





Palliative Care Australia

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t: 02 6232 4433 f: 02 6232 4434

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Download updates of the Journeys Resource List at www.palliativecare.org.au

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INFORMATION, SUPPORT SERVICES AND RESOURCES

Organisation or program	Aboriginal and Torres Strait Islander information & support	Accommodation: hospice and holiday accommodation	Bereavement, loss and grief	Carer support	Community and social support	Complementary treatments	Counselling	Deciding on another child	End of life decisions	Entertainment	Equipment	Financial support	Funeral planning	Health information and services	Helping your partner or children	Home help	Interpreting and translating	Medicines	Multicultural information and support	Palliative care information	Pastoral and spiritual care and support	Remembering your child	Resources	Respite care	Rights and responsibilities	Symptom management	Travel and transport
Aboriginal and Torres Strait Islander Access Line	*			*								*		*													
Aboriginal Medical Service	*													*													
Angel Flight Australia																											*
Assistance Dogs Australia										*																	
Australian Centre for Grief & Bereavement			*																				*				
Australian Childhood Immunisation Register														*													
Australian Community of Child Photographers																						*					
Australian Counselling Association			*				*																				
Australian Funeral Directors Association													*										*				
Australian Organ Donor Register									*																		
Bear Cottage		*																		*	*	*		*			



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Bereavement Care Centre			*				*																*				
Bereavement Info and Referral Service			*																								
Better Health						*							*	*													
Camp Quality			*							*					*												
Cancer Council Australia			*		*	*	*							*					*				*				
Canteen			*		*					*				*	*							*					
Carers Australia/ Carers Associations	*			*	*		*												*	*			*		*		
CareSearch	*		*																*	*			*				
Centre for Genetics Education							*	*											*								
Centre for Palliative Care Research and Education																				*			*				
Centrelink	*											*							*								
Cochrane Collaboration														*						*							

JOURNEYS - INFORMATION, SUPPORT SERVICES AND RESOURCES

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Commonwealth Carer Resource Centres	*		*	*	*		*					*		*					*				*				
Commonwealth Respite and Carelink Centres				*	*									*		*			*				*	*			
Compassionate Friends			*		*																						
Consumers Health Forum of Australia														*											*		
DonateLife™							*		*																		
Dougy Center			*										*										*				
Education departments																							*				
Good Grief			*		*																						
GriefLink			*																				*				
healthdirect Australia														*													
HealthInsite						*			*					*				*		*							
Health Ombudsman																									*		

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Home and Community Care Program					*											*											
Independent Living Centres											*	*															
IDEAS											*												*				*
Just Better Care																*				*				*		*	*
Kids Helpline			*				*								*												
Leukaemia Foundation				*			*							*									*				*
Life Catchers																						*					
Lifeline	*		*				*																				
Make-A-Wish Foundation										*																	
Medicare	*											*															
Medicines Line						*												*									
Medline Plus														*				*									
MensLine Australia							*								*								*				
Multicultural Development Association																			*								

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Muscular Dystrophy Australia				*			*							*									*				
myDr														*				*					*				
NACCHO	*													*													
National Association for Loss and Grief			*				*																				
National Carer Counselling Program			*	*			*																				
National Centre for Childhood Grief			*												*												
National Center for Complementary and Alternative Medicines						*																					
National Palliative Care Service Directory														*						*							
National Prescribing Service																		*	*				*				
National Relay Service																	*										
National Tay-Sachs & Allied Diseases Association					*									*													
NSW Multicultural Health Communication Service																			*	*			*				

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Office of Complementary Medicines						*																					
Organ and Tissue Authority									*														*				
Palliative Care Australia (PCA)																			*	*			*		*		
PCA member organisations	*													*					*	*			*		*		
Paediatric palliative care services			*	*		*	*		*					*	*					*	*		*			*	
Palliative Care Information Service			*	*			*													*			*			*	
Parenting SA			*		*		*												*				*				
Patient Assisted Travel Schemes												*															*
Pharmaceutical Benefits Scheme																		*									
Program of Appliances for Disabled People											*																
Psychotherapy and Counselling Federation			*				*																				
Redkite			*		*							*			*								*				
Relationships Australia							*								*								*				

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Remembering Site																						*					
Ronald McDonald House Charities		*																				*		*			
Siblings Australia					*										*												
SIDS and Kids			*				*	*							*				*				*				
Starlight Children's Foundation										*												*					
Stillbirth & Neonatal Death Support			*		*		*																				
Teddy Love Club			*	*			*																*				
Therapeutic Goods Administration						*												*					*				
TLC for Kids					*										*												
Translating and Interpreting Service																	*										
Transport Authority																											*
Twinkle Toes																						*					
Very Special Kids		*	*	*			*														*			*			

INFORMATION, SUPPORT SERVICES AND RESOURCES

Aboriginal and Torres Strait Islander Access Line

t: 1800 556 955

See **Medicare** below for further information

Aboriginal Medical Service (AMS)

See National Aboriginal Community Controlled Health Organisation

Angel Flight Australia

A charity that co-ordinates non emergency flights for financially and medically needy people. All flights are free and may involve patients or compassionate carers travelling to or from medical facilities anywhere in Australia.

t: 1300 726 567 (toll free)

t: 07 3620 8300

f: 07 3852 6646

e: mail@angelflight.org.au

w: www.angelflight.org.au

p: PO Box 1201, Fortitude Valley QLD 4006

Assistance Dogs Australia

Provides information about assistance dogs and their availability in your area. Assistance Dogs aims to deliver freedom and independence to people with physical disabilities.

t: 1800 688 364 or 02 9548 3355

e: info@assistancedogs.org.au

w: www.assistancedogs.org.au

p: PO Box 455, Engadine NSW 2233

Australian Centre for Grief and Bereavement

Provides information on grief support for all ages and carries a number of publications in its library and bookshop.

t: 1800 642 066

t: 03 9265 2100

f: 03 9265 2150

e: info@grief.org.au

w: www.grief.org.au

p: McCulloch House, Monash Medical Centre, 246 Clayton Rd, Clayton VIC 3168

Australian Childhood Immunisation Register

A national register administered by Medicare Australia. It records details of vaccinations given to children under seven years of age who live in Australia. Its hotline provides information about your child's immunisation status.

t: 1800 653 809

TTY*: 1800 552 152 (hearing impaired)

TIS: 131 450 (Translating and Interpreting Service)

e: acir@medicareaustralia.gov.au

w: http://doiop.com/acir



Download a copy of the ACIR information sheet [PDF, 137Kb] http://doiop.com/acirsheet

For information about childhood immunisation visit the Department of Health and Ageing's w: www.immunise.health.gov.au or call the immunisation infoline: 1800 671 811

^{*} What is a TTY?

A TTY is a special device, also known as a teletypewriter or a textphone, that lets people who are deaf, hearing impaired, or speech-impaired use the telephone to communicate, by allowing them to type messages back and forth to one another instead of talking and listening. For further information contact the National Relay Service.



Australian Community of Child Photographers

Dedicated to giving the gift of photographic memories to families who have children with serious and terminal illnesses. The ACOCP is a volunteer organisation of child photographers from all over Australia who have come together to provide this gift to families in a caring, compassionate and heartfelt manner. ACOCP understands time is crucial in some cases and is available to call 24 hours a day, 7 days a week.

e: admin@acocp.org.au w: www.acocp.org.au

Australian Counselling Association

Provides an online directory of accredited counsellors and psychotherapists in Australia, including specialists in grief counselling.

t: 07 3356 4255

t: 1300 784 333

f: 07 3356 4709

e: aca@theaca.net.au w: www.theaca.net.au

p: PO Box 88, Grange QLD 4051

Australian Funeral Directors Association

Can provide information on how to arrange a funeral and contact details for accredited funeral service providers. It also produces a booklet entitled: When a baby has died.

t: 1300 888 188 (advice line for enquiries)

t: 03 9859 9966

f: 03 9819 7390

e: info@afda.org.au

w: www.afda.org.au

p: PO Box 291, Kew East VIC 3102

Australian Organ Donor Register

Records patient consent details. It also contains a frequently asked questions section which briefly explains when organ and tissue donation can occur.

t: 1800 777 203

e: aodr@medicareaustralia.gov.au

w: http://doiop.com/aodr

For more information about any aspect of organ and tissue donation you can contact any of the following organisations:

KIDNEY HEALTH AUSTRALIA

t: 1800 682 531

e: vic@kidney.org.au w: www.kidney.org.au

HEALTHINSITE

Reliable information about organ donation and other health topics. For contact details see HealthInsite.

