

Access and Inclusion:

Carers in Higher Education



Prepared by the Students' Representative
Council Disabilities & Carers Collective 2013

Contents

Introduction

Carers Australia	3
Disabilities & Carers Collective	3

Who are Carers?

Definition	4
Why do they care?	4
Three tips from carers	4
Caring in all forms	4

Carers & Higher Education

How caring affects students	6
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The Solution

How Universities can help	8
---------------------------------	---

Recommendations

Recognition and awareness	10
Access and inclusion	10

Personal Stories

Anna	5
Natalie	6
Mel	7
Yaz	7
Teena	8
Claire	9
Sally	11

Related Information & Sources

Related information & sources	11
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Introduction

Carers Australia

In Australia there are over 2.6 million people who care for family or friends with a disability, mental illness, chronic condition, terminal illness, alcohol or other drug issue or those who are frail aged. Over 360,000 of these are young carers between the ages of 15 and 25.

Many carers emphasise the positive side of caring. However, when inadequately supported, health and wellbeing can be adversely affected.

The impact of the caring role on participation in education can be significant. For example, young carers are less likely to have completed year 12 (or an equivalent) than their peers, and over 60 per cent of primary carers aged 15-24 years are not studying. Research shows that isolation and social exclusion are major issues for carers, and it is not uncommon for student carers in tertiary education to withdraw from their studies and from the social aspects of university life due to the demands of their caring role.

This can have a significant detrimental effect on carers' future opportunities, with those aged 20 to 24 years more likely than their peers to be unemployed or not in the labour force.

In order to complete their studies, students who are carers require: recognition and greater understanding of their caring role and its impact on undertaking study; flexibility to meet attendance and assessment requirements; and additional support to help balance their caring responsibilities with study commitments

Carers Australia warmly welcomes the initiative of the University of Sydney's Disabilities and Carers Collective in developing this booklet to raise the profile of student carers and to identify both the need and the means to better support them during their time at tertiary education.

Ara Cresswell

Chief Executive Officer
Carers Australia



Disabilities & Carers Collective

This year we set out to raise the profile of student carers and campaign for carers' right to equitable education. As primary carers, we see a serious deficiency in the support extended to carers who value their education but often lack the opportunity and flexibility necessary to realise their educational aspirations and fulfil their potential.

The data gathered from our Student Carers Survey conducted this year reflects how many carers have substantial difficulty balancing their study and care commitments, particularly at times when their care giving demands are intensified. While many Australian universities recognise and support staff needs as carers, there is a consistent lack of formal acknowledgement and

virtually no explicit policies addressing unique needs of student carers.

We have put together this booklet to bring student carers' issues to the fore so that decision-makers may become aware of what it means to be a student who cares and how policy can powerfully affect carers' capacity to move forward beyond the caring role through higher education.

Sarah Chuah & Jasmin Camdzic

Disabilities Officers 2013,
University of Sydney SRC,
Disabilities & Carers Collective.



Who are Carers?

Definition

The term 'Carer' refers to anyone who provides ongoing (or likely to be ongoing, for at least six months) informal support, including help or supervision, to persons with disabilities, long term conditions, or older people.¹ Examples of care may include domestic, financial, practical or medical management, personal care and emotional support.

Caring duties may be shared - this impacts whether a person is the primary or secondary carer for an individual and may be carried out on a part-time or full-time basis.

Why do they care?

The most common reasons for informal care-giving are a lack of accessible and sufficient services that are affordable, as well as a sense of family obligation and expectations of responsibility.⁴

Caring in all forms

Caring roles exist across a diverse range of relationships. Although some forms of caring, such as that within the traditional family unit may be more socially acknowledged, caring responsibilities may also arise amongst indigenous people with kinship relations, those with extended family networks, and those otherwise outside traditional heterosexual couple units, such as those caring for friends.

Those in non-traditional caring roles may experience difficulty in having their caring roles recognised, and may face discrimination as carers when their complex situations are not understood.

Three Tips from Carers

1

Carers are, above all else, people and their role in society should be appreciated. Value the duties carers perform and don't belittle their contribution to their community, study, work or their family. There is no shame in being a carer unless their work is not valued and recognised.

2

When talking with us, be aware that the term "carer" is a label, and where possible use our given name or title and surname. For some carers, this label is seen as irrelevant or redundant, as significant caring commitments may be seen as inherent to their relationships with others.

3

We come from diverse backgrounds and perform many different roles apart from being a carer. Appreciate our individuality; recognise that we offer a wide range of experiences and have a varied range of talents. We are people first and foremost.

