

# **Toolkit for Student Carers**

The University of Auckland



Equity Office - Te Ara Tautika

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# Toolkit for Student Carers at the University of Auckland

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## INTRODUCTION

Many students may at some time combine their study with primary or secondary Carer<sup>1</sup> roles. The “New Zealand Carers’ Strategy Action Plan for 2014 to 2018” notes that changes in demographics and medical advances will increase the need for support of a wide range of people. This includes the rapidly increasing number of older people as well as younger ones with high support needs who are surviving and living longer.

These responsibilities impact on both men and women students despite traditional expectations that women will take a lead in caregiving. Māori, Pacific and students whose cultural backgrounds emphasise supporting family may have particularly strong engagement in caregiving. The Carer’s role as an interpreter and communicator on behalf of the cared-for, to ensure mutual understanding, can be very important when there are cultural and language differences between the person being cared for, their wider family, and other health providers. The roles may be very enriching but balancing study and Carer commitments can be stressful especially when the person being cared for is in a fragile state of health.

The “New Zealand Carers’ Strategy Action Plan for 2014 to 2018” defines a Carer thus: “A Carer provides care for someone close to them (family or friend) who needs help with everyday living because of a health condition or disability. In many contexts, whānau, aiga and family adopt a collective caring role. Carers’ effort, understanding and compassion support people to live with dignity and participate more fully in society.”<sup>1</sup>

This toolkit is designed to provide practical information and resources to support students balancing a caring role with study at the University of Auckland. It also contains advice based on direct experience of Carers at the University of Auckland (their contributions are indented). The Equity Office – Te Ara Tautika is grateful for the candour and generosity of these staff and students who have contributed to this toolkit. Thanks also to Lesley MacKay of University Health and Counselling, Lauren Hitchin (Donnan) for advice on Young Carers and Denise Lazelle of WAVE for advice on support for student Carers.

If you are also employed at the University of Auckland, even in a part time capacity, please see [Toolkit for Staff Carers](#)

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<sup>1</sup> For the purposes of this toolkit and the policies and practices University of Auckland, the term “Carer” aligns with the definition as described above.

## **SECTION ONE:**

# **Combining a Carer role and studying at the University of Auckland**

Managing the responsibilities of studying with a Carer role can be both rewarding and stressful. This guide is designed to provide clear and accessible information to support students with Carer responsibilities.

A Carer role may:

- Emerge over time, eg, an older person or someone with an illness gradually becoming frailer and requiring additional support.
- Be sudden and unexpected, eg, the result of a stroke, accident or unexpected diagnosis<sup>4</sup>.
- Involve travelling to the place of care, visiting, emotional support, providing services, living away from own home to take up Carer role, or adjusting home to accommodate the needs of the person being cared for.
- Be short or long term and it is often difficult for health professionals to give an accurate prediction.
- End positively with the person recovering or, under more stressful circumstances, the person either dies or becomes too ill or disabled to be supported in the way initially undertaken by the Carer.

Sudden transitions into a Carer role often put a person under pressure. It is not unusual for Carers to have multiple Carer roles either simultaneously or successively.

Carers generally take on the role of informal Carer because they want to. But often they begin with limited understanding of where it might lead and how it might impact on their own health and lifestyle.

*Map out a week's work – how much time is spent on work, study, recreation, etc. It is helpful to understand what the week is like so that you can map commitments from the beginning. It is easy to be over-ambitious on how you spend your time. (Postgraduate diploma student whose teenager lives with a disability)*

The [Guide for Carers](#) includes a section on balancing your caring role with work and study which includes information about your rights.

<sup>4</sup> [Stages and Transitions in the Experience of Caring. CES Report](#)

## Support for Student Carers

The University of Auckland Counselling Service is a free and confidential service available to all students. It is staffed by a team of skilled and experienced registered counsellors and clinical psychologists. They have a Māori counsellor and a Pasifika counsellor who are available for Māori and Pacific students and an Asian counsellor who counsels in both Mandarin and Cantonese.

Counselling enables you to explore issues causing you concern, such as difficulties arising from Carer responsibilities which may be impacting on your studies. Together with the counsellor, you can clarify goals and develop new skills, insights and strategies to deal with problems you are currently facing.

