



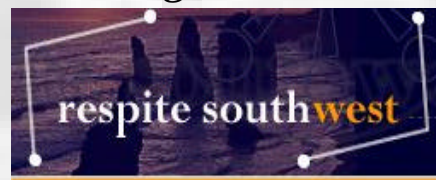
Young Carers



Young Carers Information Kit

For schools, Community Services & Health Agencies

Developed by the South West Respite Network
www.respitesouthwest.org.au



Overview

This kit has been prepared for professionals working with and supporting young people. It is designed to provide information and strategies to identify and assist young people who may be acting in a caring role.

Based upon The Australian Bureau of Statistics 1998 report “*Disability, Aging and Carers: Summary of Findings*”, there are 388,800 young people under 26 years of age in Australia (representing 6% of this population) providing care for family members or friends with a disability, mental illness, drug and alcohol issues, chronic condition or who are frail aged.

This means:

- 10% of all people in Australia aged between 15 – 25 years are carers
- 17% of all carers in Australia are under 26 years of age.

Within this group:

- 181,000 young carers in Australia are under 18 years of age
- 18,800 young people in Australia (5% of these carers) are primary carers, providing the main source of unpaid informal care for the person whom they support.

These figures are underestimates: many young carers do not identify themselves or are not formally recognised.

What do they do?

Young carers rarely have a choice about fulfilling their role; they often provide care because they are the only ones available. They are most likely to be providing care to their mother, often in a sole-parent household.

Young carers often spend most of their time thinking about the person they support or undertaking caring tasks. This can involve providing emotional support, assisting with mobility, administering medications, cooking and housework. Often they assist with more intimate tasks such as bathing and dressing which can be inappropriate for their age or relationship.

(Carers Australia, Young Carers in Australia – the facts)

This kit is based upon the “Young Carers Training Pack” developed by Carers New South Wales Inc. who have kindly given permission for the reproduction of their material that provides the vast majority of this publication. Thanks also to Julie Nankervis from Carers Victoria for her insightful input.

Tess and Tom....

Tess is seventeen and is studying for her VCE. She lives with her parents, three younger sisters and brother, Tom who is six. Tess' mother is a nurse.

Tess used to be a keen hockey player but had to give it up when her dad had his accident.

Her father worked as an architect. Then he had a car accident five years ago that left him with brain injuries.

He cannot really be left alone. He wanders and gets very distressed and anxious. During the week, he goes to a day centre for people with brain injuries. Her mother works shifts so Tess or one of the other children must often take responsibility at nights or at weekends.

It is particularly difficult when her father or one of the other children is sick—either Tess or her mother must take time off school or work.

Tess and the children help their mother with the housework, meals, gardening, shopping, paying bills and fetching medications. Sometimes when her mother is not available, Tess has to support her father with health professionals, as he can't always explain his needs.

Her mother must keep working, as the family really needs the money. It is not easy to find money for school excursions or for outings.

Tess is currently finding it very difficult to study because her father or the children interrupt her a lot. She also gets worried if her father has been too quiet.

Introduction

Young people have always been a part of family support systems. However recent research has highlighted the particularly stressful caring responsibilities of some young people. Tess is just one example of a young carer.

Young carers predominantly care for a relative with a chronic physical condition or a mental illness. They may help care for a relative with a disability. This relative may be a parent, a sibling or some other family member.

The term **Young Carers** will be used to identify young people under 26 with care responsibilities. The term recognises how many young carers see themselves. It shows how their families perceive them.

However, the use of the term should not be taken to imply that:

- These young people do all of the care of their relative
- All of their current responsibilities are appropriate.

Research has shown that children of any age may care for family members.

Caring adds extra pressure to a young person's life. It can significantly effect their educational performance. It certainly limits the time they have for leisure—to be with friends, to play sport, or to just have free time. There could also be negative effects on young persons employment performance.

Young people help with care because they love their relative and because they feel a responsibility. They, in turn, may need help, information or special consideration so they can concentrate on studies, work or care safely, or just have a break from care.

