

GUIDE



PalliativeCare
TASMANIA

YOUNG CARERS

A guide for educators and those working with young carers





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**Please note that while this resource has been developed as a tool to assist educators, it is recognised that young people may talk to other staff/adults and is relevant as a tool for all.*

Who are young carers of the dying?

This guide is aimed at supporting young carers in secondary schools. It defines young carers as those people aged 11-18 years, who are acting in a caring role for someone who has been diagnosed as having a life-limiting illness for which there is no known cure (palliative). The young carer may also provide assistance, care, or support to other members of the family, such as younger children, or other people impacted. This role is done on a regular basis and tasks taken-on by the young carer are usually associated with those of an adult.

In addition to palliative conditions it is estimated in Australia that one in ten children have responsibility of a caring role in their home. There are two to three young carers in every classroom in Australia (Carers Australia 2015). The person receiving care can be a parent, sibling, or grandparent who has a condition that requires the need for constant care, support or supervision.

Most teachers over the course of their career, will interact with students who are young carers for someone who has been diagnosed as palliative, and with students who are grieving a death.



1/20 Australian children will experience the death of a parent.

9/10 Australia children will experience the death of a close family member or friend.



Carers Australia 2015

However, teacher preparation to deal with a grieving student is uncommon. Through consultations, teachers indicate better preparation and awareness of student needs would be beneficial to support them in interacting with students that are grieving and preparing for the death of a loved one. Being unsure what to say, often leads to them saying nothing and then they worry that they may appear disinterested instead.

The information in this resource aims to raise awareness of young carers and identifies what the role of a young carer can involve. This resource also covers how the event of losing a loved one can affect a young person and provides information on how to best support a young person. These young people require support as they transition from a young carer through the grieving process.



In Australia, one in ten children have responsibility of a caring role in their home. There are two to three young carers in every classroom in Australia.

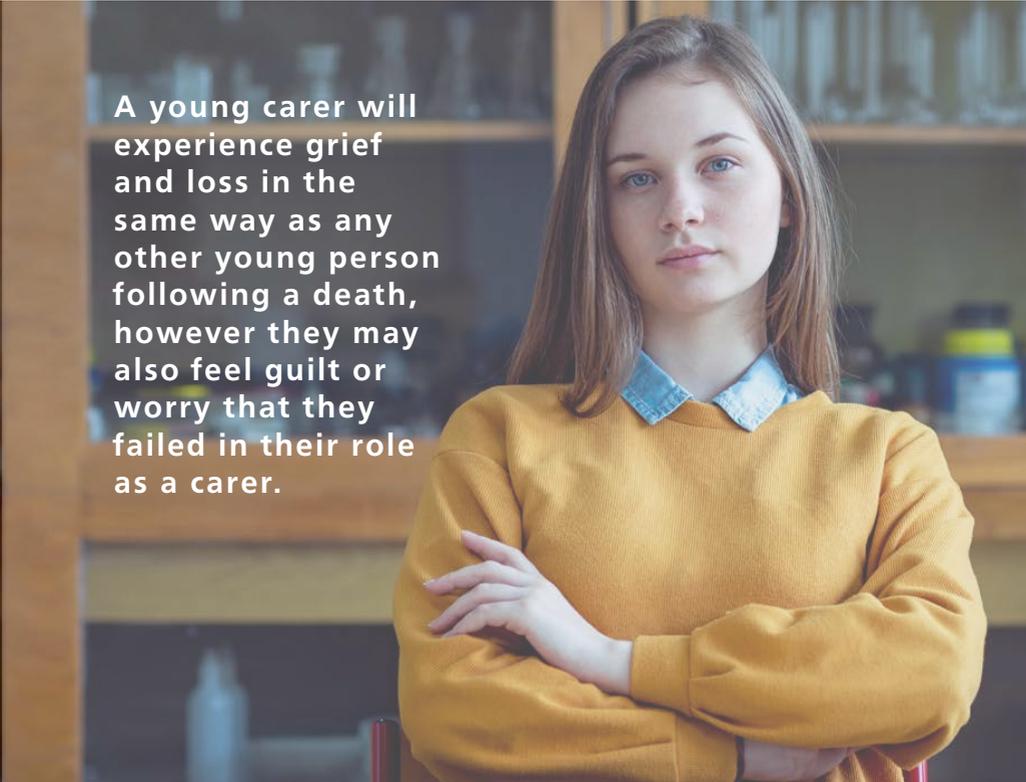
*Carers Australia
2015*

Young carers and loss

A young carer will experience grief and loss in the same way as any other young person following a death. However, they may also feel guilt or worry that they failed in their role as a carer. They may also experience a sense of loss related to the caring role.