At the City Campus, Student Health and Counselling are located on level 3, Student Commons Building, 2 Alfred St (Phone 373 7599 ext 87681). Counselling is also available at the Epsom Campus by phoning ext 48526; Grafton Campus ext 87681 and Tamaki Campus ext 87681 (Wednesdays).

If you are caring for another person there may be occasions when you cannot attend lectures, are unable to submit work on time, sit an examination or even need to withdraw from your studies.

*For students there is the risk that if they pull out of a course they can end up with a fail – it can have serious repercussions for an academic career. They should ring their academic adviser or lecturer if they are starting to have concerns about completing.*  
(Postgraduate diploma student whose teenager lives with a disability).

It is very important that your tutor, lecturer or supervisor is aware of the situation so that appropriate support can be provided. If you are a postgraduate student whose Carer responsibilities have made you temporarily unable to study it may be possible to suspend your enrolment, have an extension or consider changing from full to part-time study. For details check [The University of Auckland Calendar](#).

“Often, it is really important for staff to know what students are dealing with. If they know what is happening they will be very supportive.” (Counsellor)

PhD students see page 15 [Statute and Guidelines for the Degree of Doctor of Philosophy \(PhD\)](#).

If a crisis in Carer responsibilities has made it impossible for you to either prepare adequately, or sit a test or examination, it may be possible to apply for a compassionate pass. If your preparation for an examination is impaired, you need to see one of the University counsellors in the two weeks prior to the examination. If your performance is affected or if you are unable to sit an examination, it is necessary that you see a registered medical doctor or counsellor on the day of the examination.

If you find that it is impossible to continue with your full course of study through deterioration or a crisis in care giving, Student Counselling may be able to help with a late deletion of enrolment. This will not affect your grade point average – this means you will not get a “fail” or a “did not sit”.

Applications are made through [University Health and Counselling Services](#). Information is totally confidential.

Combining studying and caring may be challenging but studying can also be an enriching experience which provides the Carer with mental and social stimulation. One student Carer said studying “kept her sane”.

## **Support for young Carers**

National and international research shows that Young Carers rarely self-identify for a variety of [reasons](#). They also often do not respond to the term “Young Carer” until after the term has been explained to them, meaning that identification can be difficult.

Young Carers are children and young people (5 years – 25 years) who provide or intend to provide care, assistance or support to another family member. They carry out, often on a regular basis, significant and substantial caring tasks and assume a level of responsibility which would usually be associated with an adult. The person receiving care is often a parent but can be a sibling, grandparent or other relative who is disabled, has a chronic illness, mental health problem or other condition connected with a need for care, support or supervision.

A Young Carer may not be the main person who looks after their relative, but they usually have extra responsibilities at home compared to other people their age. Each young Carer helps their family in different ways.

## **Student Carer profile: Lauren Hitchen (Donnan)**

Lauren Hitchen (Donnan) is a doctoral student at the University researching the experiences of Young Carers. She describes herself as a Young Carer but notes, "I didn't even discover that I was one until last year."



This is a significant issue with Young Carers because their responsibilities can be invisible and even hidden from the Young Carers themselves. Lauren says that if the role is hidden it can be a barrier to accessing the services and resources that they need for support. Caring for her brother was something that she had done "naturally" since she was 14 years of age.

Caring responsibilities can not only impact on the Young Carer's education, social activities and working life, but it can also be challenging trying to explain these personal circumstances. At times this can lead to feelings of loneliness and isolation. However, Lauren sees huge benefits in taking on a Carer's role. It gives a greater maturity; it enhances family relationships, and it can be a very rewarding experience, providing there is the right support and services.

[To learn more watch Lauren's video.](#)

## **Advice for staff supporting students with caring responsibilities**

It is important to provide pro-active support when possible as students may be unaware of provisions available, or feel inhibited from requesting assistance. Māori and Pacific students may be particularly likely to have caring responsibilities due to cultural values of responsibility for wider extended family and because they are more likely to be mature-age students with older parents.