Young carers do not always get this support.

Supporting young carers is a valuable role for schools, tertiary education institutions, community services and health staff and for the general community.

LEARNING OUTCOMES

When you have worked through this kit, you will:

- **Know more** about young people who have caring responsibilities
- Be **aware** of identifying factors
- Be **alert** to their concerns
- Know **how to help** them

Robert...

Robert is eleven. He is in year five. He loves computer games.

He and his brother Matthew live with their father on a farm. Their father is a shearer. While his father does a lot of local work, sometimes he has to travel to other districts.

Matthew is eight and has several disabilities affecting his learning, speech, sight and motor skills. He has a short attention span and does not make friends easily. He attends the same school as Robert, although Matthew is still in Infants.

Robert and Matthew are close, although Robert gets annoyed when Matthew disrupts his computer games. Robert, at times, has to defend Matthew in the playground.

Although Dad leaves breakfast out on the table, Robert gets Matthew ready for school. He has to make sure that Matthew is dressed properly and always has to tie his shoelaces. He travels with him on the school bus. In the afternoons, Robert watches that Matthew is okay around the farm. He can get into difficulties if he is not watched.

When their father is away shearing, Robert and Matthew sometimes stay with their auntie in town.

Penny.....

Penny is fifteen, in year nine. She lives with her mother. Her mother has bouts of severe depression.

“Mum is really great most of the time. We really get on well. We like many of the same movies and some bands.

But sometimes Mum’s depression is really bad. She won’t get out of bed for days. I have to do everything. Organise for her mental health worker to visit. Get her medication from the pharmacist. Make sure she takes it. Do all the cooking and cleaning. Organise to get money from the bank. Fill out her pension forms. It gets really hard.

When she is like that, I can’t rely on her for anything.

I never know from day to day what to expect when I come home”.



Caring for a parent

Caring for a parent carries particular responsibilities and difficulties.

A young carer may care for a parent while the other parent is working. Sometimes a child may be doing much of the care, even where a partner or other adult lives in the household.

A young carer with a sole parent needing care may carry exceptional responsibilities. They may have to make decisions that no other child of their age has to make. They may have no one else to turn to for advice and support when their parents is particularly ill.

The disabilities or illness of the parent may be just one of the concerns in their life. Divorce or separation may divide their loyalties and affect their ability to choose, or not choose, caring.

If there are younger siblings, being responsible for and looking after brothers and sisters may also form a large part of their role.

In many families, caring for a parent strengthens family bonds. However, it does reverse some parent / child roles. This can sometimes upset parent / child relationships as well as parental authority.

Further, a child may be unable to negotiate caring limits with a parent.



Su Lin....

Su Lin is eleven. She is in year six. She is a keen soccer player.

She cares for her mother who has multiple sclerosis. Her mother usually now needs a wheelchair to get about, although on her infrequent good days she can move round using sticks.

Her father left three years ago.

In the morning, Su Lin helps her mother get out of bed into her wheelchair and then with her toileting, showering and dressing.

Su Lin and her mum share getting breakfast and preparing their lunches. Su Lin has to do any fine cutting or peeling. She also has to open jars and lift anything heavy or awkward.

In the afternoon, she goes straight home from school to see if her mother is okay and help her go to the toilet. Sometimes, if there are no errands, she can see her friends or kick a ball around.

On Saturdays, she helps with the shopping.

Home Care helps with the housekeeping and laundry.

Particularly for teachers

Teachers may notice the effects of caring without knowing the cause. Children may miss or be late for school, be inattentive or disruptive in class, fail to do homework or never go on excursions. Their parents may never attend parent / teacher evenings.

Often young carers do not talk about their situations. They don't want to stand out from their peers. Teachers can find out unexpectedly—say when a student is being queried about a late assignment.