When there has been a diagnosis of life-limiting illness, feelings will evolve as responsibilities and uncertainties increase and family life changes. As loved ones become more unwell and approach the end of life, these feelings intensify.

It is important to be aware of the potential of these feelings, and support accordingly by providing opportunities to talk and work through the emotions.



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Reactions to grief for young people

Young people express and process grief in a variety of ways depending on their age, personality, experience of loss, support systems available to them, and the context of the bereavement.

Young people may experience one or many of the following reactions to grief:

- Shock and/or disbelief.
- Deep sadness.
- Difficulty concentrating.
- Sense of numbness and feeling 'hollow'.
- Reluctance to go to school or to leave the house.
- Disruptive behaviours and frequent arguing or fighting.
- Non-compliance to requests.
- Hyperactivity.
- Increased need for attention.
- Feelings of abandonment, insecurity and safety concerns.
- Fear, guilt, relief, anger, rage, regret, confusion.
- Concerns about being treated differently.
- A change in values and questioning what is important to them.
- Preoccupation with death and wanting to know all details.
- A need for checking-in on surviving parents, siblings, extended family, and friends.
- Wanting to be physically close to 'safe' adults.
- Changes to sleep patterns and appetite.
- Headaches, tiredness, muscle aches and nausea.
- Anxiety about the future.

Adolescent developmental stages can affect the understanding of death and grief

Ages 11-14

- More aware of the finality of death and the impact a death will have on their own life.
- Starting to establish independence but a death, or preparing for one, can easily disrupt this and leave them feeling unsafe and become more reliant on family again.
- Ability to manage feelings may be disrupted and lead to mood swings or outbursts.
- Emotional releases are common – anger and distress. Leading to feeling scared - they need to know this is normal.
- Beginning to think about the long-term consequences of the loss.

Ages 14-18

- Peers are increasingly important as young people develop their ideas about who they are or want to be as an individual.
- Increased importance on the need to be accepted by others.
- Struggle to make long-term plans when someone is unwell or dies, often reflecting on the 'meaning of life'.
- Keeping busy and occupied can be an effective way of controlling emotions.
- Risk taking behaviours may increase during adolescence as boundaries are tested.
- Still in the emotional developmental stage and not properly equipped to manage adult responsibilities even if they believe they are.

A young carers responses may also include:

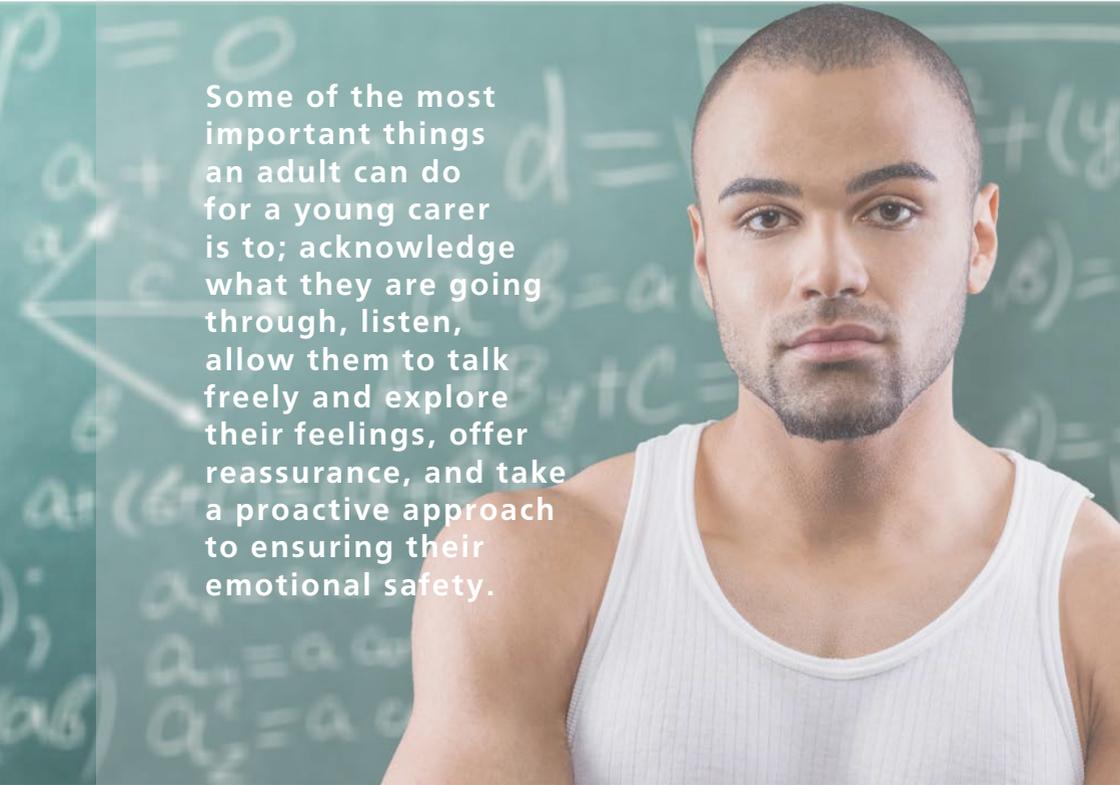
- Confusion or guilt about feeling relief from a stressful family situation coming to an end.
- Feelings of failure and guilt that they could have done more. Some young people may even have thoughts that they have caused the person's death.
- Guilt for the thoughts they may have had, i.e. anger or resentment about the role the young person have/had to take on.
- A sense of loss of the caring role they were filling.
- Fatigue due to lack of sleep and feelings of being on an 'emotional roller coaster'.
- Anger because of the changes that are occurring in their life.