Requests for compassionate passes should be referred to Student Counselling Service. Postgraduate supervisors can advise students to apply for extensions, suspensions or transition from full to part-time study (and the reverse) through the Postgraduate Office.

*Some people do not feel comfortable about disclosing personal information but it is advisable to tell your lecturer what is happening. Student Counselling can help with this conversation (Counsellor).*

## **[A Guide for Carers, He Aratohu ma nga Kaitiaki](#)**

This resource provides practical help for Carers including financial help available from government and other agencies.

## SECTION TWO: Caring for the Carer

*People must give themselves permission to acknowledge their own needs. In an in-flight emergency you have to put your own oxygen mask on first before you can help anyone else. (Counsellor)*

Becoming a Carer is not usually a deliberate choice as it is in the sense of deciding to become a parent. Depending on the situation, it is not unusual for the person who is taking on a Carer responsibility to experience a range of emotions and feel stressed or daunted at the prospect. It is also difficult to predict what the short or longer term impact will be on the Carer's own health and lifestyle.

*Always have a back-up plan if things don't work. Pool people you can draw on – when you need specialist support there may not be many you can use.*  
(Postgraduate diploma student whose teenage lives with a disability)

Without good networks Carers, especially those who have taken longer term leave, can feel isolated and stressed. It is important that they know how to access support and services needed to undertake their role (refer to Section One) and also to maintain their own health and well-being.

*It is important to be particular and well organised even with normal things like cooking. It is also very important to be reflective and take time to think 'Is this right? – Is this working for us?' Otherwise quite quickly things can become overwhelming.*  
(Postgraduate diploma student whose teenage lives with a disability)

Take all the help that people offer and don't get caught up on reciprocity at this stage. Somehow, however hard it seems, don't forget to factor your own needs in – it's that classic thing of, 'If you fall over your caring ability is compromised.' Doing this is often as simple as letting your friends in. (Carer of teenage daughter with medical issues)

The following resources may provide support and information to assist the Carer gain support for themselves in managing the different stages of caring.

### **[Carers NZ](#)**

Established in the early 1990s by family Carers, Carers NZ is now a national registered charity which provides information, advice, learning and support for families with health and disability needs.

### **[A Guide for Carers, He Aratohu ma nga Kaitiaki](#)**

This is a useful resource which provides practical help for people caring for family or friends who are older or have ill health, a disability or a mental health, alcohol or other drug issue. This guide also provides a section on "taking care of yourself" which includes options for support.

**Caring for Carers.**

The booklet, *Care for the Carers*, was produced by the National Health Committee (NHC) who looked at what could make life easier or more difficult for those who care for people with disabilities. It describes what Carers do and what they need, suggests what is hindering them from having those needs met and provides some strategies for meeting those needs. (1998)

**Parent to Parent** is a support and information network for parents of children with special needs. Support is provided voluntarily by trained support parents who have a child with the same or similar needs.

## SECTION THREE: Transition back to study or employment

The Carer role may be on-going after graduation or may come to an end while you are studying. In some circumstances the outcome could be positive with the person making a recovery but sadly the Carer role will often cease because the health of the person being cared for has deteriorated to the extent they need more intensive care, or they have died. Even positive outcomes can require significant adjustments and coping with bereavement and grief requires special support.

*I was very tired after caring – it takes a long time to unwind - very exhausting; you can't remember things. (Student Carer for an elderly parent)*

The decision of when to resume study or find employment must be carefully considered. Carers have often been too preoccupied to think about how they will live after caring.

*When caring all you have is death before you. When you go to the supermarket one kilometre away it is a whole different world of lights and people. I used to say, 'When my dad dies I will go to the movies'. Still haven't been to the movies. (Student Carer for an elderly parent)*

Support for bereavement and adjustment into a new role can be provided through [Student Counselling](#). For an appointment phone 373 7599 ext. 87681 City campus or visit

*One of the problems of caregiving was that not earning an income meant that I had no wardrobe – all our outings had been quick ones where I had to keep an eye on my father –I could not let him out of my sight and so when it came to re-entering the workforce I had no work clothes. (Student Carer for an elderly parent)*

If entering the workforce is an option students are able to gain advice from the University's [Career Development and Employment Services](#) up to three years after graduation.

