



Health

Walking with Carers in NSW

This booklet has been developed in
consultation with carers, for carers



Walking with Carers in NSW

Anyone can be a carer. Carers may be family members, friends, neighbours or other community members. They may provide care for short or long periods, or only occasionally. However, in many instances, care is provided on a regular and ongoing basis and is unpaid other than in some cases a pension or benefit.

While providing care and support can be a positive experience, caring roles can also be challenging and stressful and lead to poor health outcomes for families and carers themselves.

Supporting families and carers is pivotal to achieving strong outcomes in health care. Not only does it help ensure families' and carers' own health and well being is maintained, it also contributes to improving outcomes across the system. There is a wealth of evidence available to demonstrate that providing comprehensive and targeted support and services results in better outcomes for consumers as well as carers.

Those who provide care need reliable information, expert advice, understanding and support. *Walking with Carers* has been developed as an information resource to support the many carers in NSW providing care and support to family members and friends who have a disability, mental illness, chronic condition, terminal illness or who are frail.

The resource provides a range of useful information, advice and contacts to assist carers including:

- ◆ Their rights within the NSW Health care system;
- ◆ The location of acute and community health services;
- ◆ Information on the availability of payments and allowances;
- ◆ Contact details for counselling;
- ◆ Tips for working carers, young carers and Aboriginal carers; and
- ◆ Information and tips for carers on looking after themselves.



Walking with Carers in NSW

Given the significant physical and emotional demands which caring places on carers, the resource also provides advice to carers about the best ways to better care for themselves. Funding for the resource was initially provided under the *NSW Carers Action Plan 2007-2012*.

The NSW Carer Strategy 2014-2019 is a five year plan to improve the position of carers in NSW. The strategy builds on the work already being undertaken by government and non government organisations to deliver better services and support for carers.

NSW Carers Recognition Act

The *NSW Carers (Recognition) Act 2010* was introduced to provide recognition of carers. The Act established the NSW Carer Charter to increase awareness of the valuable contribution carers make to the community. The Act sets out the obligations of NSW Government human Services Agencies. Agencies such as NSW Health must ensure that they provide a yearly report of their compliance with these obligations.

The Carer Advisory Council was also established. The NSW Carers Advisory Council is chaired by the Minister for Disability Services. The Council provides advice to the NSW Government on legislation, policy and other matters that have a significant impact on carers.

NSW Carer Awards Program

NSW Carer Awards Program was established to acknowledge and celebrate the significant contribution that unpaid or 'informal' carers make to the person (or people) they care for and the community. For more information about the awards program see www.adhc.nsw.gov.au.

Retrieved: 13/07/11 from <http://www.adhc.nsw.gov.au/>



Walking with Carers in NSW

The NSW Carers Charter

The Carers Charter includes 13 principles that affirm the valuable contribution that carers make and provides guidance on issues of significance for carers.

1. Carers make a valuable contribution to the community

- (a) NSW recognises the valuable social and economic contribution that carers make to the community.
- (b) Carers should have the same rights, choices and opportunities as other Australians.
- (c) Carers' unique knowledge and experience should be acknowledged and recognised.
- (d) The relationship between carers and the people they care for should be respected.

2. Carers' health and well-being is important

- (a) Carers should be supported to enjoy optimum health and well-being and to participate in family, social and life, employment and education.
- (b) Carers should be supported to balance their caring role with other roles, such as work and education.

3. Carers are diverse and have individual needs within and beyond their caring role

- (a) The diverse needs of carers should be acknowledged and recognised in policy, programs and service delivery, taking into consideration culture and language, age, disability, religion, socio-economic status, place of residence, gender identity and sexual orientation.
- (b) Aboriginal and Torres Strait Islander values, heritage and concepts of caring should be respected and valued.
- (c) The additional challenges faced by carers who live in rural and remote areas should be acknowledged and recognised.
- (d) Children and young people who are carers should be supported to reach their full potential.

4. Carers are partners in care

- (a) The choices, views and needs of carers and of the people they care for should be taken into account in the assessment, planning, delivery and review of services provided to the people they care for.
- (b) Carers should be referred to, and assisted to access, appropriate supports and services.
- (c) Support for carers should be timely, responsive, appropriate and accessible.

Retrieved: 23.08.17 from <http://www.legislation.nsw.gov.au/#/view/act/2010/20/>



Your Health - Rights and Responsibilities

Everyone seeking or receiving healthcare in Australia has certain rights and responsibilities, covering issues such as access, safety, respect, communication, participation, privacy and to comment on their care.

We all have an important role to play in achieving healthcare rights and contributing to safe, high quality care, this includes patients and their carer. For more information see *Your Healthcare: Rights and Responsibilities - A guide for patients, carers and families*. Tel. (02) 9391 9968 / (02) 9391 9967 or download from the NSW Ministry of Health website:

<https://www.health.nsw.gov.au/patientconcerns/Pages/your-health-rights-responsibilities.aspx>

It is important that each patient understands their right to privacy and the need to give permission for certain people, such as their carer, to have full access to their health information. It is best that patients and their carer discuss privacy permission before coming to hospital so the patients' wishes are clearly understood and recorded for health staff.

Health staff rely on the expertise of carers to inform medical treatment and assist with planning care appropriate for the patients return home. Therefore, it is vital that health staff provide carers with information on available services, treatment options and costs in a clear and open way. If a carer requires additional information they need to be honest and open and ask questions when they do not understand. Patients and their carer have the right to access interpreter services to support communication and participation in healthcare choices.