Young carers report the following types of relationships with teachers:

- *My teachers don't know*
- *The teacher looked embarrassed, said "Okay don't be late next time" and never mentioned it again*
- *It didn't seem to matter to my teacher. He still kept on my case. He thought I was using it as an excuse. He didn't understand at all.*
- *One teacher was really great. I could talk to her. She stood up for me with another teacher.*
- *There was one teacher who wanted to arrange an award for me. I didn't want that!*
- *When things are really difficult, I can talk to my year adviser. He is great!*



Do you know of any young carers in your school?

How did you find out?

How did you react?

Were their caring responsibilities affecting their school performance?

In what ways did caring affect their health or well being?

Particularly for community service or health workers

Community services and health workers have been reported to offer different support depending upon the age, sex and cultural background of the young carer. They have been reported as not offering support once they realise a young carer is available or, withdrawing support once a young carer reaches a certain age. This action has been taken without considering the impact on the education and future of the young carer.

In some cases, community services and health support **has not complemented** family networks. Some young carers have identified that community service and health intervention has:

- Been intrusive
- Been frightening or intimidating
- Taken over roles the young carer wanted to continue
- Left them with roles from which they wanted relief.

Often services do not identify that a young person is acting in a caring role



Are there possibly young people with care responsibilities in families you work with?

Have you ever identified a young carer?

What types of care were they providing?

To whom?

How often?

How did you react?

What support did you offer?

How did you negotiate with the family and the young carer?

On reflection, are there any things you would change or do differently?

*Penny...
One worker said I should go
and live with my
grandmother. But I don't
want to do that. I love my
Mum and it's not all the time.
she needs me. I have to
help her.*

How does caring affect young people?

Caring has different effects on the lives of young people. These can be positive, negative, or a mixture of both.

Effects *may* include:

- **Strong family bonds** and pride in the young carer's maturity and responsibility
- Enhanced **sensitivity** and empathy for others in difficulties
- **Economic** difficulties because of the possibility of:
 - * a reduced earning capacity if a parent has a disability
 - * the additional costs associated with a long term illness or disability
 - * the young carer not having time for a full or part-time job
 - * restriction and disruptions to full-time work for post-school young carers
- **Restrictions** on a young person's friendships and social opportunities
- **Behavioral** changes. In their caring, young carers have to display a greater degree of maturity than many of their peers. Some report acting immaturely, as a release from their home responsibilities, when at school or away from home. Others express great frustration at the immaturity of their peers.
- **Educational** difficulties for school aged and tertiary students (lateness, absences, inability to study or do homework, tiredness, inability to be involved in excursions because they have no-one to take their care responsibilities or because their family cannot afford them).
- **Recreation and Leisure** opportunities restricted

How do young people react?

*Tess...
Not many of my friends
know about Dad. He does
act strange sometimes.*

*One time, a couple of kids
saw me with him. They
thought it was a great joke.*

Young carers may not necessarily see their situation as unusual. They may not necessarily feel that what they do is a significant imposition. For many, caring has always been a part of their life. Caring can form an integral part of their love for, and their relationship with, their relative.

However, it is not necessarily the case that a child is happily or willingly undertaking all of their caring roles. Some feel they have no choice—that they have to do it.

Those who are conscious of how different their lives are, remain anxious to minimise this. They don't want to be seen to be different by their peers. Some may be embarrassed by their situation. Others may be embarrassed about their relative's disability or problem. They may not be willing to talk about their situation. They may fear or in fact be being bullied.

Many young carers report very low self esteem and identify a range of sometimes conflicting feelings such as resentment, anger, guilt, grief and anxiety associated with their caring role

How do their families react?

*Su Lin's mother...
Recently I wasn't feeling well. I needed to go to the toilet and I couldn't hold on till Su Lin got home. I ended up in a terrible mess. I couldn't move. When Su Lin got back, she had to help clean me up and change my clothes. She hated it. I felt terrible. I hated her seeing me like that. I wish I didn't need her help. But there is nothing else that can be Done.*

This seems to be happening more often lately.

Generally, families recognise the significant contribution a young carer is making. In these cases, the young carer is acknowledged within the family and with others.