ACT - DONATELIFE™

t: 02 6244 3071

f: 02 6244 2405

w: www.donatelife.gov.au

p: Canberra Hospital, Yamba Drive, Garran ACT 2605

NSW ORGAN & TISSUE DONATION SERVICE

t: 02 8566 1700

f: 02 8566 1755

w: www.donatelife.gov.au

p: PO Box 486, Kogarah NSW

NT - DONATELIFE™

t: 08 8922 8349

f: 08 8944 8096

w: www.donatelife.gov.au

p: Royal Darwin Hospital, 1st Floor Rocklands Drive, Tiwi NT 0810

QLD - DONATELIFE™

t: 07 3240 2350

f: 07 3240 2999

w: www.donatelife.gov.au

p: Princess Alexandra Hospital, Level 4, Ipswich Rd, Woolloongabba QLD 4102

SA - DONATELIFETM

t: 08 8207 7117

f: 08 8207 7102

w: www.donatelife.gov.au

p: Level 6, 45 Grenfell Street, Adelaide SA 5000

TAS - DONATELIFE™

t: 03 6270 2209

f: 03 6270 2223

w: www.donatelife.gov.au

p: GPO 1236, Hobart TAS 7001

VIC - DONATELIFE™

t: 03 8317 7400

f: 03 9349 2730

w: www.donatelife.gov.au

p: 538 Swanston Street, Carlton VIC 3053

WA - DONATELIFE™

t: 08 9222 0222

f: 08 9222 0220

w: www.donatelife.gov.au

p: 6th Floor, Albert Facey House,

469 Wellington Street, Perth WA 6000

See also Organ and Tissue Authority below

Bear Cottage

A hospice in New South Wales. It is a place where children with a terminal condition and their families can stay for respite care or end-of-life care in a home-like environment. Bear Cottage is located in Manly, Sydney, and takes referrals from throughout New South Wales.

t: 02 9976 8300

f: 02 9976 8303

e: narellam@chw.edu.au

w: www.bearcottage.chw.edu.au

p: PO Box 2500, Manly NSW 1655

Bereavement Care Centre

The centre offers bereavement counselling and a range of resources and information for bereaved adults and children.

t: 1300 654 556

e: info@bereavementcare.com.au

w: www.bereavementcare.com.au

p: PO Box 835, Wyong NSW 2259

Bereavement Information and Referral Service

This service provides information and referral assistance to members of the general public who need information on bereavement services available within Victoria. The service can also provide information on bereavement related issues. The service is unable to provide telephone bereavement counselling to callers.

t: 1300 664 786

Better Health

A website funded by the Victorian Government to provide the community with access to online health related information. It has a section on funerals with a summary of the issues to consider when planning a funeral. Its brochure *Funerals - some issues* explained is available through its website.

t: 1800 126 637

f: 03 9616 2845

w: www.betterhealth.vic.gov.au

p: GPO Box 4057, Melbourne VIC 3001

Camp Quality

A non-profit organisation committed to bringing hope and happiness to children living with cancer, their families and communities through recreational, educational and support programs.

t: 02 9876 0500

t: 1300 662 267 (for your nearest office)

f: 02 9869 0688

e: reception@campquality.org.au

w: www.campquality.org.au

p: Suite 6, 44-46 Oxford Street, Epping, NSW 2121



Cancer Council Australia

A national non-government organisation which works to prevent cancer and reduce illness, disability and death caused by cancer. The council can provide information on cancer, links to patient support organisations and specialists, and the Cancer Council Helpline (see below). The council has member organisations in each state and territory. To find your local office visit its website.

t: 02 8063 4100

f: 02 8063 4101

e: info@cancer.org.au w: www.cancer.org.au

p: GPO Box 4708, Sydney NSW 2001

Cancer Council Helpline

A free, confidential telephone information and support service run by Cancer Councils in each state and territory. Specially trained staff are available to answer your questions about cancer and offer emotional or practical support. The helpline can provide callers with links to cancer support groups and other community resources.

t: 13 11 20 (8.30 am – 6 pm Monday - Friday)

The Cancer Council Helpline is available in languages other than English through the **Multilingual Cancer Information Line**. Callers can listen to cancer information recorded in their own language. They can also connect to a cancer nurse, assisted by an interpreter. Languages and numbers are listed below:

Arabic	9209 0160
Cantonese	9209 0161
Greek	9209 0162
Italian	9209 0163
Mandarin	9209 0164
Polish	9209 0165
Russian	9209 0166
Spanish	9209 0167
Vietnamese	9209 0168
Other languages	9209 0169

Canteen

A national support organisation for young people aged 12–24 years living with cancer, and their families.

t: 1800 226 833 (for your nearest office)

f: 02 9299 6322

e: admin@canteen.org.au

w: www.canteen.org.au

p: PO Box 3821, Sydney NSW 2001

Carers Australia/ Carers Associations

Carers Australia is a not-for-profit national organisation which provides carers with information and education resources. Several of its resources are available in different languages. For family carer support and counselling contact your state or territory Carers Association.

t: 1800 242 636 (to access your local Association)

t: 02 6122 9900

f: 02 6122 9999

e: caa@carersaustralia.com.au

w: www.carersaustralia.com.au

p: Unit 1, 16 Napier Close, Deakin ACT 2600

See also Commonwealth Carer Resource Centres

CareSearch

An online resource providing access to evidencebased palliative care information and resources. The CareSearch website also provides information and resources about palliative care for Indigenous Australians and information on state and national organisations involved in Aboriginal health.

w: www.caresearch.com.au

Centre for Genetics Education

Information on specialist services, genetic counselling and prenatal diagnosis. The centre hosts a directory to help you find the closest genetic counselling unit.

t: 02 9926 7324

f: 02 9906 7529

e: contact@genetics.com.au

w: www.genetics.com.au

p: PO Box 317, St Leonards NSW 1590

Centre for Palliative Care Research and Education

The centre offers information on palliative care, including definitions and/or words used in palliative care. It also has a frequently asked questions section and information on who can help.

t: 07 3636 1449

f: 07 3636 7942

e: cpcre@health.qld.gov.au

w: http://doiop.com/cpcre

p: Royal Brisbane and Women's Hospital,

Post Office, Herston QLD 4029

Centrelink

Provides information on how best to access a range of Australian Government programs for financial support. As a carer you may be eligible for a number of payments and services.

w: www.centrelink.gov.au

Enquiries about carer payment and carer allowance

t: 13 27 17

w: http://doiop.com/caring

Services for people with additional needs TTY: 1800 552 152 (hearing and speech impaired)

Translating and Interpreting Service

TIS: 131 450 (local call rate)

Foreign language support and brochures are

available at www.medicare.gov.au

Centrelink Indigenous Call Centre

Indigenous Australians living in regional and remote areas can talk about Centrelink payments and services.

t: 13 63 80

Centrelink's Indigenous Australians section of its website has information on the Indigenous Call Centre and Indigenous specialist officers and on Indigenous publications and programs.
w: http://doiop.com/indigenous

Centrelink Multicultural Services can help if you need information in your own language, including free interpreter services for interviews and free translation of documents relating to Centrelink business. **Centrelink Multilingual Call** also allows you to speak to Centrelink in your own language. This is not an interpreter service. You can call this service to have your questions answered directly by Centrelink employees in your own language. Service in some languages is available by returning your call.

t: 13 12 02

w: www.centrelink.gov.au

Cochrane Collaboration

An international not-for-profit organisation which offers up-to-date information about the effects of healthcare through evidence-based healthcare databases. However the information is highly technical in clinical detail and advice from a care team member may be required.

w: www.cochrane.org

Commonwealth Carer Resource Centres

Operated by Carers Associations in each state and territory of Australia. They provide professional counselling, specialist advice and information.

t: 1800 242 636

w: www.carersaustralia.com.au (for contact details of Carer Associations in each state and territory)

A free Carer Support Kit is available in English and 13 other languages. It provides practical information to support carers. An Aboriginal and Torres Strait Islanders Carers Kit is also available. Kits can be obtained by:

- 1. Phoning the Aged Care Information Line on 1800 500 853
- 2. Phoning National Mailing and Marketing on (02) 6269 1080
- 3. Visiting the Aged Care Publications website at http://doiop.com/ccrcorder

An Order form for the Packs in all listed languages is also available (pages 3 & 4 of the order form) at http://doiop.com/freepubs

See also Carers Australia



Commonwealth Respite and Carelink Centres

Provide a single point of contact for carers seeking information and advice about centres for respite services and support. These centres are run by a wide variety of community organisations across Australia.

t: 1800 052 222 (during business hours)

t: 1800 059 059 (for emergency respite supportoutside standard business hours) TTY: 1800 555 677 and ask for 1800 052 222

Speech-to-speech relay:

1800 555 727 and ask for 1800 052 222 Translating and Interpreting Service: 13 14 50

e: commCarelink@health.gov.au

w: www9.health.gov.au/ccsd

w: www.carersaustralia.com.au

(for contact details of the Network of Carer Associations in each state and territory)

Compassionate Friends

Offers self-help support to families after the death of a child. They also offer advice and information to relatives, friends and professionals who are helping the family. Their website provides links to other organisations that may be able to help.