Hospitals and Community Health Centres in your Local Health District

Some information about your health services

- ◆ Car parking fees apply at a number of hospitals including weekly parking rates. Contact the hospital for more information.
- ◆ In line with government policy, smoking is not permitted in or on any of the hospital grounds.
- ◆ Please do not keep valuables in the bedside lockers or with patients. Nursing staff can arrange for temporary safekeeping of valuables if necessary.
- ◆ There are banking facilities and automatic teller machines at a number of hospitals.
- ◆ You are entitled to a free and confidential Health Care Interpreter Service including Auslan (hearing impaired) if you need one. Please let staff know if you do.
- ◆ If you are the carer please inform staff so that your contact details can be included in the patient's medical record.
- ◆ We encourage carers to participate in care and discharge planning. We value carer involvement and input into health care processes and decision making.
- ◆ A range of home based and support services are available to assist you and the person you care for when they are discharged from hospital. Notify staff of any needs prior to discharge.
- ◆ Spiritual leaders of all denominations visit our hospitals regularly. Your nurse or the chaplaincy department, can arrange pastoral visits on request.
- ◆ Let hospital staff know if you have a problem or a complaint about anything. We aim to resolve problems as soon as possible. You can speak to :
 - ◆ The Nurse Unit Manager
 - ◆ The Facility Manager
 - ◆ The Aboriginal Hospital Liaison Officer if appropriate or
 - ◆ The patient representative.

The contact numbers for relevant staff can be obtained from the hospital or health service



Hospitals and Community Health Centres in your Local Health District

For hospitals and community health centres in your Local Health District contact NSW Ministry of Health

Tel: **(02) 9391 9000** or visit “Find Your Health Service”

<http://www.health.nsw.gov.au/hospitals/pages/default.aspx>

Metropolitan NSW Local Health Districts (LHD)

Central Coast LHD - <http://www.health.nsw.gov.au/lhd/pages/cclhd.aspx>

Illawarra Shoalhaven LHD - <http://www.health.nsw.gov.au/lhd/pages/islhd.aspx>

Nepean Blue Mountains LHD - <http://www.health.nsw.gov.au/lhd/pages/nbmlhd.aspx>

Northern Sydney LHD - <http://www.health.nsw.gov.au/lhd/pages/nslhd.aspx>

South Eastern Sydney LHD - <http://www.health.nsw.gov.au/lhd/pages/seslhd.aspx>

South Western Sydney LHD - <http://www.health.nsw.gov.au/lhd/pages/swslhd.aspx>

Sydney LHD - <http://www.slhd.nsw.gov.au>

Western Sydney LHD - <http://www.health.nsw.gov.au/lhd/pages/wslhd.aspx>

Rural & Regional NSW Local Health Districts (LHD)

Far West LHD - <http://www.fwlhd.health.nsw.gov.au/>

Hunter New England LHD - <http://www.health.nsw.gov.au/lhd/pages/hnelhd.aspx>

Mid North Coast LHD - <http://www.health.nsw.gov.au/lhd/pages/mnclhd.aspx>

Murrumbidgee LHD - <http://www.health.nsw.gov.au/lhd/pages/mlhd.aspx>

Northern NSW LHD - <http://www.health.nsw.gov.au/lhd/pages/nswlhd.aspx>

Southern NSW LHD - <http://www.health.nsw.gov.au/lhd/pages/snswlhd.aspx>

Western NSW LHD - <http://wnswlhd.health.nsw.gov.au/>

Specialty Networks:

Justice Health and Forensic Mental Health Network - www.justicehealth.nsw.gov.au

Sydney Children’s Hospitals Network - Children’s hospital at Westmead and Sydney Children’s Hospital at Randwick - www.schn.health.nsw.gov.au/

St Vincent’s Health Network:

St Vincent’s Hospital, the Sacred Heart Hospice at Darlinghurst and St Joseph’s at Auburn
<https://www.svhs.org.au>



Websites

Organisations

Ageing Disability and Homecare
Alzheimer's Australia
Association for Children with a Disability
Autism Spectrum Australia
beyondblue
Bladder and Bowel Website
Carer Gateway
Carers NSW
Carers NSW Young Carer Program
Centrelink
Children of Parents with Mental Illness
Companion Card
Department of Veterans' Affairs
Early Childhood Intervention Australia NSW/ACT
Enable NSW - (Disability Support Service)
Financial Counsellors' Association of NSW Inc
Genetic Alliance Australia
Guardianship
Health Direct Australia
Immunise Australia Program
Law Access NSW
Legal Aid NSW
Lifeline
Make Healthy Normal
Mental Health Carers NSW
My Aged Care
Way Ahead Mental Health Association NSW
Multicultural Disability Advocacy Association
Multicultural Health Communication
NPS Medicine Wise
NDIS National Disability Insurance Scheme
NSW Health
Raising Children Network
Seniors Rights Service
Sane Australia
The National Public Toilet Map
Youthbeyondblue

Web address

www.adhc.nsw.gov.au
www.dementia.org.au
www.acd.org.au
www.autismspectrum.org.au
www.beyondblue.org.au
www.bladderbowel.gov.au
www.carergateway.gov.au
www.carersnsw.org.au
www.youngcarersnsw.org.au
www.humanservices.gov.au
www.copmi.net.au
www.nswcompanioncard.org.au
www.dva.gov.au
www.ecia-nsw.org.au
www.enable.health.nsw.gov.au
www.fcan.com.au
www.geneticalliance.org.au
www.ncat.nsw.gov.au
www.healthdirect.gov.au
www.immunise.health.gov.au
www.lawaccess.nsw.gov.au
www.legalaid.nsw.gov.au
www.lifeline.org.au
www.makehealthynormal.nsw.gov.au
www.mentalhealthcarersnsw.org
www.myagedcare.gov.au
www.wayahead.org.au
www.mdaa.org.au
www.mhcs.health.nsw.gov.au
www.nps.org.au
www.ndis.nsw.gov.au
www.health.nsw.gov.au
www.raisingchildren.net.au
www.seniorsrightsservice.org.au
www.sane.org
www.toiletmap.gov.au
www.youthbeyondblue.com



Centrelink Assistance

Claiming Payments for Carers

If you are a carer you may be eligible for Carer Payment and/or Carer Allowance.

Carers or a nominated third party, thinking of claiming a Carer Payment and/or Carer Allowance, should contact Centrelink on **13 27 17** or visit your local Centrelink office where staff will ask some questions to determine individual circumstances and issue the appropriate claim forms.

Contacting Centrelink on **13 27 17**, will ensure carers minimise the amount of documentation required to claim for Carer Payment and/or Carer Allowance and ensure their intention to claim is registered from the earliest possible date.