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How to recognise a student carer who needs support

Many young people in caring roles are identified in the school environment and have supports in place. Schools may be notified on diagnosis, however, a young carer can get lost in the system and for numerous reasons, are often sometimes unwilling or unable to identify themselves as carers. Some young carers feel that they should not disclose their family's troubles, while others may find it hard to ask for help. Some young carers may fear the consequences of identifying themselves, and some may not even be aware that they are carers.



Some of the most important things an adult can do for a young carer is to; acknowledge what they are going through, listen, allow them to talk freely and explore their feelings, offer reassurance, and take a proactive approach to ensuring their emotional safety.

How to identify a young carer

Through their direct contact with students, educators may have the opportunity to identify young carers, and when additional supports may be needed for that young person.

It is essential to note that some of the behaviours listed below are not isolated to young carers and may be demonstrated by other young people at risk.

However, when a young person exhibits the following behaviours, one consideration could be, do they have caring responsibilities?

- Frequently late or miss days or even weeks of school for no obvious reason.
- Frequently tired and withdrawn.
- Difficulty joining in extracurricular activities.
- Often alone or a target for bullies (either because of the family circumstances or because they feel out of step with their peers).
- Appear more confident with adults than with their peers.
- Under-achieve or over-achieve.
- In class work ability is not demonstrated in homework.
- Demonstrate concern over the cared-for person or display over-sensitivity, especially about family members.
- Exhibit behavioural inconsistencies, e.g. is 'mature beyond their years' in the home environment, but expresses their frustration or stress at school.
- May have physical problems such as back pain from having to lift an adult.
- Rarely or never has lunch or lunch money.
- Parents do not attend school events.
- Display depression or anxiety.
- Demonstrate a sound understanding of illnesses and/or disabilities.
- Adverse to talking about home life.
- Financial difficulties.

Academic allowances for young carers and those grieving a death

Why offer academic allowances

- Often in grief there is a temporary decrease in learning ability.
- The student may be tired, not sleeping, and having difficulty concentrating.
- There may be disruptions to the home environment.

How to offer educational support

- Check in more frequently – are they keeping up with workload?
- Talk to the school wellbeing staff or counsellor, other educators, teachers and coaches for strategies.
- Do they need workload decreased or modified temporarily?
 - Would substituting major reports with shorter more manageable assignments help if student is feeling overwhelmed?
 - If the student is having trouble staying on task, consider a group project with an appropriate student match.

Managing triggers for a student returning to school after a death

Let the student know that triggers may occur at often unexpected or unexplainable times and having a preplanned safety plan can assist them in those moments.

Lessons (i.e. health education) that reference a similar type of illness or death may trigger a grief response in a student. Holidays often accentuate loss, therefore having a plan in place may assist in easing a student's mind to know that it's ok if these feelings happen to them. A young person is less likely to feel overwhelmed and remain in class and stay engaged when plans are in place.

A safety plan may simply include:

- Allowing the student to leave the room briefly if feeling upset or angry.
- Make a plan for where the young person can go within the school if they need to leave the classroom and who they can talk to.



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Building resilience in the school environment

Schools are great environments to help to prepare students for the uncertainties of life. Students learn to build resilience and develop the adaptability to cope with adversity and difficult situations that may arise at school or outside of school life.

