 days a week.

canteenconnect.org.au

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**COUNSELLING**

CanTeen counsellors are specially trained to understand the challenges cancer brings and will help develop strategies for young people to deal with the impact cancer is having on their life.

Support is available seven days a week. Phone, email and online counselling through CanTeen Connect is available 10am-10pm AEST weekdays and 11am-6pm AEST weekends.

Face to face counselling is available at most CanTeen offices, during normal business hours with scheduled after hour sessions also offered.

To speak with a CanTeen counsellor call 1800 835 932.

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**ROBOTS**

A cancer diagnosis can considerably disrupt a young person’s education. Adolescents may experience difficulties keeping up with their grades, maintaining friendships, and feel anxious about returning to school after treatment.

Providing a robot allows the young person to remotely connect with school when they are unable to attend and supports their education and connection to their peers during treatment. For more information, visit canteen.org.au/research/robots-project/
YOUTH LEADERSHIP

Empowering young people living with cancer to take up leadership builds resilience and can transform their experience into an opportunity to make a difference for others.

Through Youth Leadership at CanTeen, we provide meaningful opportunities for young people living with cancer to contribute according to their interest, experience and skill. CanTeen is proud to have young people providing direction and advice at all levels of the organisation, including the Board of Directors.

YOUTH CANCER SERVICES

The Youth Cancer Services (YCS), funded by the Australian Government and administered by CanTeen, support young people (15-25 years) diagnosed with cancer and provide age-appropriate, specialist medical, nursing and psychosocial support from diagnosis, throughout treatment and into survivorship. For more information visit youthcancer.com.au

YOUTH-FRIENDLY RESOURCES

CanTeen provides a wide range of free resources to help guide young people through the many challenges cancer brings - from how to talk to friends about cancer to what all the medical jargon means. They are available in hard copy (order online) as well as e-books or downloads from the CanTeen website canteen.org.au/resource
**INDIVIDUAL SUPPORT BY SPECIALLY TRAINED STAFF**

The young person's support needs and goals are identified through a collaborative assessment and review process between the key worker and the young person to create a tailored plan.

Examples of support include:

+ Linking and facilitating the young person’s engagement in CanTeen’s internal services such as programs, recreational days and counselling
+ The provision of information about cancer related issues
+ Advocacy and support in areas such as school/work
+ Referral to external services as appropriate – for example, mental health support, family and practical support.

**SUPPORT VIA LIVE MUSIC**

Created by Australian band Hilltop Hoods and now proudly led by CanTeen, **Side of Stage gives young people impacted by cancer free access to some of the country’s best live music gigs, festivals and experiences.** [sideofstage.org.au](http://sideofstage.org.au)

**OVERNIGHT AND ONE-DAY PROGRAMS**

These programs enable young people to make new friends, develop skills to cope with cancer and have some much needed fun too.

CanTeen offers a variety of programs that cater specifically to the young person's cancer experience, including bereavement support.

The next page provides an overview of CanTeen's program options.
All our programs are free for young people to attend and aim to:

+ Build supportive relationships with others
+ Reduce the sense of isolation
+ Provide quality respite and recreation
+ Develop effective coping skills and strategies

**DAY EVENTS**

+ Skill-based learning
  Careers/vocational workshops, cooking classes, self-care workshops

+ Recreation & Respite
  Bowling nights, laser tag, movie nights, outdoor experiences (e.g., Surfing, rock-climbing)

+ Opportunities for connection
  Group outings (e.g., local events and cafes), ‘drop in nights’ at local CanTeen offices

**SOCIAL / RECREATIONAL RETREATS**

+ Summer & Winter Retreats
  Destination based respite programs that give young people (18+) from across Australia the chance to have a unique experience while sharing their stories and connecting with others in a similar situation.