For more information, call Centrelink on **13 27 17** or visit:
<http://www.humanservices.gov.au/individuals/carers>

Help in other languages

If you need an interpreter or translation of documents for Centrelink business, they can arrange this for you free of charge.

To speak to Centrelink in languages other than English you can call the Multilingual Phone Service on **13 12 02**, or visit a Centrelink Customer Service Centre and ask for an interpreter.

For translated information visit **www.humanservices.gov.au/customer/information-in-your-language**.



Centrelink Assistance

Extra Assistance from Centrelink

If you are getting a Centrelink payment you may also be able to receive some extra assistance. The extra assistance will depend on your payment and personal circumstances.

- ◆ Concession cards e.g. Health Care Card
- ◆ Pharmaceutical Allowance
- ◆ Rent Assistance
- ◆ Telephone Allowance
- ◆ Utilities Allowance
- ◆ Special Disability Trusts
- ◆ Mobility Allowance
- ◆ Help with your bills (Centrepay)
- ◆ Pensioner Education Supplement

For more information about payments and services for carers call **13 27 17**, ask at a Centrelink Customer Service Centre or visit www.humanservices.gov.au/customer/themes/carers

Other Useful Centrelink numbers:

Indigenous Call Centre	1800 136 380
Social Work Services	13 28 50
Financial Information Services	13 23 00
Complaints and Feedback	1800 132 468



Carer Support Services

Support

Support groups offer an opportunity to come together with people in similar caring situations to you. When ideas, feelings, concerns, information and problems are shared, the experience of caring can feel less isolating.

If you would like to find out about which support groups are best suited to you and your current caring role, contact Carers NSW on **1800 052 222** or visit **www.carersnsw.org.au/groups**.

Respite

Respite care means that someone else takes over the responsibility of looking after the person you care for, for a period of time. This enables you the carer, to take time to:

- ◆ Rest
- ◆ Participate in a support group
- ◆ Make and attend appointments
- ◆ Attend a social activity, with family and friends.

Carer Gateway can assist you to find appropriate respite options and is also funded to arrange emergency respite for carers.

Respite may be for a few hours, a day or longer. There are different types of respite:

- ◆ **In-home respite** - a care worker provides care in the home or may organise to take the person you care for on an outing. In-home respite can also be overnight.
- ◆ **Centre based respite** - held at a centre or club that organises group activities for the person you care for, allowing them to meet other people.
- ◆ **Community Access respite** - provides activities to encourage a sense of independence in the person you care for by providing social interaction.
- ◆ **Residential Respite Care** - a short stay in a residential care home can be organised for the person you care for.
- ◆ **Consumer-Direct respite care (CDRC)** - a CDRC package gives you more choice about the type and delivery of respite care.
- ◆ **Emergency respite** when a carer is ill, injured or in crisis, and respite care can be arranged at short notice.

For more information about respite services or emergency care plans contact **Carer Gateway** on **1800 422 737** or visit **www.carergateway.gov.au/taking-a-break-respite** or **Aging and Aged Care:** **<http://myagedcare.gov.au/respite-care>**

HOT TIP

Planning to have regular respite is a very good idea. You deserve to have some time to yourself.



Carer Support Services

There are many services available for carers and the people that you care for.

National Disability Insurance Scheme (NDIS)

The National Disability Insurance Scheme (NDIS) is the new way of providing individualised support for people with permanent and significant disability, their families and carers.

In NSW, the NDIS will be rolled out by Local Health District's (LHD). The **NDIS** website www.ndis.gov.au shows you when each district commence the NDIS roll out. When the NDIS commences in a district, people currently receiving supports through NSW Government specialist disability services will be moving first. Existing service users and new participants will enter the scheme progressively. The NDIS provides support to all eligible Australians ensuring people with disability and their families get the support they need when they need it. It also empowers the person with the disability and their family to set their own goal and choose their own support. This is achieved by giving them control over their own support budget.

The NDIS provide carers relief from the caring role in the form of short-term direct respite and social and recreational activities.

To see if you're eligible for the **NDIS** phone : **1800 800 110**

My Aged Care (MAC)

My Aged Care (MAC) is the main entry point to the aged care system in Australia. The service aims to make it easier for older people over the age of 65, their families and carers to access information on ageing and aged care, have their needs assessed and be supported to find and access services.

My Aged Care will:

- Explain a person's eligibility for support and services.
- Provide information on services for the person, their family and/or carer.
- Explain the different types of services that are both community and residential care focused.
- Explain the costs of aged care services, including access to fee estimators.

My Aged Care assessor will:

- Ask questions over the phone to help work out your needs and care arrangements may organise a follow up face to face assessment.
- Inform you about the options and costs that are best suited to your needs or for the person for whom you are providing care to.

For more information on **My Aged Care** (MAC) call on **1800 200 422** or visit <http://www.myagedcare.gov.au/>



Working Carers

Who is a Working Carer? Working Carers are people who are in paid employment and care for a relative or friend who is ill, frail, has a disability or is ageing. They can work full-time, part-time, casually or manage their own business.

Working Carers are men and women of various backgrounds and ages. Caring responsibilities can impact on your ability to manage work, and work responsibilities can impact on the care you are able to provide. Acknowledgment and support from employers, government, service providers, family and community members is important.

Points to consider

It is advisable to inform your manager of your role as a carer as you may be able to negotiate more flexible working arrangements.

Discuss your entitlements with your manager regarding Carers' leave and/or FACS (Family and Community Service) leave.

Despite being in paid employment you are still entitled to the Carer Allowance from Centrelink.

For more information call **Centrelink** on **13 27 17** or visit:
www.humanservices.gov.au/customer/themes/carers

The **Carers Gateway** is a website that offers a variety of resources and information to support your role as a Working Carer. Visit **www.carergateway.gov.au/working-and-caring**

HOT TIP

Remember, if you do not have a computer, your local library is one location where you can access the **Carers Gateway**.



Carers NSW

Carers NSW is the peak organisation for carers in NSW. It is a member of the national Network of Carers Associations and has an exclusive focus on supporting and advocating for all carers in the state.

Carers NSW is governed by a Board of Directors. It operates as a non-profit and apolitical organisation.