Compassionate Friends of Western Australia Inc

t: 1800 628 118

t: 08 9486 8711

f: 08 9486 1299

e: tcf.wa@eftel.net.au

w: www.compassionatefriendswa.org.au

p: City West Lotteries House, 2 Delhi Street, West Perth WA 6005

Consumers Health Forum of Australia

Can provide information and tips for consumers about how to test information for its accuracy and credibility and about consumer rights and responsibilities in health care.

t: 02 6273 5444

f: 02 6273 5888

e: info@chf.org.au

w: www.chf.org.au

w: www.chf.org.au/information-papers.php (for information papers)

p: PO Box 3099, Manuka ACT 2603

DonateLifeTM

A national network of organ and tissue donation agencies. For contact details see under Australian Organ Donor Register.

Dougy Center for Grieving Children and Families

Based in the USA, the centre produces a number of publications on grieving. It also provides a check list for teachers and schools on helping grieving children.

w: www.dougy.org

The centre's online support community connects teens, young adults and their families who are grieving a death for support and inspiration.

w: www.inspire.com/groups/the-dougy-center

Education departments

Home and distance education programs and resources are available to support families that choose to educate their child at home. Advice is available through the education department in each state and territory (contact details are available in the White Pages® under the Business & Government Listings pages).

An example of the education resources available can be found at: www.education.qld.gov.au/library/resource

Other webites:

w: www.curriculum.edu.au

w: www.home-ed.vic.edu.au

Hospitals may offer specialised hospital school programs to assist your child in their education. Contact your care team or social worker for information and advice.

Good Grief

Has a Seasons for growth program for children, young people or adults who have experienced significant change or loss. It delivers a range of services, including activities for primary and high school students, as well as adults. This program is available in a number of areas. Information can be

obtained by contacting the Seasons for Growth office or referring to the website.

t: 02 8912 2700

f: 02 9923 1655

e: info@goodgrief.org.au w: www.goodgrief.org.au

p: PO Box 1023, North Sydney NSW 2059

Griefl ink

A resource on death-related grief for all ages. It provides information on resources (including books and videos), bereavement services, educational activities and courses, and information on other grief-related organisations.

e: grieflink@adelaide.edu.au

w: www.grieflink.asn.au

healthdirect Australia

A free 24-hour telephone health advice line staffed by registered nurses to provide expert health advice. It is currently available to residents of the Australian Capital Territory, New South Wales, the Northern Territory, Tasmania, South Australia and Western Australia and is scheduled to be a fully national service by 2011.

t: 1800 022 222

w: www.healthdirect.org.au

HealthInsite

Offers easy access to up-to-date and quality information about all health subjects including access to information on complementary or alternative therapies and medicines. HealthInsite is an Australian Government initiative funded by the Department of Health and Ageing. It cannot provide advice about individual medical cases.

w: www.healthinsite.gov.au

For advice about individual medical cases contact your health professional or the healthdirect Australia telephone health advice line on 1800 022 222.

See healthdirect Australia

Health Ombudsman

The Health Ombudsman in each state and territory can provide information about how to make a complaint about a health service or health care provider.

AUSTRALIAN CAPITAL TERRITORY

ACT COMMUNITY AND HEALTH SERVICES COMPLAINTS COMMISSIONER

t: 02 6205 2222

TTY: 02 6205 1666

Translating and Interpreting Service: 131 450

e: human.rights@act.gov.au w: www.hrc.act.gov.au

NEW SOUTH WALES

HEALTH CARE COMPLAINTS COMMISSION

t: 1800 043 159

TTY: 02 9219 7555 (for the hearing impaired)

e: hccc@hccc.nsw.gov.au w: www.hccc.nsw.gov.au

NORTHERN TERRITORY

COMMISSIONER FOR HEALTH AND COMMUNITY SERVICES COMPLAINTS COMMISSION

t: 1800 806 380

e: hcscc.omb@nt.gov.au

w: www.hcscc.nt.gov.au

QUEENSLAND

HEALTH QUALITY AND COMPLAINTS COMMISSION

t: 1800 077 308 (toll free outside Brisbane)

TTY: 07 3120 5997

e: info@hqcc.qld.gov.au

w: www.hqcc.qld.gov.au

SOUTH AUSTRALIA THE SA OMBUDSMAN

t: 1800 182 150

e: ombudsman@ombudsman.sa.gov.au

w: www.ombudsman.sa.gov.au

TASMANIA

HEALTH COMPLAINTS COMMISSIONER

t: 1800 001 170 (Free call)

e: health.complaints@ombudsman.tas.gov.au

w: www.healthcomplaints.tas.gov.au



VICTORIA

OFFICE OF THE HEALTH SERVICES COMMISSIONER

t: 1800 136 066

TTY: 1300 550 275 (for the hearing impaired)

e: hsc@dhs.vic.gov.au

w: www.health.vic.gov.au/hsc

WESTERN AUSTRALIA

THE OFFICE OF HEALTH REVIEW

t: 1800 813 583 TTY: 08 9323 0616

e: mail@healthreview.wa.gov.au w: www.healthreview.wa.gov.au

Home and Community Care (HACC) Program

A joint Australian, state and territory government initiative. The Program provides services such as domestic assistance, personal care as well as professional allied health care and nursing services, to support older Australians, younger people with a disability and their carers to be more independent at home and in the community and to reduce the potential or inappropriate need for admission to residential care.

t: 02 6289 8464

e: hacc@health.gov.au

AUSTRALIAN CAPITAL TERRITORY ACT HEALTH

t: 02 6207 8734

w: www.health.act.gov.au/c/health p: GPO Box 825, Canberra ACT 2601

NEW SOUTH WALES

DEPARTMENT OF AGEING, DISABILITY AND HOME CARE

t: 02 8270 2000 TTY: 02 8270 2167

w: http://doiop.com/homecareservice

p: Level 5, 83 Clarence Street, Sydney NSW 2000

NORTHERN TERRITORY

DEPARTMENT OF HEALTH AND COMMUNITY SERVICES

t: 08 8999 2400

w: http://doiop.com/hacc

p: PO Box 40596, Darwin NT 0811

QUEENSLAND

DISABILITY SERVICES QUEENSLAND

t: 1800 177 120 (toll-free within Australia) TTY: 07 3896 3471 or 1800 010 222

(toll-free within Australia)

e: disabilityinfo@disability.qld.gov.au

w: www.disability.qld.gov.au

p: HACC Unit, Citilink Business Centre, Building 1, Floor 2, 153 Campbell Street, BOWEN HILLS QLD 4006

SOUTH AUSTRALIA

DEPARTMENT OF HUMAN SERVICES

t: 08 8207 0522

e: ofta@dfc.sa.gov.au

w: www.familiesandcommunities.sa.gov.au (Department for Families and Communities)

p: PO Box 70, Rundle Mall, Adelaide SA 5000

TASMANIA

DEPARTMENT OF HEALTH AND HUMAN SERVICES

t: 03 6233 3185

w: www.dhhs.tas.gov.au/hacc

p: GPO Box 125, Hobart TAS 7001

VICTORIA

DEPARTMENT OF HUMAN SERVICES

t: 03 9096 8692

w: www.health.vic.gov.au/hacc

p: GPO Box 4057, Melbourne VIC 3001

WESTERN AUSTRALIA

DEPARTMENT OF HEALTH

t: 08 9222 4060

w: www.health.wa.gov.au/hacc/home p: PO Box 8172, Perth Business Centre,

Perth WA 6849

Immunisation Register

See Australian Childhood Immunisation Register

Independent Living Centres (ILC)

Provide access to information and advice on medical equipment and consumables (searchable database of products and equipment) through the ILC network. Local centres are able to advise on programs for funding support.

ILC Infoline

t: 1300 885 886 (You will be connected to your local state/territory ILC for the cost of a local phone call. NT callers are automatically directed to ILC at SA) w: www.ilcaustralia.org.au

AUSTRALIAN CAPITAL TERRITORY

t: 02 6205 1900

f: 02 6205 1906

e: ilcact@act.gov.au

w: www.health.act.gov.au/ilc

NEW SOUTH WALES

t: 1300 885 886

t: 02 9890 0940

f: 02 9890 0966

e: welcome@ilcnsw.asn.au w: www.ilcnsw.asn.au

QUEENSLAND

LIFETECH QUEENSLAND

t: 07 3552 9000

t: 1300 885 886

f: 07 3552 9088

e: mail@lifetec.org.au w: www.lifetech.org.au

SOUTH AUSTRALIA

t: 1300 885 886

t: 08 8266 5260

f: 08 8266 5263

e: ilcsa@dfc.sa.gov.au w: www.disability.sa.gov.au

TASMANIA

t: 03 6334 5899

f: 03 6334 0045

e: ilc@ilctas.asn.au w: www.ilctas.asn.au

VICTORIA

t: 1300 885 886 (service not available to mobile phone users)

t: 03 9362 6111

TTY: 03 9314 9001

f: 03 9314 9825

e: ilc@yooralla.com.au w: www.yooralla.com.au

WESTERN AUSTRALIA

INDEPENDENT LIVING CENTRE OF WESTERN AUSTRALIA

t: 1300 885 886 (service not available to mobile phone users)

t: 08 9381 0600

f: 08 9381 0611

e: enquiries@ilc.com.au

w: www.ilc.com.au

Information on Disability & Education Awareness Services Inc (IDEAS)

A not-for-profit organisation that offers information services and products for people with a disability, their families and carers. It has resources and fact sheets on disability and a database of information on disability services, equipment suppliers and accessible travel.

t: 1800 029 904

t: 02 6947 3377

TTY: 02 6947 3377

f: 02 6947 3723

e: info@ideas.org.au (Information Officer)

w: www.ideas.org.au

p: PO Box 786, Tumut, NSW 2720

If you need an interpreter please call the Translating and Interpreting Service (TIS) on 131 450 and ask them contact IDEAS on 1800 029 904 between 9:00 am and 5:00 pm.