However, families may be unhappy about asking their children to do so much. They may also be concerned about the types of things they have to ask their children to do. They may feel guilty that their child is their carer. They may feel that if they are seen to be not coping, their family will be broken up.

Some families don't recognise or deny the level of support provided by their children

Where possible it is important for families and children to talk to each other and discuss what is involved in the caring role and what support is needed to maintain a positive relationship and to minimise the negative effects of caring on the young persons life.

How would you identify a young carer?

Particularly for teachers

Young carers may tell you about their situation. They may tell one of the ancillary staff. But they may not tell anyone.

You need to notice patterns:

- Late arrival
- Absences
- Tiredness, absent mindedness, distraction
- Repeated failure to complete work
- Inability to mix, or relate to peers
- Repeated inability to participate in extra curricular activities
- Parental non-involvement (e.g. at parent / teacher nights).

Obviously, these patterns may have other causes, but they indicate the need for further attention.

*Tess...
Sometimes I am just so tired
I can't concentrate.
Particularly when Mum is on
afternoon shift. Or if Dad
hasn't been sleeping. Some
mornings everything takes
so long to get organised, I
end up being late for school.
Or some days I just sleep
through the alarm.*

What should young carers have a right to expect?

Australia ratified the United Nations Convention on the Rights of the Child on 17 December 1990. Governments are expected to uphold these rights. Articles particularly relevant to young carers include a child's right to:

- Be protected **without discrimination** on the grounds of race, sex, religion, origin or disability of both the child or parents(s) (Article 2)
- Be a **primary consideration** in any legal or administration decision affecting the child (Article 3)
- **Not be separated** from their parents unless it is in the best interests of the child (Article 9)
- Have their **wishes** taken into account considering their age and maturity (Article 12)
- **Privacy** (Article 16)
- Appropriate **information** especially that which will protect their well-being and physical and mental health (Article 17)
- The highest attainable standards of **health** (Article 24)
- Benefit from **social security**, taking into account the circumstances and resources of the child and family (Article 26)
- An adequate standard of **living** (Article 27)
- **Education** (Article 28)
- **Rest, leisure, play and recreation** (Article 31)
- To be protected from engaging in work that constitutes a threat to their health, education or development (Article 32)

How should you react?

- Listen** to them
- Believe** them
- Acknowledge** their contributions
- Offer** them appropriate information, support and choices
- Offer** to link or refer to appropriate support
- Protect** their privacy and confidentiality
- Respect** their wishes
- Help** to identify the best person suited to providing support in their individual situation

These characteristics in a professional help establish a trusting relationship. Acting in this way will enable you to more readily and appropriately support young carers.

When a young carer does not want immediate help or does not know their options

Tess' year adviser...

Tess' behavior really changed about 5 years ago. She had previously been a good student. Then she got really difficult in class. And in the playground.

Although we had previously had a good relationship, she wouldn't talk to me.

When I spoke to her mother, I found out what had happened and that some of the kids were teasing her. It was difficult to hear about how much she had to do at home.

Particularly for teachers

If a student has care responsibilities, it is important for year advisers or school welfare support staff to ask whether they require any help. The student may not want to discuss the situation further. The student may not want help. The situation may only be short term. They may not know what support is available.

Give the young carer confidence that support is available, within the school:

- to assist the young carer with school needs
- to find other appropriate support

Give them information.

Leave the door open for a young carer to get further information or support at a later stage.

What can you offer?

*Su Lin...
Our parent / teacher
evenings are always held
in a room on the second
floor*

There are many possible ways of helping a young carer in your school. You could:

- Offer to be available to talk with the young carer about their needs, problems and concerns
- Offer young carers flexibility in meeting educational requirements; particularly those who have to spend time away from school or who have considerable care responsibilities in non-school hours
- Consider special access requirements when arranging parent/teacher sessions (consider transport requirements for families to get to meetings)
- Seek assistance from your principal or student welfare support staff and from the school counselor or the child's year adviser, if in a high school
- Utilise the school counseling system (ensuring that other students are not aware it is being used)
- School nurses can provide a non stigmatising access point for students seeking help
- Link the carer with carers' networks
(via Carerlink 1800 806 093)
- Tell them about the Kids Help Line (1800 55 1800)—free call)
- Raise the issue of engaging with family to raise and discuss their issues
- Transfer appropriate information, with the parent or student's consent, should the child change schools.