Key issues experienced by young carers include:⁵

- **Lack of recognition and awareness**
- **Barriers to engaging in education**
- **Mental health - reduced emotional and social wellbeing**



There are 2.6 million carers in Australia³



Anna* 26, Part time University of Sydney cares for her partner's mother

During my six years at university I have been the primary carer for my partner's mother through her treatment for bowel cancer, heart failure, kidney failure, tumours, persistent and acute leg ulcers and numerous aggressive infections.

These conditions mean that whilst attending classes and undertaking assessments, I must also supervise medication administration, carry out personal care needs such as bathing and household tasks including cooking, cleaning and shopping. As her health fluctuates I must also be present at medical appointments, and apply medical aid at times of increased need.

Accessing support during times when my care needs are intensified through my university's special consideration policy is difficult and impractical, because each time something happens (which is often) I must obtain a medical

certificate from doctors or submit a statutory declaration. In the past I have had great difficulty getting a doctor's certificate when it is not my own illness that is being attended to (or the main priority in critical situations), and finding a JP to witness a statutory declaration is an added stress because it is often time consuming when I am already short on time.

My caring duties take away time from studying and socialising, and really affect me psychologically. I find myself distracted, and frustrated, being unable to focus on learning material at crucial times. I believe that carers undertaking tertiary education should be fully acknowledged and supported in their efforts by their educational institution.

"Care-giving is rewarding at times... but contributes to the feeling of isolation from other students."

Carers' work allows persons with disabilities or long term illness to remain in their community, and older people to 'age in place'.²

1 Australian Bureau of Statistics (ABS) (2008) A profile of carers in Australia.

2 Commonwealth of Australia (2011) *National Carer Strategy*.

3 ABS (2009) *Survey of Disability, Ageing and Carers*.

4 Department of Families, Housing, Community Services and Indigenous Affairs (FaHCSIA) (2009) *Young carers in Australia: understanding the advantages and disadvantages of their care giving* (Social Policy Research Paper No. 38).

5 Cass, B, Brennan, D, Thomson, C, Hill, T, Purcal, C, Hamilton, M, and Adamson, E (2011) *Young carers: Social policy impacts of the caring responsibilities of children and young adults*.

* Name has been changed to maintain privacy



Carers and Higher Education

How caring affects students

Carers experience lower rates of education participation, success and attainment than non-carers.⁶

While caring can be a very positive and rewarding experience, care-giving responsibilities can also place substantial emotional stress and practical demands on the carer most, if not all of their time, restricting the amount of time that can be dedicated to study. This can also result in student carers withdrawing from social engagements, adding to the feeling of isolation and preventing the creation of a support network of peers.



Student carers share their stories...

Natalie*, 19, full-time, University of Sydney cares for her mother and grandmother

I provide care for my mother who was diagnosed with schizophrenia and bipolar disorder eight years ago, and for my grandmother who has dementia and also lives with us. Mum has been unable to work the past five years and struggles with motivation to do things most days.

I often find myself doing the majority of domestic duties including the household cleaning, laundry and cooking because my mother is unable to do these things well. I also help my mother organise her day, write shopping lists and decide what domestic duties need doing on any given day. In addition to this I manage my grandmother's appointments and accompany her to them when needed.

I don't consider myself a 'carer' as such - I'm just really fulfilling my duties as daughter and granddaughter, however providing this support takes a large emotional/psychological toll, especially around exam periods when I get very stressed, angry, and frustrated. At times I feel that I'm not reaching my full potential, but you learn to cope.

As I try to balance my care commitments with university, casual employment, and a social life, studying can become very stressful. The hardest times are when my mother is hospitalised.

Visiting my mother in hospital is distressing in itself, and especially difficult with the added burden of having to carry out absolutely every domestic duty during this time. Sometimes I miss lectures because of my family's needs but always try to catch up at a later date.

"I believe my university education is essential to my future and will lead me to be able to assist my family in more ways."

I think a formalised adjustment system should assist carers with more flexible attendance arrangements. I believe all lectures should be recorded for the times when it's simply too hard to get to class, and more subjects' content should be available online.

I believe these formal adjustments would be an excellent way to acknowledge all the people out there who are carers, whose studies often come second to caring for another person, and would also be a great way for them to get support, if they need it.

⁶ Cass, B, Brennan, D, Thomson, C, Hill, T, Purcal, C, Hamilton, M, and Adamson, E. (2011) *Young carers: Social policy impacts of the caring responsibilities of children and young adults*.

* Name has been changed to maintain privacy

Limited education and employment opportunity resulting from one's caring responsibilities means that many carers must rely on income support after they cease their caring role.⁷

Mel, 26, part-time, University of Sydney cares for her mum

I care for my mum full-time whilst also completing a postgrad research degree, part-time. My mum has a rare autoimmune disease that has recently caused her to go blind, lose feeling in her hands and feet, have recurrent infections, a colostomy, seizures, impaired memory and cognition.