Carers NSW also provides:

- ◆ Information and referral to services
- ◆ Emotional support
- ◆ Face to face or over the telephone and group counselling
- ◆ Information about and resources for carer support groups
- ◆ Resources and publications for carers
- ◆ Older Parent Carer Program
- ◆ Young Carer Program
- ◆ Education and training
- ◆ Carer representatives, policy submissions to the government.

For Carers NSW call **1800 242 636** (*freecall except from mobiles) or visit **www.carersnsw.org.au**



Young Carers

The Australian Bureau of Statistics estimate that there are 104,055 young carers aged under 25 living in NSW (ABS, 2014).

Young Carers are children and young people who help or take on the 'caring' role in families where someone has an illness, disability, mental illness or substance abuse problems. They might help out with cleaning, preparing meals, assisting their relatives with daily tasks such as helping with medicines, showering, dressing, or by 'watching out' to make sure that they are okay.

Young Carers are under 25 years of age, some as young as six. They may be a sibling, child, grandchild or other relative.

Young Carers who provide significant care for a family member, are often unrecognized or 'invisible' carers in our community and can be especially vulnerable.

The Carers NSW Young Carers Program provides free support and connects young carers through:

- ◆ Emotional support
- ◆ Quarterly newsletters
- ◆ Counselling- individual, group face to face and telephone counselling.
- ◆ Information and referrals
- ◆ An interactive young carer website- online community for young carers
- ◆ Carers NSW Young Carers Leadership Program-Young Carer opportunities to get involved in youth issues and events.

To contact the Young Carers team call **1800 242 636** or visit **www.youngcarersnsw.org.au**

Key contact phone numbers for Young Carers:

- ◆ Life Line 24/7 **13 11 14**
- ◆ Kids Helpline **1800 551 800**
- ◆ DOCS Helpline 24/7 **13 21 11**
- ◆ After Hours GP helpline **1800 022 222**



Aboriginal and Torres Strait Islander Carers

Aboriginal people do not often identify with being a carer themselves as caring for family members and friends is a strong part of Aboriginal culture. Often Aboriginal carers are providing care for more than one person. Due to the high level of chronic disease experienced by Aboriginal people and the past experience with government services, Aboriginal and Torres Strait Islander carers need the assistance of services that understand their experience and needs.

Carers NSW provides Carer Support services and programs for Aboriginal and Torres Strait Islander Carers.

Resources include:

- ◆ Aboriginal Carers Support Guide - information for Aboriginal families who are caring for an older person or a person with a disability
- ◆ Shoulder to Shoulder - information booklet - for Aboriginal families with a child or young person with a disability (downloadable version only)
- ◆ Aboriginal Carer Relaxation CD
- ◆ Aboriginal Health and Wellbeing DVD - Looking After Ourselves Workshop for both service providers and aboriginal carers who work with or want to work with carers.
- ◆ Aboriginal Carer Support Group facilitator training and resources
- ◆ Koori Yarning Resources Manual
- ◆ Aboriginal and Torres Strait Islander Carer Kit
- ◆ Aboriginal links - websites for Aboriginal specific information
- ◆ e-bulletin - includes Aboriginal carer specific information
- ◆ Carer Life Course - online learning package which includes Aboriginal carer specific information www.carerlifecourse.org.au

For more information visit www.carersnsw.org.au/how-we-help/support/aboriginal/



Culturally and Linguistically Diverse (CALD) Carers

Carers come from all cultural and social backgrounds.

Culturally and Linguistically Diverse (CALD) carers may not readily identify with being a 'carer' as caring can be a strong part of their culture. Also the term carer doesn't always translate into all languages.

CALD carers face the same issues as all carers and may face additional barriers such as:

- ◆ Language and communication
- ◆ Understanding and use of health and service provider systems
- ◆ Stress, dissatisfaction and isolation.

There is a variety of services, organisations and resources, both ethno-specific and mainstream providing support and information to CALD carers.

Carers NSW provides several translated fact sheets into 15 community languages.

For more information on services, organisations and language specific resources for CALD carers call Carers NSW on **1800 242 636** or visit **www.carersnsw.org.au**

Interpreter Services

If English is not your first language and you need an interpreter contact the Translating and Interpreting 24 hour Service (TIS) on **13 14 50** or visit **www.tisnational.org.au**

The National Relay Service (TTY)

TTY is a 24 hour service which provides support to people who are deaf or have a hearing or speech impairment. If you need TTY services call **13 36 77** or visit **<http://relayservice.gov.au>**

Acknowledgements and References

Australian Government Department of Health and Ageing
Ageing Disability and Homecare - Carers Charter
Carers Australia
Carer's Handbook –A practical guide to caring for people who are sick, elderly or have a disability
Carers NSW
Centrelink
Department of Human Services
NSW Carers Support Offices

NSW Ministry of Health
Nepean Blue Mountains Local Health District and Western Sydney Local Health District -
formerly Sydney West Area Health
Palliative Services
My Aged Care
NDIS
Carer Gateway

To the best of our knowledge, this information was correct at the time of printing.



Quick Reference Guide

What services are available?

Financial Help

You may be eligible for a Carer Payment (income tested) or Carer Allowance. You will need to complete a form from Centrelink.

Centrelink
13 27 17
For assistance
in languages other than English
13 12 02

Do you need information about...

Meals	Personal care
Transport	Mobility Equipment
Finances	Vehicle Modifications
Legal Issues	
Domestic Help	

Carer Gateway
1800 422 737
Monday - Friday 8am to 6pm

National Disability Insurance Scheme (NDIS)
1800 800 110
For people under the age of 65
Monday - Friday 8am - 11pm

Respite

When you need a break and you need someone to look after the person you care for.

My Aged Care (MAC)
1800 200 422
For people over the age of 65
Monday - Friday 8am - 8pm
Saturday 10am - 2pm

Resources/Information

- ◆ Telephone support
- ◆ Counselling
- ◆ Emergency Care Plan
- ◆ Aboriginal and Torres Strait Islander
- ◆ CALD Carers
- ◆ Young Carers
- ◆ Mental Health
- ◆ Advocacy
- ◆ Information about carer support groups

Carers NSW
1800 242 636

Aged Care Assessment Teams (ACAT)

Contact the Aged Care Information Line in your local area. Referrals can be made by anyone - patient, carer or health professional.