See also National Relay Service

t: 133 677

Interpreting Service

Provides 24-hour access to interpreter services.

t: 131 450

See Translating and Interpreting Service (TIS)



Just Better Care

A network of locally owned agencies offering a range of services including palliative care, nursing, medication and wound care, domestic assistance, transportation, and meal preparation. They also offer respite care. Staff include community care workers, enrolled nurses and registered nurses. They operate in the Sydney metropolitan area, regional New South Wales, Queensland and Australian Capital Territory.

t: 1300 587 823

w: www.justbettercare.com.au

Kids Helpline

Provides anonymous, confidential telephone, email and web counselling for young people aged from 5 to 18 years, 24 hours a day, seven days a week.

t: 1800 55 1800 (counselling line)

t: 07 3369 1588

e: admin@boystown.com.au w: www.kidshelp.com.au

p: PO Box 2000, Milton QLD 4064

Leukaemia Foundation

A national not-for-profit organisation dedicated to the care and cure of patients and families living with leukaemia, lymphomas, myeloma and related blood disorders. The foundation provides practical care and support to patients as well as undertaking research.

t: 1800 620 420 (for your nearest Foundation office)

t: 07 3866 4000

f: 07 3866 4011

e: info@leukaemia.org.au w: www.leukaemia.org.au

p: GPO Box 9954 in your capital city

Life Catchers

Provides ideas on electronically storing photographs in a variety of formats, such as PowerPoint slides and on DVDs.

t: 02 6554 1960

e: info@lifecatchers.com.au

w: www.lifecatchers.com.au

p: 3736 Wallanbah Rd, Nabiac NSW 2312

The Life Catchers website is just one example of the services available in this area. You can contact your local supplier through the Yellow Pages® telephone directory under photographic storage or a similar term.

Information on storing and preserving photographs is also available from the Australian Institute of Aboriginal and Torres Strait Islander Studies (AIATSIS)

w: www.aiatsis.gov.au/collections/advice.html

Lifeline

Provides free telephone counselling and support services to people of all ages, 24 hours a day, seven days a week. The counselling line is staffed by trained volunteer telephone counsellors.

t: 13 11 14 (counselling line)

t: 02 6215 9400

w: www.lifeline.org.au

p: PO Box 173, Deakin ACT 2600

Make-A-Wish Foundation of Australia

A wish granting organisation which works to grant the wishes of children with a terminal condition.

t: 1800 032 260 (for your nearest office)

t: 03 9426 0777

f: 03 9426 0799

e: wishes@makeawish.org.au

w: www.makeawish.org.au

Medicare Australia

Provides access to subsidised health care programs for Australians. It provides access to general practice, specialists, radiology, pathology and optometrists services. If your family needs a lot of medicines in a year, its Safety Net helps you with the cost of medicines. Medicare also has a range of multilingual information sheets.

Medicare Public Enquiries Line

t: 132 011 (available during business hours)

e: medicare@medicareaustralia.gov.au

w: www.medicare.gov.au

Aboriginal and Torres Strait Islander Access Line

Talk with your Indigenous health care worker to be certain you and your family are fully registered and ready to receive any benefits.

t: 1800 556 955

Medicare customers in Northern Australia can access Medicare Australia information and support via the Centrelink Indigenous Call Centre.

t: 13 63 80

See also Pharmaceutical Benefits Scheme

Medicines Line

Provides consumers with access to independent, accurate and up-to-date information about prescription, over-the-counter and complementary medicines. The information is provided by experienced medicines information specialists and clinical pharmacists.

t: 1300 633 424 (Monday to Friday 9am-5pm, AEST) w: http://doiop.com/medicines

You can also ask your pharmacist for information about medicines.

MedlinePlus

Directs you to information to help answer health questions. MedlinePlus brings together authoritative information and has extensive information about medicines.

w: www.nlm.nih.gov/medlineplus

MensLine Australia

The national telephone support, information and referral service for men with family and relationship concerns. The service is staffed by paid professional counsellors, experienced in men's issues. It also offers resources and a database of men's services throughout Australia.

t: 1300 78 99 78 (24 hour support line)

e: talkitover@menslineaus.org.au

w: www.menslineaus.org.au

Multicultural Development Association

Promotes multiculturalism and provides services in the areas of settlement support, community development and advocacy.

t: 07 3337 5400

e: mailbox@mdabne.org.au

w: www.mdainc.org.au

p: 512 Stanley St, South Brisbane QLD

Muscular Dystrophy Australia

Offers information and support to sufferers of muscular dystrophy and their families.

t: 1800 656 632

t: 03 9320 9555

f: 03 9320 9595

e: info@mda.org.au

w: www.mda.org.au

p: 111 Boundary Road, North Melbourne VIC 3051

myDr

An Australian health care website providing health information, articles and items of interest about a wide variety of diseases and conditions, tests and treatments, health and fitness issues, and medications. It also has listings of health support groups and allows you to search for a health professional in your area using several criteria, including specialty and gender.

w: www.mydr.com.au



National Aboriginal Community Controlled Health Organisation (NACCHO)

The national peak Aboriginal health body representing Aboriginal Community Controlled Health Services throughout Australia. An Aboriginal Medical Service (AMS) is a primary health care service initiated and operated by local Aboriginal community to deliver holistic, comprehensive and culturally appropriate health care to the community which controls it. To find an Indigenous health worker through an AMS contact NACCHO.

t: 02 6248 0644

f: 02 6248 0744

e: irene@naccho.org.au or elaine@naccho.org.au (for further information on NACCHO)

w: www.naccho.org.au

p: PO Box 5120, Braddon ACT 2612

National Association for Loss and Grief

Runs a national telephone information and referral service for people of all ages. The association also accredits loss and grief counsellors.

NATIONAL ASSOCIATION FOR LOSS AND GRIEF (VIC)

t: 03 9650 3000

f: 03 9650 5777

e: info@nalagvic.org.au

w: www.nalagvic.org.au

p: Suite 4, Level 1, 182 Victoria Parade, East Melbourne VIC 3002

National Carer Counselling Program

The Program is delivered by Carers Associations in every state and territory and is managed by Carers Australia. Carers are able to obtain counselling from qualified counsellors on issues that are specific to the carer's needs such as depression, stress-related issues, grief and loss and coping skills.

t: 1800 242 636

w: http://doiop.com/nccp

See also Carers Australia

National Centre for Childhood Grief

Offers support in a safe place where children grieving a death can share their experience as they learn to live with its impact on their lives. The centre also offers education and training for individuals, schools and other organisations handling the grief of children and young people.

t: 1300 654 556

e: afriendsplace@me.com

w: www.childhoodgrief.org.au

p: PO Box 327, Epping NSW 1710

National Center for Complementary and Alternative Medicines

The centre is a US-Government agency which provides information about complementary and alternative treatments particularly in regard to the evidence that supports their use for specific health purposes. Information on this site is not intended to substitute the medical expertise and advice of your care team. The site can be searched by medical condition and name of treatment.

e: info@nccam.nih.gov w: www.nccam.nih.gov

National Palliative Care Service Directory

Contains information about specialist palliative care services, primary care services and other community support services. Searches can be conducted by postcode or type of service.

w: www.palliativecare.org.au

See page 22 for a list of dedicated paediatric palliative care services.

National Prescribing Service (NPS)

Offers information on medicines, including online access to all consumer medicines information and fact sheets which include the use, instructions, actions and side effects of every prescription and many non-prescription medicines.

t: 02 8217 8700 f: 02 9211 7578 e: info@nps.org.au w: www.nps.org.au

p: PO Box 1147, Strawberry Hills NSW 2012

TRANSLATED HEALTH INFORMATION ABOUT MEDICINES

The National Prescribing Service works with the Federation of Ethnic Communities' Councils of Australia (FECCA) and other partners to provide translated health information about medicines.

w: http://doiop.com/translatedhealthinfo

Online medicines search w: www.nps.org.au/search_by_medicine_name

See also Medicines Line

National Relay Service

A Commonwealth Government initiative which provides an Australia-wide telephone access service for people who are deaf or have a hearing or speech impairment. It is also available to anyone who wishes to contact a person with a hearing or speech impairment.