Independent career information advice and guidance is also provided by the Government Career Services. Free information and assistance is available online at [www.careers.govt.nz](http://www.careers.govt.nz) or by talking in confidence to a careers adviser - call 0800222733

[StudyLink](#) is a service provided by the Ministry of Social Development. It connects people with the information they need to make informed choices about student finances and other study-related issues, and provide financial support to students.

## **SECTION FOUR: General resources and types of Carer roles**

Caring for someone and balancing the service of care with study and other life responsibilities can be both rewarding and challenging. Equally, finding information about support services is often daunting especially for new Carers. This section provides a range of resources that may be of assistance to Carers generally and, where possible, for specific Carer roles.

Please note, that although the links are provided to organisations that provide support services, this does not imply that the University of Auckland formally endorses these organisations.

### **NZ Government action plans relating to Carers**

The following publications provide information related to the Government's Carer initiatives.

#### **Ministry for Social Development**

The "[New Zealand Carers' Strategy Action Plan for 2014 to 2018](#)" is part of a wider Government process to improve the choices of parents and other informal Carers so they can better balance their paid work, their caring responsibilities and other aspects of their life.

### **General Resources**

The following resources provide practical information for Carers and links to other key organisations.

#### **[A Guide for Carers, He Aratohu ma nga Kaitiaki](#)**

Practical help for people supporting family or friends who are older and need assistance, or who have a health condition, a disability or a mental health, alcohol or drug issue.

NB: A hard copy of this guide is available from the University's Equity Office.

#### **[Carers NZ](#)**

A national registered charity which provides information, advice, learning and support for families with health and disability needs. Or call 0800 777 797.

#### **[Ministry of Health](#)**

Includes a wide range of information on health topics and available support services.

### **Health and Disabilities Commissioner**

Includes the Code of Health and Disability Services Consumers' Rights

### **Families Commission**

Parenting section provides information on health and wellbeing and a parenting toolkit with links to services on a range of topics including mental health, special needs, and addiction.

### **Inland Revenue**

Outlines financial assistance available to disabled or ill people.

### **Skylight Trust**

Offers a wide range of services to support those facing tough times of change, loss, trauma and grief - whatever the cause, and whatever their age.

### **Order of St John**

Provides a number of relevant services such as the "Caring Caller" and Health Shuttles.

### **Auckland City Mission**

Auckland City Mission provides support to:

- People who are sick
- Isolated elderly
- People with mental illnesses
- People with addictions

They have a team of community social workers who can provide practical assistance and social work support to people in their own homes. By working with people where they live, social workers are able to identify appropriate solutions and review their effectiveness for the individual or family.

### **Support for Māori Carers**

Māori Carers experience many of the same issues as other Carers, including the need for information and financial support. Consideration of the needs of Māori for support requires an understanding of whānau relationships and wellbeing.

Services for both recipients and caregivers need to be culturally safe and readily accessible.

### **Ministry of Health – Māori Health**

The Government and the Ministry of Health have made it a key priority to reduce the health inequalities that affect Māori. If Māori are to live longer, have healthier lives, and fulfil their potential to participate in New Zealand society, then the factors that cause inequalities in health need to be addressed.

### **Te Puni Kōkiri**

Te Puni Kōkiri works within the public sector, and with Māori communities, to support Māori collective success at home and globally. Te Puni Kōkiri means a group moving

forward together. As the name implies, we seek to harness the collective talents of Māori to produce a stronger New Zealand.

### **Ohomairangi - Special Needs Early Intervention**

An early intervention service in the Auckland region for young children with special needs and their families. Particular focus on services for Māori.

### **Te Pou – o Te Whahaaro Nui**

Te Pou works to support and develop the mental health, addiction and disability workforces in New Zealand. Te Pou incorporates Disability Workforce Development and Matua Raki.

### **Māori Disability support services**

The Ministry of Health is one of a number of agencies providing support and services for disabled people. A number of Māori provider organisations offer services for Māori who have a disability, and have services specifically for Māori.

