



# Young Caring: approach with care

*"I feel very proud of Mum not giving up, and sad and angry that it's her and not me (she doesn't deserve it)... My friends have a rough idea of what I do but I don't feel I can talk to them about it... it's the emotional side of things that gets to me. I think I need someone to talk to, someone who can understand how I feel, and a good solid punching bag"*

Steven, 14years

**Y INTO  
AGED**

**ACT LEGISLATIVE**

**IG COMMITTEE**

**ON HEALTH**

**JUNE 2002**



## CONTENTS

PAGE:

---

<b>Introduction</b> .....	<b>3</b>
• Who or what is a young carer?	3
• How many young carers are there?	3
• What do they do?	3
• How does caring impact on their lives?	4
•     Physical	4
•     Mental Health	5-6
• Needs of Young Carers	7
• Recommendations	8

**This submission was written by Tim Moore, co-ordinator of CYCLOPS<sub>ACT</sub>. He can be contacted by phone (02) 6262 8892 or email [tim@cyclopsact.org](mailto:tim@cyclopsact.org) for further information.**

**CYCLOPS<sub>ACT</sub> is a service for young carers (young people who care for a parent or relative with an illness or disability) that provides supports and opportunities to lessen the negative impacts of caring and connects young people who care to mainstream opportunities.**

**CYCLOPS<sub>ACT</sub> is a service of Anglicare Canberra-Goulburn Youth and Family Services and is funded by the ACT Department of Education and Community Services.**

**CYCLOPS<sub>ACT</sub> is a member of the ACT Young Carers Network.**



## **YOUNG CARERS:**

### *Who or what is a young carer?*

Young carers have been defined as 'children and young people who are placed in a position of responsibility for the care of a sick, disabled, chronically, mentally, physically ill or frail relative in the home'.

"I usually get up at about 4:30am so that I can get Mum out of bed, wash her, take her to the toilet and get her dressed. Then I get my brothers up and get them ready for the day. I'm usually really tired at school and I'm always getting in trouble for not doing all my home-work. I just wish someone else could help me." (Samantha, 9years)

### *How many young carers are there?*

Within Australia, it has been estimated that some 388 800 young carers – young carers accounting for ten percent of Australia's children and youth population. 18 800 of those identified are the main providers of care (primary carers) to their family member (CA 2002:6), often solely responsible for the intimate care and support of the care recipient. Many identify as starting their caring as young as six though the majority of them are between 12 and 14 years of age. Half of all primary young cares are caring for a parent with another third caring for their own partner or child. If caring for a parent, it is more likely to be their mother and also likely to be in a sole-parent household – often sustaining them in a position of financial disadvantage.

### *What do they do?*

Young carers are responsible for providing health care treatment ranging from dressings through to catheter bags; emotional support and assistance in the maintenance of a healthy, organised household. Young carers' responsibilities range from cleaning and cooking through to more major tasks such as bathing, dressing and providing assistance with toileting etc to incapacitated family members. Some young carers caring for a family member with a mental health condition are also required to provide other types of support sometimes including restraint of suicidal relatives, and emotional and behavioural monitoring. Often providing primary care, young carers take on significant caring responsibilities.

### *How does caring impact on their lives?*



It is important to note that caring can be, when well managed, an incredibly positive experience for children and young people who are able to “care for” those they “care about” – many young carers report that their caring experience has developed their life skills, their feelings of connectedness, positive relationships in the families and a sense of purpose within their communities. Unfortunately, however, young carers are often unsupported and therefore responsible for inappropriate levels of care and / or types of care.

In these cases, care undertaken is that commonly assigned to adult parents or professional adults employed by the community. The work is often physically and emotionally demanding with negative impacts being sustained in the areas of physical health, emotional and mental well-being, social participation, relationships with peers and family, finances, education, employment, and transition into adulthood (Sweet 1998:6).

“I feel very proud of Mum not giving up, and sad and angry that it’s her and not me (she doesn’t deserve it)... My friends have a rough idea of what I do but I don’t feel I can talk to them about it... it’s the emotional side of things that gets to me. I think I need someone to talk to, someone who can understand how I feel, and a good solid punching bag” (Steven, 14years)

### *Physical:*

It is well documented the incidence of illness dramatically escalates within families that provide informal care. In a study of 678 elderly Californian residents, for example, it was discovered that spouses were 70 percent more likely to become ill during the first six months of providing care to a partner (Satariano, Minkler & Langhauser 1984). The investigators discovered in their study that the stress experienced by these spouses may be in part attributable to their carrying out personal and household tasks and that their illness was a psychosomatic response to this new-found role.