TTY/Voice: 13 36 77

Speech-to-speech relay: 1800 555 677

The National Relay Service has a Helpdesk to assist people in using the relay service.

t: 1800 555 660 TTY: 1800 555 630 SMS: 0416 001 350

e: helpdesk@relayservice.com.au w: www.relayservice.com.au

For general information, advice or training requests relating to the National Relay Service

Voice: 1800 555 660

(Monday to Friday 9am to 5pm, Sydney time)

TTY: 1800 555 630

National Tay-Sachs and Allied Diseases Association

A US-based organisation dedicated to the treatment and prevention of Tay-Sachs, Canavan, and related genetic diseases and works to provide information and support services to individuals and families affected by these diseases.

w: www.ntsad.org

NSW Multicultural Health Communication Service

Produces brochures on palliative care in 20 languages.

t: 02 9816 0347 f: 02 9816 0302

e: mhcs@sesiahs.health.nsw.gov.au

w: www.mhcs.health.nsw.gov.au

p: Locked Mail Bag No 5003, Gladesville NSW 2111

Office of Complementary Medicines

See Therapeutic Goods Administration

Organ and Tissue Authority

(The Authority) is an independent statutory authority within the Australian Government Health and Ageing portfolio. It works to establish a nationally coordinated approach to organ and tissue donation for transplantation. It offers information on organ and tissue donation.

t: 02 6198 9800 f: 02 6198 9801

w: www.donate life.gov.au/The-Authority/About-us

p: PO Box 295, Civic Square ACT 2608

Family Discussion Kit

The kit will help your family to have an informed conversation about each other's donation wishes.

w: http://doiop.com/family-discussionkit

See also **Australian Organ Donor Register** for details of the **DonateLife™** Network.



Palliative Care Australia (PCA)

Is able to provide information on palliative care and palliative care services across Australia. Its website contains various publications and resource guides including a brochure on patient rights and responsibilities.

t: 02 6232 4433

t: 1800 660 055

f: 02 6232 4434

e: pcainc@palliativecare.org.au

w: www.palliativecare.org.au

p: PO Box 24, Deakin West ACT 2600

Information and resources on palliative care and treatment options in different languages can also be obtained from the state or territory palliative care organisations listed below under **Palliative Care Australia member organisations**.

Palliative Care Australia member organisations

ACT PALLIATIVE CARE SOCIETY

t: 02 6273 9606

f: 02 6273 9590

e: office@pallcareact.org.au w: www.pallcareact.org.au

PALLIATIVE CARE NT

t: 08 8922 6769

e: pcnt@palliativecare.org.au w: www.nt.palliativecare.org.au

PALLIATIVE CARE NEW SOUTH WALES

t: 02 9206 2094 / 0403 669 491

f: 02 9206 2094

e: info@palliativecarensw.org.au w: www.palliativecarensw.org.au

PALLIATIVE CARE QUEENSLAND

t: 07 3633 0096

t: 1800 660 055

f: 07 3633 0086

e: enquiries@palliativecareqld.org.au w: www.palliativecareqld.org.au

PALLIATIVE CARE COUNCIL OF SOUTH AUSTRALIA

t: 08 8291 4137

f: 08 8291 4122

e: pallcare@pallcare.asn.au

w: www.pallcare.asn.au

TASMANIAN ASSOCIATION FOR HOSPICE AND PALLIATIVE CARE

t: 03 6285 2514

f: 03 6239 6030

e: tahpc@intrepidonline.com.au

w: www.tas.palliativecare.org.au

PALLIATIVE CARE VICTORIA

t: 03 9662 9644

f: 03 9662 9722

e: info@pallcarevic.asn.au w: www.pallcarevic.asn.au

PALLIATIVE CARE WA

t: 08 9382 9367

t: 1300 551 704

f: 08 1300 551 704

e: pcwainc@palliativecarewa.asn.au

w: www.palliativecarewa.asn.au

Paediatric palliative care services

NEW SOUTH WALES

Department of Pain Medicine and Palliative Care

The Children's Hospital at Westmead Cnr Hawkesbury Road and Hainsworth Street Westmead NSW 2145

t: 02 9845 0000

f: 02 9845 2111

e: judithf@chw.edu.au or SarahP4@chw.edu.au

Contact: Judy Frost or Sarah Potter

Bear Cottage

2 Fairybower Road, Manly 2095

t: 02 9976 8300

f: 02 9976 8303

e: NarelleM@chw.edu.au

w: www.bearcottage.chw.edu.au

Contact: Narelle Martin

Sydney Children's Hospital Pain and Palliative Care Service

High Street, Randwick NSW 2031

t: 02 9382 2095

f: 02 9382 7946

e: cncpalliativecaresch@sesiahs.health.nsw.gov.au

Contact: Clinical Nurse Consultant – Palliative Care Services: multidisciplinary, consultative service

Paediatric Pain and Palliative Care Service

John Hunter Children's Hospital Lookout Road, New Lambton NSW 2305

t: 02 4921 3387

f: 02 4921 3599

e: paedpallcare@hnehealth.nsw.gov.au

w: http://doiop.com/johnhunterchildrenshospital

Contact: Dr Sharon Ryan

Services: this service is Newcastle-based. It serves the Hunter New England and Northern New South Wales regions. Please note that in order for the service to be involved in the care of a child, a referral from the child's treating doctor is required.

QUEENSLAND

Paediatric Palliative Care Service'

Children's Health Services District 1st Floor, South Tower Royal Children's Hospital Herston Rd, Herston, QLD 4029

t: 07 3636 9480

f: 07 3636 9432

e: PPCS@health.qld.gov.au

w: www.health.qld.gov.au/cpcre/rchpallcare.asp Contact: Lee-Anne Pedersen or Anthony Herbert Services: consultative service for children with cancer and non-cancer life-limiting or life threatening conditions

SOUTH AUSTRALIA

Paediatric Palliative Care Service

Childrens Youth Womens Health Service 72 King William Rd, North Adelaide, SA 5006

t: 08 81617994

VICTORIA

Very Special Kids

321 Glenferrie Road, Malvern, Vic 3144

t: 03 9804 6222

f: 03 9822 1252

e: amurphy@vsk.org.au

w: www.vsk.org.au

Victorian Paediatric Palliative Care Program

Royal Children's Hospital

Parkville Vic 3052

t: 03 934 55374

f: 03 934 55585

w: www.rch.org.au/rch_palliative

Contact: Jenny Hynson or Melissa Heywood Services: state-wide consultation-liaison team

WESTERN AUSTRALIA

WA Statewide Paediatric Palliative Care Programs

Princess Margaret Hospital for Children Roberts Road, Perth, WA 6006

t: 08 9340 8222

f: 08 9340 8384

e: marianne.phillips@health.wa.gov.au

Contact: Dr Marianne Phillips

Services: oncology/haematology and

non-oncological life-limiting illnesses programs

and services

Palliative Care Information Service (QLD)

A free community information based telephone support service for Queenslanders. It provides up-to-date information on services available in metropolitan, regional and remote areas of Queensland, information and links for people with a terminal condition and their carers.

t: 1800 772 273

t: 07 3632 8333

e: info@pcis.org.au

w: www.pcis.org.au

p: PO Box 2020, Windsor QLD 4030



Parenting SA

Supports parents in South Australia with help through its Parent Helpline which offers information, counselling and support. Parenting SA also has a range of resources, many of which are in different languages.

Parent Helpline

t: 1300 364 100 (24 hours a day, seven days a week, every day of the year)

Parenting SA

t: 08 8303 1660

w: www.parenting.sa.gov.au

p: 295 South Terrace, Adelaide SA 5000

Patient Assisted Travel Schemes (PATS)

Enable patients living in rural areas to access specialist medical services not available at local level by providing financial help for the cost of travel and accommodation access treatment. Every state and territory health department has a scheme. The eligibility requirements for the schemes vary.

AUSTRALIAN CAPITAL TERRITORY

INTERSTATE PATIENT ASSISTANCE TRAVEL SCHEME

t: 02 6205 3299

w: http://doiop.com/iptasact

NEW SOUTH WALES

ISOLATED PATIENTS' TRAVEL AND ACCOMMODATION ASSISTANCE SCHEME

t: 02 6058 4511

w: http://doiop.com/iptaasnsw

NORTHERN TERRITORY

PATIENT ASSISTED TRAVEL SCHEME

t: 1800 186 026

w: http://doiop.com/patsnt

QUEENSLAND

PATIENT TRAVEL SUBSIDY SCHEME

t: 07 3236 4833

http://doiop.com/patienttravelscheme

SOUTH AUSTRALIA

PATIENT ASSISTANCE TRANSPORT SCHEME

t: 1800 188 115

w: www.rah.sa.gov.au/country/pats.php

TASMANIA

PATIENT TRAVEL ASSISTANCE SCHEME

t: 03 6222 8225- Royal Hobart Hospital

t: 03 6348 7249 – Launceston General Hospital

t: 03 6430 3673 - North West Regional Hospital

w: http://doiop.com/ptas

VICTORIA

VICTORIAN PATIENT TRANSPORT ASSISTANCE SCHEME

t: 03 9616 7777

w: www.health.vic.gov.au/ruralhealth/vptas/index.htm

WESTERN AUSTRALIA

PATIENT TRANSPORT SCHEME (WA)

t: 1300 135 030

w: http://doiop.com/wachs

Pharmaceutical Benefits Scheme (PBS)

Through the PBS the Australian Government subsidises the cost of a wide range of prescription medicines. Medicare administers the PBS.

t: 132 290 (enquiries and support call)

e: pbs@medicareaustralia.gov.au

w: www.medicare.gov.au/provider/pbs/index.jsp

See also Medicare Australia.