Aged Care Information Line
1800 200 422

More services next page

Quick Reference Guide continued

What services are available?

Community Services

- ◆ Allied Health Services
- ◆ Aged Day Care
- ◆ Community Nursing
- ◆ Continence Clinic
- ◆ Dietetics
- ◆ Occupational Therapy - home modifications
- ◆ Physiotherapy
- ◆ Podiatry
- ◆ Women's Health
- ◆ Palliative Care for Residential Aged Care Facility
- ◆ Aboriginal Liaison Officers
- ◆ GP Liaison
- ◆ Orthoptist
- ◆ Hearing Services
- ◆ Play gym
- ◆ Parenting groups
- ◆ Counselling
- ◆ Speech Pathology
- ◆ Multicultural Health Services

Please note: Not all services are available at all locations

For Community Health Centres in your Local Health District contact
NSW Ministry of Health
9391 9000

Early Childhood Intervention Infoline

For parents of children with diagnosed disabilities or development delays

www.parentline.org.au
1300 130 052

Healthdirect Australia

24 hour Health Information line

1800 022 222

Mental Health Information Service Mental Health Line NSW Lifeline

1300 794 991

National Continence Helpline

1800 330 066

Medicare Australia

13 20 11
(local rate 24 hours, seven days a week)



Carer Health & Wellbeing

This booklet has been developed in
consultation with carers, for carers



Advance Care Planning

Advance Care Planning is a process that is all about thinking and talking about your personal values and preference for health and lifestyle decisions, just in case there comes a time when you cannot speak for yourself. Planning care in advance can be reassuring to the patient, and may reduce anxiety and guilt felt by carers, because it is the patient's 'own voice' directing health treatment choices rather than the opinion of the carer or other family members.

Advance care planning:

- May need more than one discussion with key people
- Should include all key people such as, carers, other family members, health professionals, and religious/spiritual advisors so everyone can hear what the patient wants, and what care can be offered. Hearing this information together may avoid later conflict
- May result in the patient writing their wishes and expectations down in a document, which is called an Advance Care Directive/ or Plan
- Can be arranged with the help of the patient's treating doctor, nurse, or a social worker
- Discussions may occur in the community or in hospital. If the patient is in hospital the decisions reached will be recorded on a special form, which will go into the patient's file for that admission, so that everyone is aware of the patient's wishes.

Patients need another person to make health care decisions for them if they are unable to say what their choices are. In NSW the person who can legally make decisions for a patient is called the 'person responsible'.

Patients should talk to their family members about who their 'person responsible' is. If a patient does not have a guardian then the 'person responsible' is a spouse or partner, carer, or other close friend or relative.

HOT TIP

Consider thinking about the development of your own Advance Care Plan, as well as talking to the person you care for about their wishes and expectations for their future medical care. You can find out more information regarding advance care planning from the following websites:

NSW Health www.health.nsw.gov.au/patients/acp

Advance Care Planning Australia www.advancereplanning.org.au

Person Responsible Factsheet

http://www.ncat.nsw.gov.au/Documents/gd_factsheet_person_responsible.pdf

Your Legal Concerns

Planning ahead

As a carer you may be responsible for the legal and financial affairs of the person you care for. This responsibility can be overwhelming but it is important to plan for the future for your security and that of the person you care for. It is helpful to be organised for times of crisis or emergency. Please consider:

- ◆ Financial arrangements - for both yourself and the person you are caring for.
- ◆ Who would care for the person you are caring for if you were unable to do so due to illness or injury?
- ◆ Having an Emergency Care Plan in the event of something happening to you the carer. Refer to the Emergency Care Plan section of this booklet.

There are a variety of legal arrangements that you can make to organise the affairs of the person you care for. Some things to think about are:

Will

- ◆ A will is a legal document that sets out who will receive your assets when you die and ensures assets are distributed according to your wishes.
- ◆ A will must comply with strict legal requirements to be valid.

Power of Attorney

- ◆ Gives you the ability to manage the financial business of the person you care for if they have the capacity to appoint you. 'Capacity' means that a person is able to understand the nature and effect of the decision to be made and is able to communicate their decision in some way.
- ◆ Can be cancelled at any time as long as the care recipient is of sound mind.
- ◆ Ceases to have effect when the person loses capacity to make decisions for themselves.

Enduring Power of Attorney

- ◆ Is appointed by the person when they are of sound mind and allows for continuous management of legal and financial issues whether or not the person has capacity.
- ◆ Ceases when the person dies.

Enduring Guardianship

- ◆ A patient with capacity may appoint a person of their choice to be their enduring guardian.
- ◆ This enables the person appointed to make health and lifestyle choices for the person they care for if they become unable to do so themselves.
- ◆ A solicitor, barrister or registrar of the local court must witness the signature on the enduring guardian appointment form.

HOT TIP

The above arrangements need to be made in advance whilst the person being cared for is of sound mind.

For information about Guardianship visit the NSW Civil and Administrative Tribunal website www.ncat.nsw.gov.au/Pages/guardianship/guardianship.aspx

For general legal advice contact LawAccess NSW (a free government telephone service) on **1300 888 529** or visit www.lawaccess.nsw.gov.au

Your Money

There are many costs involved with being a carer which place pressures on your individual or family budget. There is financial assistance available from government agencies to help compensate for some of these costs.

As a carer you may be eligible for financial assistance. Centrelink supports carers with a range of payments.

Carer Payment - is an income support payment that provides support to people who because of the demands of their caring role are unable to support themselves through substantial paid employment.

Carer Allowance - is a fortnightly supplementary payment that is free of the income and assets test, is not taxable and can be paid in addition to wages, Carer Payment or any other Centrelink payment.

Carer Supplement - is an annual lump sum payment to help with the costs of caring for a person with disability or medical condition if you are receiving Carer Payment or Carer Allowance.

Child Adjustment Payment - is one off payment to help families deal with the increased costs of caring for a child younger than 7 years who has had a sudden and severe illness or accident.

Child Disability Assistance Payment - is an annual lump sum payment to help with the costs of caring for a child with a disability.