In a study conducted by Carers NSW it was found that 81% of young carers stated that caring had a negative impact on their health with just under half of these suggested that it had impacted ‘a lot’ (Matthey 2001:3). Though studies of such effects are limited within the area of child carers it has been clearly shown that children too are affected physically due to their caring role. Often less informed and thus confused about the condition of their



relative, writers such as Ell (1990) suggest that children too respond psychosomatically to the anxiety and fear surrounding the illness or condition of those for whom they care.

Due to the physical strain of working with an immobile parent or sibling, young carers who are working with physically disabled relatives also report a variety of physical ailments resulting from the caring role. Muscle strain, fatigue, and exhaustion are common ailments reported. Such injuries are directly caused in the general provision of the caring role.

In addition to these physical impacts, other aspects have been noted in young carer literature. The ABS 1998 Survey results showed, for example, that just under a quarter of primary carers under 25 years recognized that caring had impacted on their sleeping and that this had a detrimental impact on their daily activities.

### *Mental Health:*

As the incidence of physical conditions has shown to increase within caregiving families so has the incidence of emotional distress and psychological illness. In a study of families of cardiac patients, for example, it was discovered that wives were likely to be more frequently distressed than patients during acute hospitalisation (Mayou, Foster & Williamson in Ell & Northern 1990:69). High anxiety, depression, an illness has also been found among other members of the family (Ell & Northern 1990:42). A lack of control in medical events, lack of opportunities to express distress, lack of information and inadequate or poor social support have all shown to be triggers for such responses.

Informal interviews suggest that the most common trigger of distress within young carers was the fear that those they cared for might need them during their time away. Being children, young carers are also often restricted from access to information about their relative's condition and thus encounter immense confusion and frustration.

These concerns are quantified in a study of former young carers that found that 70% revealed long-term psychological effects.

Young carers too have reported anxiety, depression and illness as a result of emotional distress. Children of dialysis patients were found to be more likely to be depressed and have school problems and to exhibit latent aggressive



feelings toward the sick parent (Haber 1989:27). In a study of siblings of children with cancer, the siblings showed even more distress than the patients in the areas of perceived isolation and fear of expressing negative feelings (Ell & Garden 1990:72).

Due to their assuming adult responsibilities too early in life, compounded by limited or missed opportunities and social isolation, many young carers' overall psychosocial and emotional development are both impacted upon in both the short and long-term (Langer 1999:73).

Concerns for the future have also seen to be common and likewise detrimental to the mental health of young carers. This often relates to a lack of knowledge about their family members illness or disability or as the very real fear of their family member dying and leaving them alone.

Young carers also report as having low self-esteem as they experience a lack of understanding from their peers and can sometimes have limited friendships (ACTYCN 2000).

Finally, it has been shown that feelings of bitterness, anger, resentment and sometimes guilt or loss commonly persist into adulthood and that these feelings, if left unresolved, can have a huge impact on all aspects of life in the future.

All of these factors whether in combination or alone, can result in depression, emotional breakdown and mental ill-health in later life (Langer 1999:105).



### *Needs of Young Carers:*

The most fundamental need of young carers is the need for recognition within the community of their existence, their needs and their rights. To achieve this, young carers must be empowered and supported to ensure formal recognition, understanding and respect and that these are reflected within appropriate policy and service responses.

Carers Australia have identified the needs of young carers as also being the need for: appropriate information, support, access to appropriate, flexible and affordable services and the opportunity to enjoy their childhood and youth.

Becker and Aldridge suggest that there are a number of overriding principles for meeting young carers needs. These are, ensuring young carers:

- (a) are protected from having to take on inappropriate responsibilities that may be harmful to their general health and well-being; and*
- (b) Have the opportunity to a full range of choices, independence and participation in society.*

### **CYCLOPS<sub>ACT</sub> asserts that:**

- Young carers need to be recognized.
- They need to be supported in mainstream and alternative settings.
- They need to be provided information about illness and disability and given child-friendly advice on how to best support their family member.
- They need opportunities to create networks of support and re-connect with community.
- They need flexible, innovative and holistic services – responding to both their needs and the needs of their families.



## **KEY RECOMMENDATIONS**

**It has been shown that the negative impacts of young caring proportionately correspond to the lack of services available to assist family members. It is thus imperative:**

- **That the ACT Department of health increase funding for in home respite services to allow young carers to attend activities that promote their social development and emotional wellbeing, and provide more access to transport services.**
- **That disability, health and community services recognize the impacts of caring on family members, of young carers in particular, and adopt whole-of-family responses to service delivery.**
- **That health and disability services develop strategies for the identification of young carers.**
- **That young carers are recognized as a priority for the delivery of mainstream health services**
- **That support programs and the availability of community services to be better publicised in schools and other places young people access to enable students to access support and information without having to identify as "at risk".**
- **That the Department of Education and Community Services and the Department of Health co-fund the Young Carers Network in order to ensure the on-going support and advocacy role this network performs.**