

Phase 2 Confirmation of illness or condition Summary and useful information and contacts

Confirmation of illness or condition

A doctor or health care professional confirms something is not right, and you learn the extent of the illness or condition.

Carer needs

Many carers need as much information as possible about:

- the illness or condition of the person requiring care
- health care professionals roles and responsibilities
- hospitals and residential facilities
- working with confidentiality in the health system
- consumer and carer rights

Carers need support in understanding how to work with the medical and health care system.

Carers may need support and information to make decisions:

- about where the person requiring care will live
- about financial and work arrangements

Carers may benefit from general carer education programs and information about carer support groups and respite options.

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 seek your doctor's assistance to check up on symptoms or health concerns.

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

Dealing with the hospital system (fact sheets with focus on frail/aged)

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

Medical tests, treatments, medications, medical procedures (Conditions and Treatments) www.betterhealth.vic.gov.au

How to make a complaint about services

ADHC (ADHC-funded and HACC services)

www.adhc.nsw.gov.au/contact_us/complaints_procedure

Health Care Complaints Commission www.hccc.nsw.gov.au

1800 043 159

NSW Ombudsman www.ombo.nsw.gov.au/

02 9286 1000

Outside Sydney 1800 451 524

Medicines Line (search by medicine name) www.nps.org.au

1300 888 763

Major illnesses or conditions

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

Medicines and Treatments/ Complementary therapies (refer 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

(See Caring for an older person, above)

Accommodation Choices for Older Australians and their Families (see Seniors)

www.fahcsia.gov.au

Accommodation for young people (see People with a Disability)

www.dadhc.nsw.gov.au

Caring for someone at home

Aged Care Assessment (see Caring for an older person)

Continence Foundation of Australia (see 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

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NSW Dementia Behaviour Management Advisory Services
1800 699 799 (24 hours)

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 or download fact sheet)
www.nscchealth.nsw.gov.au/carersupport/resources
- Patient and carer rights (refer 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

Managing work and caring www.workingcarersgateway.com.au

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

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

Older Parent Carer Program (for older carers caring for an adult child with a disability or chronic condition) www.carersnsw.asn.au
1800 242 636

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

Special Disability Trust (see Financial, above]

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Carer tips

At this phase the care role intensifies and carer health and wellbeing may begin to suffer. Carers may benefit from having someone to talk things over with or to vent their emotions. Grief and loss may begin to set in.

Get free carer support kits and fact sheets from Carers NSW www.carersnsw.asn.au 1800 242 636.

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

Talk to someone about your situation or call Carer Line 1800 242 636 (Mon-Fri 9am to 5pm).

Carer support groups

Information on carer support groups and how to find a support group for your needs (Information and resources) www.carersnsw.asn.au

Carer education

At this phase general carer information and basic information about the illness or condition, as well as beginning coping strategies might be helpful.

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

- Cancer Council NSW www.cancer council.com.au
- Carers NSW (Education and Training) www.carersnsw.asn.au
- Alzheimer's Australia (Education and Training) www.alzheimersaustralia.org.au

Look at other illness-specific websites to check for available carer education courses.

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

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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/

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