Program of Appliances for Disabled People (PADP)

Each state and territory provides assistance for families who require access to a range of equipment to help them care for their child at home. In some states the programs are called Program of Appliances for Disabled People. Access is criteria-based and may vary from state to state. These programs will also be able to advise on services including home and care modifications and access to a specialist child occupational therapist. Ask your care team (specifically your social worker) for information on how best to access these schemes.

Psychotherapy and Counselling Federation of Australia has an online Find a therapist list of accredited counsellors and psychotherapists. You can search by name, suburb, state or postcode.

t: 03 9486 3077

f: 03 9486 3933

e: info@pacfa.org.au w: www.pacfa.org.au

p: 290 Park Street, Fitzroy North VIC 3068

Redkite

An Australian charity that supports children and their families through cancer by providing emotional guidance, financial relief and educational services. It offers professional counselling support for bereaved parents and other family members through telephone and email Support. Redkite operates in New South Wales, Queensland, Victoria and Western Australia.

For information

t: 1800 334 771

e: info@redkite.org.au w: www.redkite.org.au

For support

t: 1300 722 644

(Monday to Friday between 9am to 5pm AEST)

e: support@redkite.org.au

National and NSW office

t: 02 9219 4000

f: 02 9280 1518

e: national@redkite.org.au

p: PO Box 3220, Redfern NSW 2016

Queensland office

t: 07 3832 8853

f: 07 3832 8871

e: qld@redkite.org.au

p: PO Box 1889, Toowong QLD 4066

Victorian office

t: 03 9857 4155

f: 03 9857 4166

e: vic@redkite.org.au

p: PO Box 1220 G, North Balwyn VIC 3104

Western Australia office

t: 08 9382 3321

f: 08 9380 4533

e: wa@redkite.org.au

p: 34 Coghlan Road, Subiaco WA 6008

Relationships Australia

Provides resources to couples, individuals and families to help enhance and support relationships. Its website includes a list of the locations where it operates.

t: 1300 364 277

w: www.relationships.com.au

Remembering Site

This is a USA-based not-for-profit initiative where you can upload your memories. It contains ideas on making memories of all kinds through story writing, photograph collections and recording.

e: support@therememberingsite.org

w: www.therememberingsite.org

A number of other websites provide ideas on scrapbooking - a way to store, record and share photographs and memories.

w: www.scrapbooking.com

w: www.scrapjazz.com

w: www.scrapbooking.about.com

w: www.creativememories.com.au

Local craft and art shops can also generally provide information and can be contacted via the Yellow Pages® telephone directory under art and craft.

Ronald McDonald House Charities

Work to improve the health and wellbeing of seriously ill children. Their work includes the Ronald McDonald Houses which are attached to major women's or children's hospitals and provide a 'home-away-from-home' for seriously ill children and their families. Access criteria apply.

t: 02 9875 6666

f: 02 9875 6588

e: rmhc@rmhc.org.au

w: www.rmhc.org.au

p: PO Box 392, Pennant Hills NSW 1715



Siblings Australia Inc

Develops and co-ordinates services for families, and in particular, brothers and sisters of children with special needs such as disability or chronic illness.

t: 08 83571214 08 8357 1216

e: info@siblingsaustralia.org.au

w: www.siblingsaustralia.org.au

p: 23A King William Road, Unley SA 5061

Although Siblings Australia provides some services to siblings and their families, they are not a crisis support service. If you would like to talk to someone urgently about a concern, they recommend you contact:

Kids Helpline - 1800 55 1800

Lifeline - 13 11 14

beyondblue info line – 1300 22 4636

SIDS and Kids

Provide access to information and support networks for all ages across Australia. SIDS and Kids also has a wide range of booklets for bereaved families. Hard copies are available through your local SIDS and Kids office.

t: 03 9819 4595

f: 03 9818 4596

e: national@sidsandkids.org

w: www.sidsandkids.org

p: Suite 1, 98 Morang Road, Hawthorn VIC 3122

For advice or bereavement support

t: 1300 308 307 (to contact your local SIDS and Kids member organisation)

Starlight Children's Foundation Australia

The foundation runs various programs for seriously ill children and their families. Its programs include Starlight Express Rooms and Fun Centres in various hospitals, as well as Starlight Escapes and the Starlight Wish Granting Program. It can also provide information on how to purchase the right to name a star in your child's name.

t: 1300 727 827 (for your nearest office)

f: 02 9437 4634

e: starlight@starlight.org.au w: www.starlight.org.au Other websites which include information on purchasing a star are:

w: www.starlight.org

w: www.starregistry.com

Stillbirth and Neonatal Death Support (SANDS) Australia

Provide details of local services for parents and families following the death of a baby. SANDS has local offices throughout Australia.

t: 03 9899 0217 (SANDS VIC)

e: info@sands.org.au

w: www.sands.org.au

SANDS (QLD) INC

t: 1800 228 655 (outside Brisbane and within Queensland) or 1800 228 655

t: 07 3254 3422

f: 07 3358 2533

e: sandsqld@powerup.com.au

w: www.sandsqld.com

p: PO Box 934, New Farm QLD 4005

SANDS SOUTH AUSTRALIA

t: 08 8277 0304

e: info@sandssa.org (for general queries)

e: support@sandssa.org (for support)

w: www.sandssa.org

p: PO Box 380, Park Holme SA 5043

SANDS VICTORIA

t: 03 9899 0217 (administration)

t: 03 9899 0218 (support)

f: 03 9899 0219

e: info@sandsvic.org.au

w: http://www.sandsvic.org.au

p: Suite 208, 901 Whitehorse Road, Box Hill VIC 3128

Teddy Love Club (TLC)

An Australia wide pregnancy and infant loss support program. The club supports parents and families who have experienced a neo-natal death.

t: 1800 824 240

w: www.teddyloveclub.org.au

e: contactus@teddyloveclub.org.au

Therapeutic Goods Administration (TGA)

The TGA carries out a range of assessment and monitoring activities to ensure therapeutic goods available in Australia are of an acceptable standard with the aim of ensuring that the Australian community has access to therapeutic advances. All approved goods appear on the Australian Register of Therapeutic Goods (ARTG).

t: 1800 020 653 (for publications or general enquiries)

t: 02 6232 8610 (for publications enquiries

t: 02 6232 8444 (switchboard)

TTY: 1800 555 677 then ask for 1800 020 653 Speech-to-speech relay: phone 1800 555 727 then ask for 1800 020 653

f: 02 6203 1605

e: info@tga.gov.au

w: www.tga.gov.au

p: PO Box 100, Woden ACT 2606

Australian Register of Therapeutic Goods

w: http://doiop.com/artg

Complementary medicines fact sheets and enquiries

The Office of Complementary Medicines regulates and provides information on complementary medicines for Australians.

Enquiries about complementary medicines

t: 1800 020 653 (freecall within Australia)

t: 02 6232 8634

TTY: 1800 555 677 then ask for 1800 020 653 Speech-to-speech relay: phone 1800 555 727 then ask for 1800 020 653

f: 02 6203 1657 (preferred) or 02 6232 8577

e: ocm@tga.gov.au

w: www.tga.gov.au/cm/cm.htm

p: Office of Complementary Medicines, TGA, PO Box 100, Woden ACT 2606

Enquiries about access to unapproved medicines

(includes Special Access Scheme, clinical trials, authorised prescribers, personal importation)

t: 1800 020 653 t: 02 6232 8111

TTY: 1800 555 677 then ask for 1800 020 653 Speech-to-speech relay: phone 1800 555 727 then ask for 1800 020 653

f: 02 6232 8112

e: eds@health.gov.au

p: Office of Prescription Medicines, TGA, PO Box 100, Woden ACT 2606

TLC for kids

A registered children's charity which provides support services for sick children in hospitals, medical centres, organisations working with sick children and children receiving home care. TLC for kids only takes referrals from healthcare professionals and does not take solicitations from parents.

t: 1300 361 461

f: 03 9372 2061

e: info@tlcforkids.org.au w: www.tlcforkids.org.au

p: 15B Ascot Vale Road, Flemington, VIC 3031

Translating and Interpreting Service (TIS)

Can help you if you need assistance with a language other than English. It is a national service providing 24 hour a day access to interpreter services.

t: 13 14 50

w: http://doiop.com/translating

Transport Authority

State transport authorities may provide special parking permits to make it easy to park close to medical centres and hospitals, or in wheelchair parking. To obtain a permit, contact your local transport authority. You will require your doctor's signature on the form. Check under transport in the Business & Government Listings of your local White Pages®.