The Continence Aids Payment Scheme (CAPS) - is an Australian Government scheme that provides a payment to assist eligible people who have permanent and severe incontinence to meet some of the costs of their continence products.

Contact The National Continence Helpline **1800 330 066**.

Financial Counsellors' Association of NSW Inc is a free financial and counselling service.

For more information call **1300 914 408** or visit **www.fcan.com.au**

HOT TIP

If you feel you need more professional assistance or advice on any financial matters, here are some services you might like to think about contacting:

- ◆ A **Centrelink** social worker or **Centrelink's Financial Information Service**
- ◆ Your bank, building society, or credit union
- ◆ A solicitor
- ◆ A financial advisor.

Your Health

If you are caring for others it's easy to forget about yourself. Caring can be physically and emotionally draining and many carers put their own needs last.

It is important to try to maintain healthy habits such as eating well, sleeping well and being physically active.

Unhealthy eating and not enough physical activity can easily lead to an increased risk of developing a chronic disease such as some cancers, heart disease, and type 2 diabetes.

Small steps can make a big difference. Here are some healthy eating and physical active tips to help you stay healthy and feel good.

Tips for healthy eating

- ◆ Eat more fruit and vegetables (at least two servings of fruit and five servings of vegetables every day).
- ◆ Eat regular meals – and don't forget breakfast. Planning meals ahead can help.
- ◆ Eat more fibre by including high fibre foods in your diet such as oats, bran, legumes, vegetables and fruit in your meals and snacks.
- ◆ Drink plenty of water. Water is the best and cheapest drink. Water provides the fluid we need, without the added kilojoules or caffeine found in many other drinks.
- ◆ Be active every day.
- ◆ Small amounts of exercise can make a big difference to your health.
- ◆ Walk to work or the shops.
- ◆ Walk and chat with friends instead of meeting for coffee.
- ◆ Get up and move during ad breaks.
- ◆ Stay mobile by walking when you are on the plane.

There are tremendous benefits in even a small amount of physical activity each day. This combined with healthy eating, is the easiest way to reduce your waist measurement and lower your risk of chronic disease.

Be Active Everyday

Staying physically active is the single most important factor to stay fit, healthy and independent. Every movement counts – take every opportunity to move throughout the day.

The first step to get active is:

- ◆ **Motivation**
- ◆ **Overcoming** your fears related to time, effort, energy and ability.

Once these two steps are taken, you will realise the:

- ◆ **Value** of everyday activity for your body, mind and soul
- ◆ **Enjoyment** of everyday activity is vital; so put on your shoes and get active.

Aim for 30 minutes of exercise each day or try it in 10 minute blocks, 3 times during the day.

Regular physical activity improves health and wellbeing. It can:

- ◆ Maintain or improve physical function and independent living
- ◆ Improve activities of daily living, social interactions, quality of life, and reduce depression
- ◆ Reduce the risk of chronic disease
- ◆ Build and maintain healthy bones, muscles and joints, reducing the risk of injuries from falls.

Healthy Lifestyle and Exercise Programs

Get Healthy Service - a free telephone based coaching service helping people to make changes regarding healthy eating, being physically active and achieving and maintaining a healthy weight.
www.gethealthynsw.com.au

Active and Healthy for over 50's - find an exercise program in your area
www.activeandhealthy.nsw.gov.au

Make Healthy Normal visit www.makehealthynormal.nsw.gov.au to find out more about healthy eating and being physically active, download mini workouts and sign up for the 10 week challenge.

HOT TIP

There are walking tracks around most hospital facilities. Ask staff for a map or directions. It is a good opportunity to stretch your legs whilst the person you care for is in hospital. Alternatively take a walk around your neighbourhood

Be Active Everyday continued...

The pictures demonstrate activities which improve strength and balance. These can be incorporated at anytime into your daily routine.

Sit to stand



- ◆ Sit towards the front of the chair, with your feet firmly on the floor
- ◆ Practice standing up, use arms for support if needed
- ◆ Stand tall then slowly lower yourself back into the chair
- ◆ Repeat 5-12 times

Calf raises



- ◆ Commence facing a chair
- ◆ Transfer your weight forward onto balls of the feet
- ◆ Slowly rise onto the balls of the feet keeping abdominals in and knees relaxed
- ◆ Hold, then slowly lower heels to floor
- ◆ Repeat 5-12 times

Side leg raises



- ◆ Take one leg out to the side
- ◆ Lift leg as high as comfortable
- ◆ Hold for 3 seconds
- ◆ Slowly return leg back to the starting position
- ◆ Repeat 5-12 times

Stepping practice



- ◆ Stand with feet shoulder width apart and knees relaxed
- ◆ Slowly practice transferring weight while stepping in different directions
- ◆ Commence with small steps
- ◆ Repeat 5 times to each direction

HOT TIP

To increase the intensity, hold the positions longer or increase the number of repeats.

For more information and tips, go to www.activeandhealthy.nsw.gov.au

Your Support

Carers provide physical and emotional support to the person they care for, and often have a habit of neglecting their own health and wellbeing. There are services to support you the carer, including:

- ♦ Carer support groups
- ♦ Community health centres
- ♦ Food services
- ♦ Home help
- ♦ Home maintenance and modification
- ♦ Home nursing
- ♦ Palliative care
- ♦ Respite
- ♦ Transport
- ♦ Disability Support Services

For more information on accessing these services visit www.carergateway.gov.au

Most of these services will make an assessment to find out what level of service is needed for you and the person you care for. Your local doctor may need to provide detailed information about the person you care for and your caring responsibilities.

Department of Veterans' Affairs (DVA)

- ♦ War veterans and defence force personnel are entitled to a number of services.
- ♦ Please contact DVA on **13 3254** for more information or visit www.dva.gov.au

Companion Card

- ♦ Available for people with a significant and permanent disability who always need a carer with them to participate in community activities and venues.
- ♦ The Companion Card allows the person's carer free entry into participating venues and events.

For more information call **1800 893 044** or www.nswcompanioncard.org.au

Enable NSW

Enable NSW provides equipment and services to people in NSW with chronic health conditions or disability to assist them with mobility, communication and selfcare.