Mum sometimes finds it hard to communicate with people and has poor balance causing her to fall a lot, which makes it hard for her to dress and bathe herself. With her loss of vision, she is also unable to get food, drinks and do her medication by herself. Mum's health often deteriorates quickly and dramatically, so we have many trips to the hospital and ICU. Because of this she needs someone with her all the time. Living as part of a busy family and with someone who needs 24 hour care means that I often have to miss meetings

and conferences and don't make adequate progress on my study.

"In the past I have had to suspend my degree and considered withdrawing many times as a result of my caring role."

Caring for someone who requires so much help and whose future is so uncertain takes a considerable emotional and physical toll, making it hard to concentrate on my studies. It also impacts on my ability to interact with my friends who are my support network.



Yaz, 40, part-time, University of Sydney cares for his disabled parents

I began providing care for my parents at 15 years of age when my father went blind from glaucoma - this was a traumatic time for my family with the added burden of losing our main source of income.

Completing high school was a struggle as my mother's health also began to fail and my caring duties increased. After a number of years I made the decision to enroll in university in order to improve the quality of life for both myself and my parents. I found myself relishing an environment that valued knowledge and critical thought, however during my degree, my mother's health issues became increasingly difficult to manage, and without adequate support, the responsibility fell upon me to provide essential medical care.

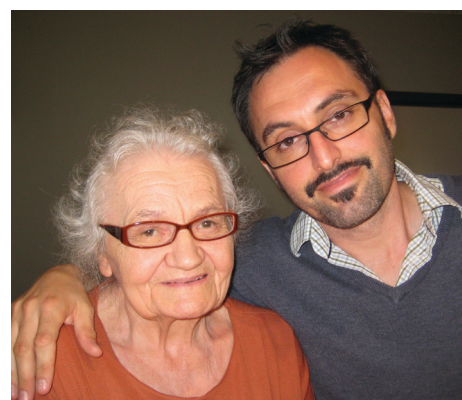
During this period I did not acknowledge my role as a 'carer' and despite my efforts was unable to access community support services. Around this time I was also diagnosed with the same disease that caused my father's blindness. Without any external support, my psychological health suffered and I finally withdrew from my degree.

After many years of struggle with my mother's recurrent illnesses I now acknowledge the significant contribution I have made to my parents' well-being and have managed to return to Sydney University.

Since re-enrolling, my father has developed dementia and I am battling my own difficulties with glaucoma, but despite this I am determined to complete my degree.

My experience caring for my parents has been difficult, but has shown me that I have the capability to navigate through trying circumstances and successfully accomplish what I set out to. It is my hope that other student carers out there need not struggle along as I have for many years, but instead find support from their communities and universities.

Carers need acknowledgement as well as moral and practical support so that they can reach their full potential, despite the difficult circumstances in which they find themselves.



"Due to the high level of care that was needed, I was unable to attend classes and manage my study workload but felt reluctant to seek help from teaching staff for fear of stigma and negative attitude."

⁷ FaHCSIA (2012) *Young carers in receipt of Carer Payment and Carer Allowance 2001 to 2006: characteristics, experiences and post-care outcomes* (Occasional Paper No. 47).

The Solution

How universities can support carers

Greater flexibility in course delivery is often needed for carers who find attending classes on campus, completing assignments and studying for exams overwhelming and monumental tasks when emotionally and physically exhausted from their care commitments.

University policies should accommodate the needs of carers by incorporating flexibility in terms of attendance requirements, assignment deadlines and the provision of out-of-school learning options, such as online lecture recordings or notetaking services.

Student carers feel they would greatly benefit from targeted university support including:

- Formal recognition
- Increased awareness of student carers' presence at university
- Flexible education arrangements
- Financial support such as scholarships or bursaries
- Social networks for carers on campus

“Student carers should be given academic support; someone to liaise with lecturers and supervisors on their behalf, especially in times of crisis, and to help with tutoring, time management and organisation.” Mel, part-time student carer



Teena, 60, part-time, Deakin University cares for her husband

I am a full-time carer for my husband who has cancer and cardiac failure. While at present this does not entail personal care it does require considerable emotional and supportive care. I am required to attend all medical appointments and to administer medication on a strict routine. Some days are good and I can achieve my study commitments while other days I achieve none. Studying off campus has allowed me to juggle all commitments and still achieve good marks. Although it is a juggle, the faculty I am with has always shown tolerance and support when things are bad which has assisted me in continuing to learn and develop.

It is invaluable to one's sanity and academic achievement that the role and duties of carers

are fully acknowledged and appreciated by all areas of the tertiary sector.

“Carers play a very unique role and it is important that the support and tolerance shown to me by my faculty, such as assignment extensions, be available to all student carers.”