Twinkle Toes – Baby hands and feet sculptures

Provides a service for making a sculpture of your child's hands and feet.

t: 1300 78 11 55

w: www.twinkletoes.com.au



Very Special Kids (VSK)

Provides counselling and support services to families caring for a child diagnosed with a terminal illness. The organisation also offers a sibling program and bereavement support. The Very Special Kids House is a hospice for children, providing respite and end-of-life care.

t: 1800 888 875

t: 03 9804 6222

f: 03 9822 1252

e: mail@vsk.org.au

w: www.vsk.org.au

p: 321 Glenferrie Road, Malvern, VIC 3144

OTHER SOURCES OF INFORMATION AND SUPPORT

Children's hospital. Contact your closest children's hospital to see what resources they may have available.

Community libraries and toy libraries provides access to books and toys to loan.

Community support organisations. There are many community groups that provide support for patients and families with specific medical conditions. These groups are a good source of information about treatment options and networking with families experiencing similar journeys.

To find a support group relevant to your child's illness:

- talk with your care team members
- contact the Commonwealth Carer Resource Centre
- look in your local Telstra phone directory or in the White Pages® online: www.whitepages.com.au
- check the Yellow Pages® directory under community service organisations or community health centres and services.

Holiday accommodation. Access to holiday homes in several destinations across Australia is provided by many generous families and organisations. Some are free of charge, while others charge only a minimal payment. Each has its own requirements, conditions and availability with the majority being

wheelchair-friendly. To learn more about these holiday places talk with your care team member.

Private health insurance. If you have private health insurance, the fund may provide reimbursement for certain health care costs, depending on the level and type of private health insurance cover you have. Contact your private health fund directly to be fully aware of the services you are entitled to claim.

Workplaces. A number of workplaces have dedicated employee assistance programs to support staff members, and sometimes their family members. Contact the human resource team at your workplace for information and advice.

JOURNEYS - BOOKS

All of the books listed in this resource are readily available.

Library/bookshop - the listing includes the full title, author and ISBN. This is all the information the library or bookshop will need to find this book for you.

Hospital/healthcare centre - check with your care team. There are many collections of books and reading materials available for loan.

Internet purchasing - each of these books is currently available for online purchasing at any major online bookstore.

Where a book or resource is available from another source, supplier contact details are included.

BY AUDIENCE

FOR PARENTS AND CARERS

Title	ISBN	Author/Publisher/Date	Contact
35 ways to help a grieving child	1-890534-03-x	Dougy Center for Grieving Children - Dougy Center, (1999)	w: www.dougy.org
Armfuls of time: The psychological experience of the child with a life-threatening illness	0822955652	Sourkes, B University of Pittsburgh Press (1996)	
Bereaved children and teens: A support guide for parents and professionals	0807023078	Grollman, E Beacon Press (1996)	
Can I take my panda daddy?	1921054549	Crooks, G Boolarong Press (2005)	North Queensland clients t: 0448 684 379 e: nq@boolarongpress.com.au p: PO Box 1420, Innisfail QLD 4860 All other clients t: 07 3373 7855 e: publish@boolarongpress.com.au w: www.boolarongpress.com.au p: PO Box 308, Moorooka QLD 4105
Carer Support Kit (available in English and 13 other languages. An Aboriginal and Torres Strait Islander Carer Kit is also available)		Department of Health and Ageing	t: 1800 500 853 or 02 6269 1080 w: www.health.gov.au w: http://doiop.com/healthfreepub
Children mourning, mourning children	1560324473	Doka, K Hospice Foundation of America (1995)	
Helping children cope with the loss of a loved one: A guide for grownups	1575420007	Kroen, W. & Espeland, P Free Spirit Publishing (1996)	

Title	ISBN	Author/Publisher/Date	Contact
Listen - my child has a lot of living to do: The partnership between parents and professionals in caring for children with life-threatening conditions	0192619616	Baum, J.D. & Dominica, F. Woodward, R Oxford University Press (1990)	
Palliative care for children with cancer: A guide for parents		Queensland Children's Cancer Centre - Royal Children's Hospital, Brisbane (2002)	Dr Anthony Herbert Staff Specialist in Paediatric Palliative Care Royal Children's Hospital, Brisbane t: 07 3636 1357 e: Anthony_Herbert@health.qld.gov.au w: www.health.qld.gov.au w: http://doiop.com/rchpallcare
Talking about death: A dialogue between parent and child	9780807023631	Grollman, E Beacon Press (1991)	
What's dead mean? How to help children cope with death	0855723165	Zagdanski, D Warwick Publishing (2008)	
When bad things happen to good people	9780330490559	Kushner, H.S Pan Macmillan (2002)	
When someone has a very serious illness: Children can learn to cope with loss and change	0962050245	Heegaard, M Woodland Press. (1992)	

FOR MEN

Title	ISBN	Author/Publisher/Date	Contact
Swallowed by a snake: The gift of the masculine side of healing	9780965464918	Golden, T.R Golden Healing Publishing, Inc (2008)	
When a man faces grief: 12 practical ideas to help you heal from loss	9781885933270	Miller, J.E. & Golden, T.R Willowgreen Publishing (1998)	
When men grieve: Why men grieve differently and how you can help	9781577490784	Levang, E Fairview Press (1998)	

Talking to children about dying and death

2 - 5 YEARS

Title	ISBN	Author/Publisher/Date	Contact
Jenny angel	0140545255	Wild, M Penguin Books Australia (1999)	
Lifetimes: The beautiful way to explain death to children	0553344021	Mellonie, B Bantam (1983)	
Remember the secret	1883672791	Kubler-Ross, E Celestial Arts (2004)	
The very best of friends	0152006257	Wild, M. & Vivas, J Harcourt (1990)	

Title	ISBN	Author/Publisher/Date	Contact
Aarvy Aardvark finds hope: A read aloud story for people of all ages about loving and losing, friendship and hope	1878321250	O'Toole, D Compassion Books (1988)	
Animal crackers: A tender book about death and funerals and love	1561231010	Marshall, B Centering Corp (1997)	
Badger's parting gifts	0688115187	Varley, S. Harper - Trophy (1992)	
Bilby moon	9781876288297	Spurling, M. Working Title Press (2007)	
Charlotte's web		White, E.B.	
Daddy's chair	0970248210	Lanton, S Lanton Haas Press (2001)	
Gentle willow: A story for children about dying	1591470722	Mills, J Magination Press (2003)	
I had a friend named Peter: Talking to children about the death of a friend	0688066852	Cohn, J William Morrow & Co (1987)	
I'll always love you	0517572656	Wilhelm, H Dragonfly Books (1988)	
Just in case you ever wonder	0849909783	Lucado, M Tommy Nelson (1992)	
My many coloured days	0099266598	Seuss, Dr Gardners Books. (2001)	
Old Pig	9781741757064	Wild, M Allen & Unwin (2009)	

Title	ISBN	Author/Publisher/Date	Contact
Remembering: Helping young children cope with death and loss (Book 1 - age 5-8)		Star Bear Foundation	Loss and Grief Centre t: 08 8301 4208 e: starbear@anglicare-sa.org.au w: http://doiop.com/starbear
Sadako and the thousand paper cranes	0698118022	Coerr, E Puffin Books (1999)	
Sad isn't bad: A good-grief guidebook for kids dealing with loss	0870293214	Mundy, M Abbey Press (1998)	
Tear soup	0961519762	Schweibert, P. & DeKlyen, C Grief Watch (2003)	
The dead bird	0064436683	Wise Brown, M William Morrow & Co (2007)	
The fall of Freddie the leaf: A story of life for all ages	9780805071955	Buscaglia, L Henry Holt & Company (2003)	
The kite and Caitlin	9780099561316	McGough, R Random House (2000)	
The tenth good thing about Barney	0689712030	Viorst, J. & Blegvad, E Aladdin Paperbacks (1987)	
Two weeks with the Queen	006440482X	Gleitzman, M Trophy Press (1993)	
Waterbugs and dragonflies: Explaining death to young children	082981180X	Stickney, D Pilgrim Press (1997)	
What's heaven?	0307440435	Shriver, M Golden Books Adult Publishing (1999)	
When dinosaurs die: A guide to understanding death	9780316119559	Brown, L.C. & Brown, M Little, Brown & Company (2004)	