For more information call **1800 362 253** or visit www.enable.health.nsw.gov.au

HOT TIP

Consider using private providers, they may be easier to access and possibly have shorter waiting times. There may be waiting lists and costs for these services.

Your Time

Carers sometimes care for a few hours a week or all day every week. Caring can be physically and emotionally demanding.

It is important to make time for yourself to help reduce the strain and pressure of caring. Taking time for yourself gives an opportunity for you to maintain independence and have a rest from your caring role. This time for yourself is called respite and there are a number of services that can help you with this.

The type of respite you need will depend on what suits you and the person that you care for. Time for yourself can begin with short breaks initially increasing over time. The time, length and cost of the respite depends on the service you contact and how often you need it.

The **Carer Gateway** is able to help you locate the type of respite service most suited to your needs. Many services have waiting lists so it is important to plan ahead.

Respite can be:

- ◆ Centre-based day care
- ◆ In-home respite
- ◆ Respite in an aged care facility
- ◆ Younger people in a respite facility
- ◆ Weekend and holiday programs
- ◆ Camps for siblings and young carers under 18.

For more information visit

www.carergateway.gov.au

HOT TIP

Remember it is important for your health and wellbeing to take regular time out from your caring role.

Your Caring Role

Your role as a carer can be at times an overwhelming responsibility, and as the carer, you are an important member of the health care team. In order to keep all health information together, a useful tool is the red **My Health Record** book.

You can obtain free copies from your community health centre, or health care provider. You can also order a copy from Better Health Centre. Using this book will enable you to keep all of the information about the person you are caring for together. Information such as medications, appointments, emergency contacts and medical history can be kept in one place and updated regularly.

Some other suggestions to assist you in your caring role:

- ◆ Ask for the health professionals' name, title, organisation
- ◆ Make a list of questions you may have
- ◆ Ask for information to be written down when you don't understand it
- ◆ Make an appointment without the person you care for to talk through your concerns
- ◆ Keep a diary, or a phone log to keep track of phone conversations
- ◆ Ask for help filling out the red **My Health Record** book and any other forms
- ◆ Ask your pharmacist or doctor for more information about medications
- ◆ Speak up if you don't understand what is happening
- ◆ Ask for the contact details of service providers
- ◆ Ask for time to think about decisions rather than being rushed.

HOT TIP

There are no 'silly' questions. Clarify any uncertainty about health care or treatments. Keep asking if you do not get a satisfactory answer.

You are entitled to ask for a second opinion about treatment options. For more information about the **My Health Record** book visit My Health Record website

<https://myhealthrecord.gov.au> or call **Better Health Centre** on **02 9887 5450** to get a free copy

Yourself

It can be challenging to consider your own health needs when you are caring for someone. It is important to take care of yourself so you can continue in your caring role. Here are some things for you to consider:

- ◆ Try to continue activities that you enjoy
- ◆ Try to share your feelings with a trusted friend or neighbour
- ◆ Try to make time for regular exercise
- ◆ Eat healthy meals regularly
- ◆ Get enough sleep
- ◆ Drink plenty of fluids –particularly water
- ◆ Regulate your alcohol and cigarette intake
- ◆ Keep your own medical appointments
- ◆ Let your GP and health care workers know you are a carer
- ◆ Ask your GP about which vaccinations are available to you and the person you care for
- ◆ Plan to take regular breaks
- ◆ Remind yourself of the happy times.

Carers NSW can provide information about support groups where you can meet with others who are in similar caring roles. Going to a support group or talking to other carers can help to reduce feelings of social isolation and loneliness. Support groups can also provide you with practical caring advice.

For more information about support groups contact:

Carers NSW on **1800 242 636** or visit **www.carersnsw.org.au**

Sometimes the pressures of caring can manifest themselves in physical or psychological symptoms including:

- ◆ Headache
- ◆ Backache
- ◆ Neck pain
- ◆ Diarrhoea and vomiting
- ◆ Stomach upset
- ◆ Ulcer
- ◆ Tiredness
- ◆ Depression and anxiety.

HOT TIP

If you have any of these symptoms please see your GP to talk about them.

Make your own health a priority; book regular healthcare check-ups for yourself such as health screens, dental checks and blood tests.

Your Emergency Care Plan

An Emergency Care Plan is a document that provides instruction and guidance to allow someone else to step in and provide the care which you normally provide.

You can obtain a free Emergency Care Kit which contains:

- ◆ An **Emergency Care Plan**: to record emergency contacts, emergency financial arrangements, health information, care required, and community services involved
- ◆ A **Medi-List**: to record current medications
- ◆ A **Carer Emergency Card**: that informs emergency services and health staff that you are a carer

To obtain a free copy of an **Emergency Care Kit** you can contact the following:

Carers NSW on **1800 242 636** or visit: www.carersnsw.org.au/advice/plan-ahead/emergency-plans

or

Carers Gateway on **1800 422 737** or visit: www.carergateway.gov.au/planning-for-an-emergency-situation

or

Aging and Aged Care visit:

<https://agedcare.health.gov.au/older-people-their-families-and-carers/caring-for-someone/emergency-care-plan>

HOT TIP

- ◆ Always keep your **Emergency Care Plan** and **Medi-List** up to date.
- ◆ Keep the **Emergency Care Plan** somewhere that will be easy to find in an emergency, like on the fridge or near the telephone.
- ◆ Provide updated copies of your **Emergency Care Plan** to the people that are your emergency contacts.
- ◆ Keep your **Carer Emergency Card** with you, in a prominent place in your wallet or purse where ambulance or other emergency personnel can see you have a caring responsibility.

Your Feelings

Being a carer is a demanding role that involves many emotions. These feelings vary from carer to carer. Often carers experience feelings of:

- ◆ Confusion
- ◆ Being overwhelmed
- ◆ Love
- ◆ Sadness
- ◆ Frustration
- ◆ Happiness
- ◆ Grief
- ◆ Resentment
- ◆ Shock
- ◆ Guilt
- ◆ Fear
- ◆ Obligation
- ◆ Joy
- ◆ Anger
- ◆ Loss

HOT TIP

As these feelings are very individual so are the ways in which carers cope. Talking with family members, friends and other carers in a support group or to a professional counsellor can help.