### **Support for Pacific Carers**

Support for Pacific Carers is likely to come from their extended family, aiga and churches. Pacific people will often be accompanied by family members when they attend medical appointments and will consult carefully with family about appropriate care. Cultural expectations related to age and gender can result in young people caring for older relatives.

### **Ministry of Health – Pacific Health**

The Ministry of Health is committed to working with the health and disability sector to improve Pacific peoples' health outcomes and reduce inequalities experienced by Pacific peoples.

### **LeVa**

Le Va takes a holistic perspective to flourishing and wellbeing - encompassing the physical, mental, social, environmental and spiritual dimensions of wellbeing. This is reflected in Le Va's diverse portfolio across Pacific mental health, addiction, disability, public health, general health, suicide prevention, education, as well as in sport and with local government.

### **Vaka Tautua**

Vaka Tautua is a charitable organisation that aims to help improve the health and wellbeing of Pacific people in New Zealand. They provide community support for older people, people living with disability and those needing support for mental health.

### **Fonua Ola**

Fonua Ola is a social services provider based in Auckland, predominantly supporting the local Pacific community in times of economic, social and cultural adversity. With a head office in Otahuhu, network members are based in Mount Albert, Otara, Glen Innes and Mangere. Services include social work, counselling, youth mentoring, parenting programmes and budgeting.

## Resources for specific Carer responsibilities

The following organisations provide support services and/or information related to caring for people in particular categories. Please note that the first section, "Caring for older people", includes information on resources that may equally apply to younger people with certain conditions, eg, dementia and stroke.

### 1. Caring for older people

An increasing proportion of caregiving is dedicated to older people, and this trend is predicted to continue as the Baby Boomer population ages. Māori, Pacific and students whose cultural backgrounds emphasise supporting family and the elderly may have particular responsibilities for older people.

While many older men and women are able to continue living independently there may be times where they require some level of caring, eg, through an accident or illness where periods of more intensive care are required. In other cases a gradual decline in health and wellbeing means that ongoing support will be required.

Support services and information related to caring for older people are available from a range of organisations. Terminology includes "adult dependent care" and "eldercare".

*The University is a place which can enhance the life of a Carer. It is about honouring your teachers and parents and completing your degree. (University of Auckland PHD student).*

Links to key organisations are provided below.

#### [Ministry of Health and Support Services](#)

- "Health of Older People in New Zealand"
- "Disability in NZ"

#### **Needs Assessment**

A Needs Assessment to identify a person's support needs and services required, is available for people over 65 years of age. Contact the Older Persons Health unit in [your local DHB](#).

#### [Guidelines for Aged Care of LGBT](#).

A resource kit to educate rest home workers about homophobia is getting the thumbs-up from the gay community. The package was created by the University of Auckland's School of Nursing in collaboration with a working group drawn from the aged care and gay sectors.

#### [Eldernet](#)

Eldernet undertakes to provide "timely, relevant, and comprehensive information about

services for older people in New Zealand. The Eldernet site includes a nationwide database directory and comprehensive information about community groups and organisations, home help services, rest homes, retirement villages, residential care, private hospitals, dementia care, public hospitals and other third age services for seniors”.

### **[Mental Health Commission](#)**

Provides information which may be relevant if you are caring for an older person who has a mental health issue (eg, dementia).

### **[Inland Revenue](#)**

Outlines financial assistance for those over 65 years.

### **[Age Concern](#)**

Age Concern produces publications that promote positive ageing and suggest ways for older people, caregivers and families to keep seniors safe and healthy.

### **[Access](#)**

A national healthcare organisation, specialising in home-based healthcare and support.

### **[Older People’s Health \(Auckland District Health Board\)](#)**

Older People's Health looks after the over 65-year-old population of Central Auckland and offers assessment, treatment and rehabilitation services. This website also provides information on common conditions.

### **[Alzheimers New Zealand](#)**

A support and advocacy organisation for people with dementia, their Carers, family, whānau and community.

## **2. Caring for someone with a disability**

Disability can impact on anyone at any time. It may be due to complications during the birth of a baby, diagnosed during childhood, acquired after an accident, caused by the natural and inevitable effects of ageing, or the result of illness or medical misadventure.