Through lessons, books, training, community crises and personal or peer experiences, students and educators become aware that grief is healthy and normal. Students and educators can both learn that grief is a uniquely personal experience from which people can heal when given a supportive environment. It is acknowledged that there are difficulties in providing openness to the grief process in a school setting. Research states that those who advocated for accepting a child's grief and validate the process through listening, and that offering unconditional compassion, can have a profoundly positive effect. (O'Connor & Templeton, 2002)

The following recommendations were developed to assist with integrating the grief process across the entire school: (O'Connor & Templeton, 2002)

- See the ability to process grief as a necessary attribute throughout life.
- Use opportunities to recognise and reflect on losses with students.
- Be conscious and accepting of others' grief.
- Recognise the importance of "good-byes" within the school.
- Speak to individuals about death and loss.
- Be honest and share what is known, what is not known, and what is not able to be discussed and why.
- Avoid pity; be compassionate.
- Show emotion openly.
- Provide opportunities for the outlet of grief, for example journals, writing, painting, music.
- Maintain routines, rules and expectations.
- Remember losses.
- Support colleagues.

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O'Connor & Templeton, 2002



Death, bereavement and building resilience into the school curriculum

The UK organisation “Winston’s Wish” suggests the school curriculum allows for the opportunity to explore experiences and feelings associated with death and bereavement in such lessons as Health, Physical Education or through English Literature or Sciences. Within the Australian Curriculum, this integration of the topic throughout the eight key learning areas, would give educators and students an opportunity and dedicated time to talk about relationships, feelings and emotions. This would enable thinking about how to manage these in relation to family events and support building *personal and social capability* and potentially *intercultural understanding*. Through thoughtful planning discussions about life and death can assist to add insightful and relevant learning.

Providing such education in schools would likely promote resilience in young people around death, loss, ageing, dying and grief. Young people are now far more likely to be involved in the dying process of their relatives than previous generations. Therefore, they will need to be more resilient, compassionate and develop a positive, proactive approach to death.

Before going ahead with lessons, consider those who may be bereaved in the class and consult, with the bereaved young person or carer, if they wish to attend the lessons or if additional support may be needed. It may be useful to provide a summary of what will be covered in the lesson to prepare students. Lessons will also need to take into account religious and cultural beliefs of the class participants more broadly.

Please refer to the reference and resource list for further support for bereaved young carers and students.

Offering your support following a death

Often young carers do not want to receive special treatment and when they lose a parent or loved one after illness this can be especially true. However, some bereaved young people feel that schools should take their situation into account. This contributes to the difficult dilemma for teachers and those working with these young people, who can find themselves responding at the extremes:

- Inaction can be perceived as disinterest, a lack of awareness and/or an unwillingness to help by the adults, and this can leave the young person confused about what has happened and how to approach staff if they need assistance.
- Being overly concerned may cause embarrassment and self-consciousness, which may result in the student withdrawing from asking advice and seeking support or academic considerations.

What not to say/do

- Nothing that starts with ‘at least’ i.e. “at least they are no longer in any pain” or “at least you still have your father”.
- Don’t attempt to ‘cheer up’ a grieving young person.
- Don’t feel you must hide your own emotions.
- Don’t wait until you know the perfect thing to say.
- Don’t refuse to acknowledge the death.
- Avoid changing the subject when they mention the person who died.
- Don’t make any comments which imply blame or fault on anyone.
- Don’t say that you know how they feel.
- Don’t make judgements about the progress of their grief.
- Don’t tell them to suppress their emotions; do not tell them not to cry.

What to say/do

- Be genuine and authentic.
- You could say “sorry for your loss” – ask what they are feeling – how are they doing.
- Remember that nothing you say can make things better right now.
- Listen more than talk.
- Acknowledge the death and express your concern.
- Let them talk and express their feelings as much as they are able to.
- Be ‘present’ and available to properly listen with your full attention.
- Follow routine to maintain a sense of safety and comfort at school.
- Set limits to ensure a secure and safe environment for both this young person, and for all your other students.
- Recognise that grief has no time limit and varies from person to person.
- Practice ongoing support, past the initial first few months.
- Encourage peers to be a source of support.
- Provide advice and practical suggestions when invited to do so.

Cultural considerations

Cultural issues should be considered when supporting those dealing with death, or with grief and loss.

Bereavement, grief reactions and methods of coping are influenced by cultural factors and are neither universal nor uniform within any given ethnic group. While knowledge and understanding of all cultural groups is not possible, having an understanding of how culture orders a person’s perceptions, experiences and behaviours would help with transcultural care for indigenous, immigrant and refugee populations. (O’Connor & Templeton, 2002)

Educators could be guided by friends or family of bereaved students or those of the same culture on what may be appropriate and not appropriate. Take note of body language; how others are interacting with the student; and the language the student uses themselves (refer to multifaith resources listed at the back of this guide).