+ Adventure
  Whether it’s hiking through the wilderness or learning to sail, our 3-day Adventure Programs enable young people (under and over 18) to get out into nature, form new bonds and challenge themselves.
FOR YOUNG PEOPLE WITH A PARENT WITH CANCER

+ **Truce**
Caters to young people aged 14-22 with a parent or caregiver who has been diagnosed or relapsed with cancer in the past five years. This weekly group program (7 weeks) enables young people to come together and connect over their shared experiences while developing important coping and communications skills.

FOR BEREAVED YOUNG PEOPLE

+ **Sensing our Grief**
A weekly group program (6 weeks) for young people aged 12-25 who have lost a family member to cancer. It allows young people to explore and express their grief, share experiences and learn from others who have faced a significant loss.

+ **Good Grief Program**
This 3-day retreat is offered to young people in both under and over 18 cohorts who are bereaved following the death of a parent or sibling to cancer. This program helps young people work through their grief and form connections with other bereaved young people.

FOR CANCER SURVIVORS

+ **Recapture Life**
A weekly online group for young cancer survivors aged 15-25 that aims to build resilience and help young people find their ‘new normal’ after cancer. Topics include: common experiences of young people during and after treatment, reconnecting with friends after cancer, dealing with tricky thoughts, getting back into hobbies and how to work towards future goals when cancer gets in the way.

+ **Places You’ll Go Program**
A 3-day program that brings together young people aged 12-17 from around Australia who are cancer survivors. Young people learn about how to deal with key survivorship issues such as identity, coping with difficult emotions and communicating about cancer.

FOR CANCER IMPACTED BY CANCER

+ **Big Picture Art Therapy**
Our weekly art therapy group allows young people (12-25 years) to creatively express their emotions. It aims to increase their knowledge of effective, Acceptance and Commitment Therapy (ACT) based coping strategies (psychological and practical).

+ **EXPLORE**
Aims to develop the foundational emotional skills young people need to face the challenges cancer brings. This 3-day program for young people aged 12 to 17 years is based upon the principles of Acceptance and Commitment Therapy (ACT) and is guided by a positive psychology approach, recognising resilience and focusing on strengths, interests, abilities, knowledge, and capacities.

+ **PEER**
A 3-day program for young people aged 12-17 years that provides recreational opportunities so that young people can escape from the daily experience of cancer, while also addressing their unique needs and building coping and resilience skills.
Research shows that when parents cope better with cancer and communicate openly, their children are less likely to experience distress and anxiety.

In response, CanTeen services now extend to parents impacted by cancer to support them through the parenting challenges that cancer can bring.

Our parent support services include:

**Canteen Connect for Parents**
An online community where parents impacted by cancer can connect with each other, find evidence-based resources and chat to a counsellor.

[parents.canteenconnect.org.au](parents.canteenconnect.org.au)

**Parenting Through Cancer**
This resource provides practical advice and tips to parents impacted by cancer on communicating and supporting their children through cancer. Available in print and online.

[canteen.org.au/resource](canteen.org.au/resource)

**Locally Based In-Person Counselling**
Concentrates on the parenting challenges cancer can bring and is focused on skills building and communication in the family. For more information, please contact your local CanTeen office.

See page 17 for contact numbers.
“I got a call back for a routine mammogram. That’s how it all started, back on Tuesday 31 March, 2015. That was the day I was told it was 90 per cent likely I had breast cancer. Two days later, it was confirmed.

My children Sally, Michael and Liam were 14, 12 and nine at the time. It affected them all differently.

“After my first chemo session when all my children first realised that their parents are fragile – we’re not invincible.”

I collapsed from dehydration, but with my eyes open, so they all thought I was dead. I had to go back to the [Chris O’Brien] Lifehouse to be rehydrated, and it was the lovely nurse there, Keith, who told us about CanTeen.

I strongly recommend getting involved with CanTeen to any family battling cancer. Because the thing is, when you’re diagnosed with cancer, it’s as if everyone around you starts talking in a different language. But CanTeen is like a translation service for teenagers – it allows them to communicate at their own level in language that is age appropriate and applicable to them.