### **[Ministry of Health Funded Family Care](#)**

The Ministry of Health provides funding for some disabled people to pay a family member to provide personal care and household management.

*There will be people you meet along the path who are unjust. In the disability sector people need to advocate for themselves. Websites are great but it can be good to learn through a network of people. (Postgraduate diploma student whose teenager lives with a disability).*

### **[Weka](#)**

This website provides information for disabled people, their families, whānau and caregivers, health professionals and disability information providers. It includes key processes and points of contact for support, information and resources.

### **[CCS Disability Action, New Zealand](#)**

Provides information on the advocacy and support of children, youth, adults and their family and whānau.

## **3. Caring for someone with a mental health impairment**

Mental health illness is a term that refers to a group of illnesses that affect a person's mind. It is invisible but can affect how a person thinks, talks, feels and behaves towards others and themselves.

Current statistics show that one in four adult New Zealanders experience mental health or addiction problems.

Many young people also experience these problems and specialist support services are available to them and their family/ whānau. There is a wide range of mental health impairments, with depression and anxiety related illnesses among the most common. Other serious, but less common, mental illnesses include schizophrenia and bipolar disorder (Everyday people and mental illness Ministry of Health 2007).

[Caring for someone with a mental health impairment](#)

### **[Mental Health Foundation](#)**

This website includes resources and links to support groups.

### **[Mental Health Commission](#)**

Provides information on the different types of mental health services available, treatments, support, recovery and leaving Mental Health Services.

### **[Like Minds](#)**

"Like Minds, Like Mine" is a national, publicly-funded programme aimed at reducing the stigma and discrimination associated with mental illness.

This website provides information and resources on the programme, looks at who is involved and shows how you can contribute to creating a nation that truly values and includes people with mental illness.

### **[Supporting Families in Mental Illness New Zealand](#)**

(Formally Schizophrenia Fellowship New Zealand)

Supporting Families NZ has a network of branches throughout the country that provide information, education, support and training to the families/whānau of people experiencing mental illness.

### **[The Wharerātā Group](#)**

This an international network of Indigenous leaders working in mental health and

addictions, in which Indigenous peoples achieve and maintain their optimal health and wellbeing.

#### **[Eating Disorders Association of NZ](#)**

EDANZ is an incorporated society established to provide support and education for parents and caregivers of people with eating disorders. The society was established in September 2007 by a group of Auckland parents who all have children with eating disorders.

**[Student Counselling Services](#)** at the University of Auckland provides a range of online self-help resources which students can access including information on eating difficulties.

### **4. Caring for someone with an addiction**

Information and support services relating to addiction are often included as part of resources for those mental health issues. The following links are to information relating specifically to addiction.

#### **[Alcoholics Anonymous](#)**

Alcoholics Anonymous is a fellowship of men and women who share their experience, strength and hope with each other that they may solve their common problem and help others to recover from alcoholism.

**[Al-Anon](#)** Family Groups are a fellowship of relatives and friends of alcoholics who share their experience, strength, and hope, in order to solve their common problems with alcohol.

#### **[Drug Foundation](#)**

The NZ Drug Foundation takes the lead in Aotearoa New Zealand educating, advising and standing up for healthy approaches to alcohol and other drugs

#### **Families Commission Kōmihana ā whānau**

Download the report: "[Living with Addiction: exploring the issues for families](#)".

#### **National Helpline Numbers**

- Gambling Problem Helpline Service 0800 654 655
- Alcohol Drug Association 0800 787 797
- Alcoholics Anonymous 0800 229 6757
- Alcohol Hotline 0800 787 797

#### **[University of Auckland Counselling Services](#)**

This website offers a range of self-help resources which staff can access online including information on gambling and on alcohol and other drugs.

### **5. Caring for someone with medical issues**

Medical issues can occur for anyone at any time. They may be the result of genetics, illness, accident, or caused by the natural and inevitable effects of ageing. Medical issues may be short or long term or episodic and it is often difficult for health

professionals to give an accurate prediction of this.