Title	ISBN	Author/Publisher/Date	Contact
Bridge to Terabithia	0064401847	Paterson, K. and Diamond, D Harper Trophy (1987)	
Sadako and the thousand paper cranes	0698118022	Coerr, E Puffin Books (1999)	
Remembering: Helping young children cope with death and loss (Book 2 - age 9-12)		Star Bear Foundation	Loss and Grief Centre t: (08) 8301 4208 e: starbear@anglicare-sa.org.au w: http://doiop.com/starbear
Tear soup	0961519762	Schweibert, P. and DeKlyen, C Grief Watch (2001)	
Two weeks with the Queen	06440482X	Gleitzman, M Trophy Press (1993)	
When someone has a very serious illness: Children can learn to cope with loss and change	0962050245	Heegaard, M Woodland Press (1992)	
When someone very special dies: Children can learn to cope with grief	0962050202	Heegaard, M Woodland Press (1988)	

TEENAGERS

Title	ISBN	Author/Publisher/Date	Contact
Fire in my heart, ice in my veins: A journal for teenagers experiencing a loss	1561230561	Traisman, E. S Centering Corporation (1992)	
Healing your grieving heart for teens: 100 practical ideas	1879651238	Wolfelt, A Companion Press (2001)	
Helping teens cope with death	1890534021	Dougy Center for Grieving Children - Dougy Center (1999)	w: www.dougy.org/
How teenagers cope with grief: Something I've never felt before	0855721995	Zagdanski, D Michelle Anderson Publishing (1998)	
I'll always love you	0517572656	Wilhelm, H Dragonfly Books (1998)	
Part of me died too: Stories of creative survival among bereaved children and teenagers	0525450688	Lynn Fry, V Dutton Children's Books (1995)	
Remembering: Helping young children cope with death and loss (Book 3 - age 13-16)		Star Bear Foundation	Loss and Grief Centre t: (08) 8301 4208 e: starbear@anglicare-sa.org.au w: http://doiop.com/starbear
Remember the secret	1883672791	Kubler-Ross, E Tricycle Press (1998)	
Straight talk about death for teenagers: How to cope with losing someone you love	0807025011	Grollman, E Beacon Press (1993)	
The sibling slam book: What it's really like to have a brother or sister with special needs	1890627526	Gallagher, D Woodbine House (2005)	
Views from our shoes: Growing up with a brother or sister with special needs	0613776739	Myer, D Tandem Library (1997)	

For grandparents

Title	ISBN	Author/Publisher/Date	Contact
For bereaved grandparents	9781561230020	Gerner, M.H Centering Corporation (1990)	
Grandma's tears: Comfort for grieving grandparents	9780801052644	Kolf, J.C Baker Publishing Group (1995)	
Grandparents cry twice: Help for bereaved grandparents	9780895032041	Reed, M.L Baywood Publishing Company Inc. (1999)	
Grandparent to grandparent		SIDS and Kids	SIDS and Kids www.doiop.com/grandparents
When a grandchild dies: What to do, what to say, how to cope	0967441609	Galinsky, N Gal In Sky Publishing Company (1999)	

For friends and family

Title	ISBN	Author/Publisher/Date	Contact
I don't know what to say: How to help and support someone who is dying	0679732020	Buckman, R Vintage Books (1992)	
Stuck for words: What to say to someone who is grieving	0855722371	Zagdanski, D Michelle Anderson Publishing (1994)	
The needs of the dying: A guide for bringing hope, comfort, and love to life's final chapter	0060958219	Kessler, D Harper Perrenial (2000)	

For teachers

Title	ISBN	Author/Publisher/Date	Contact
Helping the grieving student: A guide for teachers	1890534013	Dougy Center for Grieving Children - Dougy Center (1998)	w: www.dougy.org/
Teaching children with life-limiting illnesses: A manual for schools		The Children's Hospital at Westmead	Cost \$15 Sarah Potter, Department of Pain Medicine and Palliative Care Locked Bag 4001, Weastmead NSW 2145 t: 02 98452275 e: Sarahp4@chw.edu.au
When death impacts your school	1890534056	Dougy Center for Grieving Children - Dougy Center (1999)	The Dougy Centre for Grieving Children and Families w: www.grievingchild.org w: www.dougy.org

BY TOPIC

Bereavement support

Title	ISBN	Author/Publisher/Date	Contact
A baby has died		SANDS (WA) Inc (1999)	w: www.doiop.com/ababyhasdied
A grief observed	0060652381	Lewis, C.S Harper San Francisco (2001)	
A journey lived: A collection of personal stories from carers	0975229516	Palliative Care Australia (2005)	w: www.palliativecare.org.au w: http://doiop.com/ajourneylived
Beyond endurance: When a child dies	1418472220	Knapp, R AuthorHouse (2005)	
Beyond sympathy: What to say or do for someone suffering an injury, illness or loss	0934793212	Lord, J Pathfinder Publishing of California (1989)	
Coping with grief: A self-help guide	0759669678	Komar, C.A 1st Books Library (2002)	
Coping with grief	9780733304385	McKissock, M & McKissock, D ABC Books (2001)	ABC Shop w: www.shop.abc.net.au
Don't forget I hurt too	0646049712	Peddey, E Winning in Life Presentations (1991)	Bereavement Recovery & Educational Consultants PO Box 286, Port Adelaide, DC 5015 t: 08 8248 6539 or 0429 674 598
Help for the hard times: Getting through loss	1568380852	Hipp, E Hazelden (1995)	

Title	ISBN	Author/Publisher/Date	Contact
How teenagers cope with grief: Something I've never felt before	0855721995	Zagdanski, D Michelle Anderson Publishing (1998)	
Loss and grief: Helping Aboriginal people cope, where to go for help		Central Australian Aboriginal Congress – Social Emotional Wellbeing Branch	PO Box 1604 Alice Springs NT 0870 t: 08 8951 4457 f: 08 8958 4515 w: www.caac.org.au/social
Motherless daughters: The legacy of loss	0385314388	Edelman, H Delta (1995)	
No time for goodbyes: Coping with sorrow, anger and injustice after a tragic death	0934793689	Harris Lord, J Pathfinder Publishing (2000)	
On life after death	0890876533	Kubler-Ross, E Celestial Arts (1991)	
Tears of joy		Canteen	Canteen t: 1800 226 833 e: admin@canteen.org.au
The bereaved parent	0140050434	Sarnoff Schiff, H Penguin (1978)	
The courage to grieve: Creative living, recovery and growth through grief	0749309369	Tatelbaum, J William Heinemann Ltd (1993)	
The death of an adult child: A book for and about bereaved parents	0895031787	Webster Blank, - J. Baywood Publishing Company (1997)	
The grief book: Strategies for young people	1876372524	Vercoe, E. & Abramowski, K Black Dog Books (2004)	
The time in between: Motherhood grief	0646069004	Hill, P Inland Womensource, (1994)	

Title	ISBN	Author/Publisher/Date	Contact
What to do when one of 'our mob' passes away			Centrelink t: 1800 050 004 http://doiop.com/whattodo
When bad things happen to good people	1400034728	Kushner H Anchor, (2004)	

Deciding on another child

Title	ISBN	Author/Publisher/Date	Contact
Another baby: The decision is yours		National SIDS Council of Australia	SIDS and Kids t: 03 9819 4595 w: http://doiop.com/anotherbaby

Funeral planning

Title	ISBN	Author/Publisher/Date	Contact
Choices in arranging your child's funeral			SIDS Australia w: www.sidsandkids.org/publications
Funerals: Some issues explained			w: http://doiop.com/funeralsexplained
What about the kids? Understanding their needs in funeral planning and services	1890534048	Dougy Center for Grieving Children - Dougy Center (1999)	w: www.dougy.org/

Resource List

Helping yourself

Title	ISBN	Author/Publisher/Date	Contact
Handbook for mortals: Guidance for people facing serious illness	0195146018	Lynn, J Oxford University Press (2001)	
Living with life-threatening illness: A guide for parents, their families and caregivers	0787940488	Doka, K Macmillan (1998)	
Love, medicine and miracles	0060919833	Siegel, B HarperPerrenial (1990)	
Peace of mind: How you can learn to meditate and use the power of your mind	0895294478	Gawler, I Avery Publishing (1989)	
Quest for life: A handbook for people with life-threatening illness	188322005X	King, P Dawn Publications (1994)	
The needs of the dying: A guide for bringing hope, comfort, and love to life's final chapter	0060958219	Kessler, D HarperPerrenial (2000)	
The wealth within	0906798388	Meares, A Ashgrove (1989)	

Symptom management

Title	ISBN	Author/Publisher/Date	Contact
Paediatric palliative care: Caring for your child at home	better arrangement	Drew, D Sydney Children's Hospital (2005)	Palliative Care Centre – Children's Cancer Blood Disorders Sydney Children's Hospital (02) 9382 1739
Palliative care for children with cancer – A guide for parents		Queensland Children's Cancer Centre (2002)	Royal Children's Hospital, Brisbane (07) 3636 1357





Journeys: Palliative care for children and teenagers is available in hard copy free of charge.

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