As for now? I feel well. I am braver. And I am fearless. Because you know, what’s the worst that could happen in this life? The worst did happen, and I got through it.”

Mary
mother of 3
CanTeen is here to help you and the wider school community support students who are affected by cancer. We can:

1. **PROVIDE IN-SCHOOL CANCER AWARENESS EDUCATION**
   CanTeen has developed a free, interactive school based program When Cancer Comes Along to educate young people about:
   - What cancer is
   - Cancer warning signs
   - Cancer risk factors
   - How to support a friend who is impacted by cancer

   The program aligns with the national curriculum for health and physical education. To host the program at your school or find out more visit [canteen.org.au/schoolawareness](http://canteen.org.au/schoolawareness)

2. **SEND FREE RESOURCES**
   CanTeen provides resources to help friends and classmates better understand what a young person goes through when cancer crashes into their world and how they can help.

   See our full range of books and order free copies at [canteen.org.au/resource](http://canteen.org.au/resource)

3. **PROVIDE TAILORED, INDIVIDUAL SUPPORT TO YOUR STUDENTS IMPACTED BY CANCER**
   If a student needs more help dealing with their cancer experience, you can connect them with a CanTeen social worker who will develop an individually tailored care plan with them.

   You can refer your student to CanTeen through our quick online form at [canteen.org.au/refer](http://canteen.org.au/refer) or call 1800 835 932.

   You can also encourage the young person to join CanTeen’s online community to connect to other young people impacted by cancer and find out more about CanTeen events and services [canteenconnect.org.au](http://canteenconnect.org.au)
CanTeen has 11 offices nationally, covering every state and territory. Our local offices are here to support you and your students. Please contact via the below numbers, or visit canteen.org.au for further information and support.

- Sydney: (02) 9007 0190
- Newcastle: (02) 4906 1122
- Canberra: (02) 6101 2207
- Brisbane: (07) 3108 1444
- Townsville: (07) 4700 5636
- Melbourne: (03) 9912 4221
- Adelaide: (08) 8122 6492
- Hobart: (03) 6200 5556
- Launceston: (03) 6135 4310
- Perth: (08) 6260 7771
- Darwin: (08) 8985 2013
FUNDRAISING IN SCHOOLS FOR CANTEEN

Join us to help make sure that no young person goes through their cancer journey alone. Our annual fundraiser National Bandanna Day, is held on the last Friday in October each year.

Get your school involved and find out more canteen.org.au/bandanna-day

The group workshops were amazing, I could open up knowing that the people around me would understand what I was going through. I just had a really good time and really want to go on more overnight programs because talking about my experience has really helped release some of the emotional pressure. - Explore program attendee.
It's absolutely amazing to meet people who just understand what it's like to have cancer. Whenever I'm on a Canteen program, I feel like I'm with my family. Honestly, without Canteen, I don't know what I'd be doing right now.

- Jasmine, aged 16

REFERENCES

*Australian Institute of Health and Welfare (2011) Young Australians: their health and wellbeing 2011. Cat. no. PHE 140 Canberra: AIHW;


Patterson P, McDonald FEJ, White KJ, Walczak A, Butow PN (2017) Wiley. Psycho-Oncology: Levels of unmet needs and distress amongst adolescents and young adults (AYAs) impact by familial cancer.

**Australian Institute of Health and Welfare 2018. Cancer in adolescents and young adults in Australia. Cat. no. CAN 110. Canberra: AIHW.


^Patterson P, McDonald FEJ, White KJ, Walczak A, Butow PN (2017) Wiley. Psycho-Oncology: Levels of unmet needs and distress amongst adolescents and young adults (AYAs) impact by familial cancer.

HOW TO REFER A YOUNG PERSON TO CANTEEN

1. Get permission from young person/parent to provide us with their details
2. Fill in the easy, online form canteen.org.au/refer
3. Our qualified staff will get in touch with the young person/parent in 1-2 business days.