What can community services and health agencies offer?

Among other things, community services and health agencies can help with:

- Respite - having a break
- Information about the disability or illness and how to care
- Information about special activities and services for young carers
- Equipment and home modifications to make caring easier and safer
- Cleaning, housekeeping, meals, gardening, transport
- Showering, bathing, dressing and toileting
- Counseling
- Referral to specialist staff or support groups
- Information about other support options (e.g. legal or financial advice, housing etc).

Centrelink can provide advice about eligibility for Austudy, Abstudy , Carer Payment and Carer Allowance.

Your local Carerlink 1800 806 093 or Commonwealth Carer Respite Centre 55 618 150 can provide further information on all the above.

Support should be offered to ensure that young carers' caring responsibilities do not significantly and negatively affect their:

- Family relationships
- Health
- Friendships
- Personal development
- Sport and leisure activities
- Other aspects of their well being

They may need additional support or respite during, or in the lead up to, examinations and throughout the VCE years.

They will need special support when the person for whom they care:

- Has family conflicts
- Has unstable health
- Is particularly sick
- Is hospitalised,

Or if the person is dying or dies.

*Penny...
Sometimes they won't listen
to me because I am just a
kid. But I know Mum best.*

*It can be difficult sorting out
her pension with Social
security when she is sick.
Or sometimes she goes out
and spends all our money. I
then have to go to St Vincent de
Paul for help.*

*Organising Mum's drugs
used to be a real problem.
But I've now found a
Pharmacist who tells me
about how the drugs work
and puts them in a special
pack for Mum.*

- Ensure you **validate** the young carer's experience
- Ensure you **value** the young carer's contribution to caring
- Assist the parent(s) to **involve** the young carer in planning and decision making
- Recognise any **authority** given to the young carer by the parent or person for whom they care. This may include their right to speak for or negotiate on behalf of the person for whom they care.
- Offer appropriate **information, support and technological assistance** to ease the physical and emotional stress loads
- Refer** the carer to specialist staff or support groups, as appropriate
- Consider communication and physical **accessibility** issues when negotiating and developing support options - this can include issues around physical distance
- Offer **choice**
- Reinforce the right of the family and the young carer to **reject** support or to **complain**
- They may need **financial** assistance. Consult Centrelink about eligibility for Austudy, Abstudy or the Carer Payment

Complex and exceptional cases

Consider **cross agency co-ordination** and use of a **care co-ordinator** or case manager for complex situations. Contact Carerlink for more information. Phone 1800 806 093

In very exceptional situations, reference may have to be made to **child protection** guidelines.



What can you do to be flexible and responsive to the needs of young carers?

What networking opportunities can you offer the young person to assist them to deal with their situation?

What support options can other agencies in your community offer?

What issues do you think would arise in supporting Tess, Tom, Su Lin, Robert, Penny and Jacob?

Do you think you treat young carers differently because of their age, sex or culture? When is this inappropriate?

What do you think are the health, safety and emotional issues associated with a young person undertaking personal care?

How do you negotiate differences between the aspirations and needs of a carer and the person for whom they care?

Other services available

There are many other services available to support carers of older people, persons with mental illness and those with disabilities including:

- Respite
- Carer Support
- Advocacy
- Information Services
- Transport
- Alcohol, Drug & Gambling Services
- Health Services
- Support Groups
- Counseling Services
- Employment, Education & Training Services
- Financial & Legal Services
- Housing Services

For further information

Please contact:

- ***CarerLink 1800 806 093***
- ***Commonwealth Carer Respite Centre
Barwon/South West 1800 059 059
or (03) 5561 8150***
- ***Carers Victoria 1800 242 636***