Face-to-face, telephone, and group counselling may be accessed through Carers NSW.

The National Carer Counselling Program is available for carers throughout Australia Monday to Friday 9am to 5pm. For more information call **1800 242 636** or visit **www.carersnsw.org.au**

A carers guide for unrecognised grief loss or grief issues in carers is available through **www.carersnsw.org.au**

Your Safety at Home

Ensuring your home is safe can help make your caring role easier. Things you might like to consider:

- ◆ Possible trip hazards e.g. mats, rugs, cords
- ◆ Reducing clutter
- ◆ Adequate lighting in toilets and hallways
- ◆ Security of your home
- ◆ Smoke detectors in working order
- ◆ Plan for evacuation in case of a fire
- ◆ Access to your home for emergency service providers, like the ambulance.

HOT TIP

Occupational therapists and physiotherapists at your local community health centre can offer advice on modifications and equipment.

For a home safety checklist please refer to the **Staying active and on your feet** booklet. To obtain a copy go to www.activeandhealthy.nsw.gov.au/publications_and_research

To find dementia specific home safety information visit www.thiscaringhome.org

Carer Do's and Don'ts

DO

- Have regular meals
- Get enough sleep
- Exercise
- Eat healthy food
- Drink plenty of water
- Moderate your consumption of cigarettes and alcohol
- Be patient
- Keep in touch with your GP and local support services
- Try to understand the condition of the person you are caring for and where possible keep in touch with health staff
- Ask about what services are available to support you by using the contact details in this booklet
- Talk to others in similar situations to yourself
- Access support groups and share your experience
This can help you and other carers
- Remember to ask your GP about which vaccinations are available to you

DON'T

- Be afraid to ask questions
- Isolate yourself from family and friends
- Be ashamed to feel frustrated and angry at times, those feelings are normal
- Use cigarettes and alcohol as a support
- Think you are alone
- Neglect your own health and wellbeing
- Forget to take time out for yourself or to remember the good times
- Forget to identify yourself to health staff so they know that you are a carer

Your Participation in Health

NSW Ministry of Health seeks to involve consumers, carers and the local community in the planning and delivery of local health services.

Services provided by your Local Health District are based on the values of respect, good communication and high standards of safety and quality service delivery. The Local Health Districts can only continue to achieve these principles with appropriate and timely input from consumers, carers and community representatives. We encourage you as a carer to provide feedback and raise any issues about the health service.

There are a variety of ways that you can be involved and have input into the way health services are developed and improved. These include:

- ◆ Completing surveys and agreeing to be interviewed by staff asking for feedback
- ◆ Talking to staff or service managers
- ◆ Coming to public meetings or forums and having a say
- ◆ Becoming a community representative on a committee
- ◆ Being active in the care planning of your own health or the health of someone you care for.

Your Caring Experience

Feelings of loss can occur for a variety of reasons throughout your caring role. Sadness is a normal response to a painful loss or change in lifestyle or health conditions. Grief may take place before an actual loss occurs. We all respond to grief and loss in different ways.

Carers often experience feelings of loss and grief relating to:

- ◆ Loss of their independence and that of the person they care for
- ◆ Loss of employment opportunities
- ◆ Not having the opportunity to socialise as often as in the past
- ◆ The change in relationship with the person they care for and
- ◆ Loss of future hopes and plans.

HOT TIP

Sometimes it may be helpful to talk with your local doctor, counsellor, psychologist or family and friends. Also, carer support groups can be a place to share these feelings with others who may understand. Consider contacting your local doctor, a friend, a family member or Carers NSW on **1800 242 636**. For an interpreter call **13 14500**.

Your Voice

Advocacy is acting on behalf of someone or speaking up for a person who may not be able to do so themselves.

- ◆ Carers advocate for the person they care for in a number of ways. Types of advocacy may include speaking, acting or writing on behalf of the person they care for.
- ◆ By advocating for the person they care for carers:
 - improve quality of life of the care recipient
 - reduce social isolation and vulnerability.

For further information about advocacy call **Carers NSW** on **1800 242 636** (*freecall except from mobiles) or visit **www.carersnsw.org.au**

If you are concerned about a health service provided to you, talk to your provider as soon as possible. Often this is the fastest and most effective way of resolving your concerns.

Complaints are often the result of poor communication between the patient and their health service provider. When you raise your concerns, in most cases the health service provider will try to resolve them.

If you cannot resolve your concerns, you can contact the NSW Health Care Complaints Commission on **1800 043 159**

For further information **www.hccc.nsw.gov.au**

Planning the transition from hospital to home

Good planning before the patient leaves hospital ensures a safe transition from hospital to home, residential care or other location. It is not unusual for planning to be discussed with you, the carer, early in the patient's stay. This involves talking with health care team members about the future care needs specific to the person you care for and yourself.

There are many supports and services which may assist you with this transition. Consider how you will manage the following, and talk to staff if you are concerned.

How will you?

- ◆ Manage housework
- ◆ Prepare meals
- ◆ Travel home from hospital
- ◆ Shop
- ◆ Look after pets
- ◆ Travel to follow up appointments.

Make sure you are clear on any follow up plans that have been arranged, and know who to contact.

Check you are aware of:

- ◆ Changes to medication
- ◆ Support services needed e.g. meals on wheels
- ◆ Equipment required e.g. shower chair
- ◆ Referrals for ongoing therapy e.g. physiotherapy
- ◆ Carer respite.

Planning the transition from hospital to home continued...

While in hospital issues and concerns that a carer and patient have regarding transfer of care from hospital to home, should be communicated to health staff as early in the patient's hospital stay as possible, and certainly before going home.

If you, the carer, become the patient, consider support and respite services for when you go home. Ask health care staff about the necessary level of support you will need. Seek staff assistance to organise these services.

HOT TIP

If you have any concerns about how you will manage at home, talk to the nurse in charge, a continuing care coordinator or a social worker.

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Further copies of this document can be downloaded from the Nepean Blue Mountains LHD Website www.nbmlhd.health.nsw.gov.au/carers-program