*Friends' support included giving me vouchers for massages to help with my equilibrium and stress levels. They organised food rosters while my daughter was in intensive care and the period following that and I had to learn to accept this and gracefully say thank you. (Carer of a child with medical issues).*

Information and support services are generally found under the specific medical category concerned. The following links are to organisations that provide information across a range of categories.

### **[The Ministry of Health](#)**

Provides a range of information including Health Topics AZ.

### **[The Cancer Society Auckland](#)**

Offers a range of free support services for people affected by cancer, their family/whānau and friends.

### **[New Zealand Stroke Foundation](#)**

Provides help and support to people and their families/whānau affected by stroke.

### **[Parkinson's New Zealand](#)**

Provides education, information and support for all people with Parkinson's, their caregivers, friends and families.

### **[Community Partners](#)**

Community Partners works together with The Centre for Brain Research in The University of Auckland's Faculty of Medical Health Sciences to provide a network of charities and support groups to help people living with neurological disease. Specific information and links to relevant organisations is provided on:

- Aphasia
- Dementia
- Epilepsy
- Huntington's disease
- Motor Neurone Disease
- Multiple Sclerosis
- Muscular Dystrophies
- Parkinsonism
- Stroke

## **6. Caring for children with special needs**

"Special needs" can include physical, intellectual, medical and behavioural. Some children and young people may have a combination of these special needs, for example physical and intellectual.

*Some people do not always acknowledge and understand the specialised care our children require. They say things like "all children need care" but it is different when a child has a significant disability because you can't just leave them with anyone –*

*it's not fair on them or your child.* (Postgraduate diploma student whose teenager lives with a disability).

### **[A Guide for Carers, He Aratohu ma nga Kaitiaki](#)**

This guide includes a section on children with special needs and what help is available.

### **[Parent to Parent](#)**

Parent to Parent is a support and information network for parents of children with special needs. Support is provided voluntarily by Trained Support Parents

## **7. Caring for someone with a terminal illness**

There are few experiences more difficult than caring for someone diagnosed with terminal illness or at the end of their life. [Hospice NZ](#) has a booklet, A Guide for Carers which may assist. Topics include; on being a caregiver, caring for a loved one, circles of support, home nursing tips and practical matters.

The Cancer Society NZ also has a range of resources on living with cancer, relationship and communication and a booklet, Talking about Grief and Loss.

The UK National Health Service has a helpful website with information on coping, planning and communicating when you have been diagnosed with a terminal illness. See [Coping with a terminal illness](#).

## SECTION FIVE: Research and Publications

This section provides links to research and publications that are relevant to the Carer role.

### Publications:

**Ministry for Social Development** *The New Zealand Carers' Action Plan 2014-2018* is part of a wider government process to improve the choices of parents and other informal Carers so they can better balance their paid work, their caring responsibilities and other aspects of their life. See [Action Plan](#)

### Responding to an aging academic workforce

Universities New Zealand - Te Pōkai Tara commissioned Business and Economic Research Limited (BERL) to analyse the academic workforce, identify possible scenarios for the future and present the universities with options and recommendations to prepare for these changes. BERL's report, entitled *Academic Workforce Planning - Towards 2020*, is the latest contribution to a wider academic workforce planning project. A summary of key findings from the BERL report and the report in its entirety may be downloaded from the Universities NZ Website ([www.universitiesnz.ac.nz](http://www.universitiesnz.ac.nz)).

### Research reports related to the experiences of Carers in New Zealand:

**The [Experiences of Informal Caregivers](#)** in New Zealand (January 2009) Jorgensen, D. Parsons, M. & Jacobs, S. The Carers Assessment of Needs Study, carried out by Dr Diane Jorgensen of Auckland University's School of Nursing during 2007/2008, is one of the largest qualitative studies about Carers in the world. It was undertaken with help from national non-profit Carers NZ, which enlisted Carers to participate.

**The [LiLACS NZ longitudinal study](#)** was started in 2010 by the School of Population Health at the University of Auckland and is ongoing. It is a world leading research programme that aims to determine the predictors of successful advanced ageing and understand the trajectories of health and wellbeing in advanced age.

The study has produced numerous reports about both the care and carers of the elderly.