Resources available to increase understanding

Respite, help and advice:

carergateway.gov.au/tags/young-carers

Top 10 tips for students:

carergateway.gov.au/tips/student-tips

Helpful tips:

youngcarersnetwork.com.au/learn-some-helpful-tips

Young carer stories:

youngcarersnetwork.com.au/read-young-carer-stories

Learn about young carers:

youngcarersnetwork.com.au/learn-about-young-carers

Resources for teachers to support young carers:

youngcarersnetwork.com.au/i-am-a-teacher

New Zealand Institute of Wellbeing & Resilience:

nziwr.co.nz/

Understanding the dying process and key considerations for carers: *The Dying Process* by Palliative Care Australia

Supporting students through their faith:

spiritualhealth.org.au/multifaith-resources

References used in the development of this resource

Carers Australia - Young Carers Network

The Young Carers Network is a place for young carers to learn about support services, access resources and share their story and opinions. youngcarersnetwork.com.au/

Carer Gateway 1800 422 737

(Monday to Friday 8am to 5pm your local time)

Carer Gateway is a national service that provides practical information and advice; helps you to get the services and support you need; provides free counselling services over the phone; provides free coaching to help you in your role; and lets you connect with other carers through a community forum.

Recommended Tip Sheet:

carergateway.gov.au/tips/student-tips

Carers Australia 1800 422 737

Carers Australia provides support to family and friend carers across the nation. They provide recognition, support and advice to make sure that carers get the help that they need to fulfil their role as carers to the best potential.

Contact and connect with your regional office:

carersaustralia.com.au/work-and-care/contact-and-connect/

Kids Helpline 1800 55 1800

Kids Helpline is a free and private phone and online counselling service. Available 24/7 for young people aged 5 to 25 years old. Call 000 if life is in danger.

eheadspace 1800 650 890 or 1 on 1 chat or email via headspace.org.au/eheadspace/connect-with-a-clinician/

eheadspace is a national online and phone support service for 12–25 year olds, and their family and friends. It provides a safe, secure and anonymous place to talk to an experienced youth focused professional – whenever they need, wherever they are. Available 9am – 1am (AEST time) seven days a week. Call 000 if life is in danger.

Further resources

Lifeline

Is a phone and online crisis support service. You can contact Lifeline via 131 114

1 Crisis support chat now available between 7pm - midnight (*AEST time*) 7 days a week

2 Via text on 0477 131 114 (*available 6pm - midnight AEST, seven days a week*)

3 Using the 131 114 number, available 24/7 for everyone or call 000 if life is in danger

CanTeen Australia supports young people (aged 12-25 yrs) living with cancer. Member categories include siblings and offspring, as well as patients. Programs for siblings and offspring are targeted to meet the needs of young people dealing with caring roles, grief and loss, and in bereavement.
canteen.org.au/

Specific Assistance

The Young Carer Bursary Program supports young carers to continue with their education. The program offers a limited number of bursaries of up to \$3,000 each year. Young carers across Australia can apply from late July until early September: youngcarersnetwork.com.au/young-carer-bursary

Youth Law Australia (02) 9385 9588

Youth Law Australia is a community legal service that is dedicated to helping children and young people in Australia and their supporters to find a legal solution to their problems. Previously named the National Children's and Youth Law Centre and known as Lawstuff, they are Australia's only national, technology-based community legal service.

Companion Card Program

1800 009 501

The Companion Card Program enables carers of people with disability to attend participating venues or activities without incurring the cost of a second ticket for themselves. The program aims to support greater social inclusion for people with a disability and their carers.

Websites of interest

carersaustralia.com.au/about-carers/young-carers2/

carerstas.org/are-you-a-carer/young-carers/

childrenssociety.org.uk/sites/default/files/supporting-young-carers-and-their-families_0.pdf

dougy.org/grief-resources/how-to-help-a-grieving-teen/

eprints.qut.edu.au/1052/1/templeton.pdf

grief.org.au/uploads/uploads/Adolescents%20and%20Grief.pdf

O'Connor & Templeton, 2002. *Grief and Loss: Perspectives for School Personnel*, Published in: *Australian Journal of Guidance & Counseling*, 12(1) p97- 106

palliativecare.org.au/teachers-supporting-students-at-school

schoolcrisiscentre.org/resources/teacher-training-modules/

theeducationhub.org.nz/category/school-resources/

winstonswish.org/

youngcarersnetwork.com.au/



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