

Phase 4 Managing Summary and useful information and support

Managing

You learn how to incorporate the carer role into your everyday life, having more experience with the illness or condition and its course in treatment or recovery.

Carer needs

Many carers need:

- to be notified about what's happening and any changes
- explanations about warning signs of a new crisis and what to do, and who to call for assistance
- reassurance that what they're experiencing is normal

Many carers struggle in this phase with their caring role and require information on:

- grief and loss
- positive coping strategies
- explanation of the benefits of carer education programs
- respite options
- someone to assist with referrals to services

In Phases 3 and 4 families are most vulnerable to falling apart and require family relationship support.

Young Carer Program www.youngcarersnsw.asn.au

1800 242 636

Older Parent Carer Program

1800 242 636

Useful information

Health and medical system

It is important to understand how to work with health care professionals, and patient and carer rights and responsibilities.

Contact:

Doctor or Community Health Centre
Aboriginal Medical Service 02 9319 5823 (all locations)
Telephone Interpreter Service 13 14 50

Going to Hospital (information about NSW Government hospitals)

www.health.nsw.gov.au/hospitals/going_to_hospital/index.asp

Emergency Care Plan (Carer support kit) from Carers NSW www.carers.nsw.asn.au

1800 242 636

Medicines Line (search by medicines name) www.nps.org.au/consumers

1300 633 424

Carer Life Course



Patient and carer rights (see NSW)

<http://www.survivingthemaze.org.au/BCFC/BCFCNSW/BCFCNSW.htm>

NSW Carer Legislation

www.legislation.nsw.gov.au/fullhtml/inforce/act+20+2010+cd+0+N

Major illnesses or conditions

Carer Life Course / Resources www.carerlifecourse.org.au/resources/index.html

Complementary therapies/ Medicines and Treatments/ Medical tests, medical procedures. (see Conditions and Treatments) www.betterhealth.vic.gov.au

Caring for an older person (see NSW)

www.survivingthemaze.org.au/BCFC/BCFCNSW/BCFCNSW.htm

General information on care and resources for caring for an older person

www.agedcareaustralia.gov.au

Palliative and End of life care www.caresearch.com.au

Residential services

Caring for an older person (see NSW)

www.survivingthemaze.org.au/BCFC/BCFCNSW/BCFCNSW.htm

Accommodation Choices for Older Australians and their Families (download from Department of Families, Housing, Community Services and Indigenous Affairs website, under Seniors) www.fahcsia.gov.au

Accommodation for young people (Ageing, Disability and Home Care website, under People with a Disability) www.dadhc.nsw.gov.au

Caring for someone at home

Aged Care Assessment (see Caring for an older person, above)

Continence Foundation of Australia (bowel and bladder control)

www.continence.org.au/site/index.cfm

Health and Safety in the Home (fact sheets on health and environment)

www.health.nsw.gov.au/factsheets/environmental/index.asp

HOME Hospice (home-based end of life support) www.homehospice.com.au

1800 132 229

NSW Dementia Behaviour Management Advisory Services

1800 699 799 (24 hours)

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NSW Health Disability Aids

www.health.nsw.gov.au/initiatives/disabilityequipment/index.asp

Palliative or end of life care www.caresearch.com.au

Practical tips handbook for parents of children with a disability (download Operation Adaption Guide) www.ebility.com.au/fsf/

Legal and judicial

- How to work with Confidentiality and medical treatment (Common Questions at Office of the Public Guardian website)
www.lawlink.nsw.gov.au/lawlink/opg/ll_opg.nsf/pages/OPG_index
- Legal arrangements (Carer support kit available from Carers NSW) on 1800 242 636 or www.carersnsw.asn.au
- Patient and carer rights (see NSW and Dealing with Hospitals or Family member in Residential Care)
www.survivingthemaze.org.au/BCFC/BCFCNSW/BCFCNSW.htm

Financial

Information on carer benefits and financial planning

- Centrelink 13 27 17
- Financial Counsellors Association NSW 1300 914 408

Living Caring Working (improving quality of life for people with a life threatening illness, their families and communities) www.livingcaringworking.com

Negotiating with workplace about reducing hours and/ or changing work situation
www.workingcarersgateway.com.au

Medicare Australia www.medicareaustralia.gov.au
13 20 11

NSW Companion Card www.nswcompanioncard.org.au
1800 893 044

Private health insurance (see Health and Wellbeing) www.healthinsite.gov.au

Special Disability Trust (see Publications and listed in alphabetical order)
www.centrelink.gov.au
1800 734 750

Future planning

Future planning is about making decisions about the future care of the person needing care.