Claire, 23, part-time, University of Wollongong cares for her best friend and father

I care for my best friend of 18 years who has cerebral palsy and uses a wheelchair, and my father who has bowel cancer. I started studying at UOW in 2009 following my HSC where I expected to study full-time for 3 years, graduate, and find work. This has not yet happened. Five years later I am still studying on a part-time basis due to my caring responsibilities.

My father is currently undergoing chemotherapy and radiotherapy to treat bowel cancer. He got sick very suddenly in June last year and underwent radical surgery followed by twelve months of aggressive therapies. Dad needed round-the-clock care for the six weeks following his operation which coincided with final exams. Since then his needs have fluctuated, typically increasing with chemotherapy treatment every three weeks. In addition to this, my best friend from kindergarten has cerebral palsy and relies heavily on me for community access.

Caring for my dad and best friend means that I often must miss classes and exams, submit assessments late, and struggle to achieve the results I am capable of. I managed to pass three of the four subjects I have attempted in the last year, however, most were bare passes in comparison to my general high distinction average.

As it is my father's illness which is affecting my

studies, I have found it impossible to obtain special adjustments, as the university's policy requires me to constantly provide medical certificates, which at the end of the day are too difficult to obtain given that I am spending all my time and energy looking after my dad. I considered deferring but decided not to as university was the only part of my life that was just for me. University helps me thrive on a personal level - I have a disability and mental health condition myself and need to stay focused in order to survive.

“A formalised adjustment system for carers would greatly benefit me.”

I currently have a reasonable adjustment document which allows me certain considerations when I am myself unwell - a similar system would be fantastic for carers attending University. With such a system, I could as a carer happily provide the initial documentation from my father's specialist, and then not need to worry about continually obtaining medical certificates throughout the session.

Recommendations

“ Only four per cent of primary young carers between the ages of 15 to 25 years remain in education compared to 23 per cent of young people in the same age group.” ⁸

Recognition and awareness

- 1 Formally recognise carers in university policy by encompassing a broad consideration of caring circumstances and addressing the impacts on study that can result from caring duties.
- 2 Facilitate greater recognition of student carers amongst staff and students by providing relevant information on the unique and valuable role carers play in society and the complex issues they may face in an education context.
- 3 Ensure teaching staff are appropriately resourced and informed about university policy for student carers to effectively encourage equitable access to education.
- 4 Gather demographic data upon enrolment to widely assess carers' involvement and continued engagement in higher education.

Access and Inclusion

Provide resources specific to carer needs to assist them to successfully negotiate their studies, including:

- 1 Flexible study arrangements to accommodate the often unpredictable and unique nature of care-giving.
- 2 Support services such as a caseworker/ liaison officer to mediate between carers and their lecturers and/or supervisors, to help with alternative study arrangements, time management and organisation.
- 3 Direct financial assistance and scholarships to assist with the financial issues faced by student carers.
- 4 Support networks and groups on campus to encourage carers' participation in university life, strengthen social support and target carer isolation.

⁸ Carers Australia, Young carers research project, 2002, p. 2.

Related information & sources

Carers Australia:

www.carersaustralia.com.au

State and Territory Carers Associations:

Carers ACT: www.carersact.org.au/

Carers NT: www.carersnt.asn.au/

Carers NSW: www.carersnsw.asn.au/

Carers QLD: www.carersqld.asn.au/

Carers SA: www.carers-sa.asn.au/

Carers TAS: www.carerstas.org/

Carers Victoria: www.carersvictoria.org.au/

Carers WA : www.carerswa.asn.au/

Related Sources

Commonwealth of Australia (2011) National Carer Strategy, Commonwealth of Australia, Canberra.

Sally, 60+, part-time, University of Sydney cares for her chronically ill daughter

For me, there is a grey line between being a carer and being a mother. My daughter developed severe Chronic Fatigue Syndrome (ME/CFS) about twelve years ago when she was fifteen. Although she has years of good health, last year she suffered a major relapse and is now living with us, virtually bed-bound.

ME/CFS is more than being tired all the time. There are constant muscle aches, “brain fog” and unrefreshing sleep. My daughter also has problems with anxiety and depression.

Caring for her affects my studies in several ways. As a carer and a mother I am constantly walking the line between support and interfering. Apart from the underlying concern about when she will

be able to lead a full life, there is the physical care; cooking (she has food sensitivities), checking that she has eaten/drunk enough, encouraging her to get out of bed, doing a crossword with her, taking her to appointments. Not to mention keeping up with the literature on CFS.

As a (very) mature student, I am fulfilling a dream, not establishing a career; I have “been there, done that”. And I am fortunate to have a partner to share (some of) the burden. But the impact of caring for a young adult with a disease which has no known cause or cure has greatly diminished my university experience.

For more information on ME/CFS, see www.mecfs.org.au





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