Advanced care planning www.ccdgp.com.au/site/index.cfm?display=23902

Family Agreement Plan (discussing future care plans with family members)
Contact Carer Line 1800 242 636 if this is difficult for you and your family.

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Guardianship Tribunal www.gt.nsw.gov.au
1800 463 928

Legal arrangements (Carer support kit available from Carers NSW) on 1800 242 636
or www.carersnsw.asn.au

Special Disability Trust (see Financial, above)

Carer tips

At this phase the carer may benefit from having someone to talk things over with or to vent their emotions. Partner and/or family relationships may be vulnerable to falling apart. Grief and loss may need to be addressed.

Useful fact sheets are contained in the Carer support kit available from Carers NSW on 1800 242 636 or www.carersnsw.asn.au

- Taking Care of Yourself
- Feelings
- Loss and Grief
- Safety at Home
- Taking a Break
- Cope with challenging situations or behaviours (download information from Publications and links) www.disability.wa.gov.au

Assertiveness for carers (download fact sheet from Information and resources)
www.carersnsw.asn.au

Caring for the carer: How talking with a counsellor helps (download fact sheet from Information and resources) www.carersnsw.asn.au

Handbook for Practical Caring is compiled by St John Ambulance and full of lots of practical tips for carers. To order contact Carer Line 1800 242 636.

Contact:

- Carer Line 1800 242 636 (Mon-Fri 9am to 5pm)
- Commonwealth Respite and Carelink Centre www9.health.gov.au/ccsd/
1800 052 222
- Relationships Australia (relationship support) www.nsw.relationships.org.au
1300 364 277
- Interrelate (relationship and family support) www.interrelate.org.au
1300 736 966

Carer support groups

Information on carer support groups and how to find a support group for your needs can be found at Carers NSW website (Information and resources)
www.carersnsw.asn.au

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Carer education

At this phase carers may benefit from more specific skills and knowledge, including First Aid and:

- Psychotherapeutic courses
- Self care and stress relief
- Positive coping strategies
- Grief and loss

Contact Carer Line for information about available carer education courses and programs 1800 242 636.

Advocacy training and opportunities

Carers may want to develop skills in advocacy for improved services and care. Visit the Carers NSW website (Information and resources) to download the Carer Action Pack or contact Carers NSW for information about the Carer Representation Program.

Carers NSW www.carersnsw.asn.au
02 9280 4744

Carer specific support and advocacy

Some carers may be able to access help with accessing services or other support.

- Carer Support Officer (all carers)
Carer Line 1800 242 636
- Older Parent Carer (carers of an adult child with a disability or chronic condition)
Carer Line 1800 242 636
- Family and Carer Mental Health Program
Carer Line 1800 242 636

NSW Health – Local Health Districts has information about carer support services in your local health district www.health.nsw.gov.au

Share with other carers online

Web forums and online support groups

- MyTime (parents of child with a disability) www.mytime.net.au
- Your Shout (adolescent sibling carers) www.liquidsalt.com.au/yourshout
- Cancer Connections www.cancerconnections.com.au
- Raising Children Network www.raisingchildren.net.au
- Livewire (families) www.livewire.org.au

Children and Young People

- Young Carers www.youngcarersnsw.asn.au
- Head Space (young people and mental illness) www.headspace.org.au/

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Sibling

- Siblings Australia www.siblingsaustralia.org.au
- Young Carers www.youngcarersnsw.asn.au

Spouse or partner

- Relationships Australia (relationship support) www.nsw.relationships.org.au
- Interrelate (relationship and family support) www.interrelate.org.au

Parent

- Association for Children with a Disability (useful downloads) www.acdnsw.org.au
- Head Space (young people and mental illness) www.headspace.org.au/

Carer Life Course / Resources www.carerlifecourse.org.au/resources/index.html