



Resource Guide for Families

Carers' Rights

As a carer you have rights. These are outlined in legislation. Many services also have carers' rights outlined in their service delivery policies. These policies will need to be complementary to legislation. Knowing your rights can help you advocate for you and the person you are supporting. Knowing your rights can also help you communicate better with health professionals and other service providers. It can help you understand why they make certain decisions and when you have a right to request further information or to question the decisions being made.

The Carers' Recognition Act 2004 provides a definition of the term 'carer', outlines a 4-point Carers Charter, and allows for the provision of a 10-member Carer Advisory Council. The Act is the first step to providing an inclusive approach to community care, in that carers' are very often key care partners, and yet are regularly left out of care planning. Carers also have their own significant needs apart from the needs of the care recipient, as the caring role can impact in many ways.

The Carers' Recognition Act 2004 will primarily affect the Health Department of WA (including public hospitals, Home and Community Care and organisations funded by this department) and the Disability Services Commission and funded services.

For Further Information visit: www.carersaustralia.com.au

RESOURCE GUIDE FOR FAMILIES

Knowing where to access information, services or support can play a vital role in optimising day-to-day quality of life. The Resource Guide for Families outlines services that may be of assistance and how you may access them. This guide has been developed to help answer the questions frequently asked by families who have had difficulty locating services and resources when the need arises.

I need advice or support... Who can I call?

<p>Healthdirect Australia is a toll free 24 hour, 7 day health advice line to all people calling from within Western Australia. Healthdirect's experienced nurses provide immediate professional advice on how urgent a health concern is and what to do about it.</p>	<p>1800 022 222 TTY: 1800 555 677 then ask for 1800 022 222</p>
<p>Rural Link provides a single point of contact for after-hours information, advice, assessment and/or referral for people dealing with depression, suicide, anxiety, psychosis, mental health issues or mental health crisis. Where necessary, it provides access to appropriate mental health services or follow up. RuralLink operates from 4.30pm – 8:30am Monday to Friday and 24 hours Saturday, Sunday and public holidays.</p>	<p>1800 522 002 TTY: 1800 720 101</p>
<p>Perth Home Care Services: If your primary carer has a crisis and is unable to provide essential support, you can get emergency help through our Crisis Respite Support. This service provides help in your house for up to three days.</p> <p>It is specifically for incidents occurring without warning that result in your carer being unable to continue to care for you. We provide back-up support until alternative arrangements can be made.</p> <p>The service operates every day, including Christmas and Easter. This service operates 24 hours, seven days a week.</p>	<p>(08) 9204 7801</p>
<p>National Relay Service is an Australian-wide phone solution for people who are deaf or have a hearing or speech impairment. 24 hours, 7 days a week.</p>	<p>TTY 133 677 Speak and listen users: 1300 555 727</p>
<p>Kids Help Line is a free and confidential, 24-hour telephone counselling and online service for 5 to 25 year olds in Australia.</p>	<p>1800 55 1800 (counselling line) www.kidshelp.com.au</p>
<p>Ngala Parenting Line is for parents of children aged 0-18 years. We provide support, understanding and strategies to address parenting concerns. Available 7 days a week - 8am to 8pm.</p>	<p>(08) 9368 9368 or country access 1800 111 546</p>
<p>Anglicare WA is a not for profit community service organisation. We support people, families and their communities to cope with the challenges of life by building their resilience and capacity. We assist people with relationship issues, financial problems, and housing difficulties. Ultimately, we want our clients to thrive in today's society.</p> <p>Our Relationship Counsellors are trained professionals who can assist with a wide variety of issues. Counselling can be provided to individuals, couples or whole families if necessary. We offer telephone counselling for people who cannot attend a session, including those who live in rural or remote regions.</p>	<p>1300 114 446 bookings@anglicarewa.org.au</p>
<p>The Compassionate Friends (TCF) provides support for bereaved parents, siblings and grandparents affected by the death of a child, through any cause.</p>	<p>(08) 9486 8711 www.compassionatefriendswa.org.au</p>
<p>Lifeline provides a 24-hour telephone counselling service. Online Crisis Chat hours: 7pm –4am (AEST) 7 days week</p>	<p>13 11 14 crisischat.lifelinewa.org.au</p>

Can I get advice from other professionals? (early intervention services)

<p>Physiotherapy can help with moving and breathing</p> <p>Australian Physiotherapy Association.</p>	(08) 9389 9211
<p>Speech Pathology can help with speech, swallowing and feeding.</p> <p>Speech Pathology Australia</p>	(08) 9450 8281
<p>Occupational Therapy can help with developing independence with everyday tasks.</p> <p>WA Occupational Therapy Association</p>	(08) 9388 1492
<p>Next Challenge is a dynamic team made up of Speech Pathologists, Occupational Therapists, Physiotherapy and Clinical Psychology. We work together with families to support children to reach their potential within family, social, educational and any chosen community environments.</p>	(08) 9201 0707 www.nextchallenge.com.au
<p>Skillbuilders provides therapy support to children, including Occupational therapy, Physiotherapy, and Speech Therapy. They provide regular therapy programs, as well as specialised holiday programs and group programs. Skillbuilders also have an extensive range of therapy products.</p>	(08) 9417 4903 www.skillbuilders.com.au
<p>Kids are Kids! provides a range of government funded programs (and privately funded services) to children and their families. Our programs offer high-quality Speech Pathology, Occupational Therapy, Physiotherapy and/or Psychology services to support your child's skill development and increase their independence and participation in the community.</p>	(08) 9313 6566 www.kidsarekids.org.au
<p>Wize Therapy provides physiotherapy, occupational therapy and speech pathology to young children with disability. Therapy services involves the provision of specialised services for infants, toddlers and children with developmental delay or an identified disability to maximise their participation in their chosen family, school and community activities.</p>	(08) 9317 7932 www.wizetherapy.com.au
<p>Genetic Counselling is the provision of information and support regarding genetic disorders, birth defects, health concerns or test results relating to the individual or their family. This may involve the diagnosis of a genetic condition and supportive counselling to assist decision making and the adjustment process that occurs when a condition is new to a family or individual.</p>	(08) 6458 1525 www.gswa.health.wa.gov.au
<p>Genetic counselling may occur via telephone counselling or by appointment where the family or individual is reviewed at a genetic clinic. Additional services such as prenatal diagnosis, carrier detection, predictive testing and newborn screening services are often important components of the genetic counselling process and provide valuable information to the individual, family and health professionals. A referral is required at Genetic Services Western Australia (GSWA).</p>	

I need more information and support... Who can I ask?

Genetic and Rare disease Network (GaRDN) provides practical support and information for individuals and families living with a genetic condition.	(08) 9485 8999 or visit www.gardn.org.au
Disability First Stop can direct you to appropriate agencies, includes providing information, supported referrals to relevant services, provision of professional advocacy support, self-help and access to counselling and interpreters.	(08) 9485 8900 1800 193 331 TTY: (08) 9386 6451
Ethnic Disability Advocacy Centre provides information and advocacy to ensure ethnic people with disabilities and their carers gain equitable access to services.	(08) 9388 7455 1800 659 921
Yura Yungi Medical Service provides healthcare services to Indigenous and non-Indigenous people in the Halls Creek area.	(08) 9168 6266
Derbarl Yerrigan Health Service provides a range of health services to meet the needs of Aboriginal families and Aboriginal communities across the Perth metropolitan area. This service is staffed by health professionals including Aboriginal Health Workers, Care Aides, Home and Community Care Workers (HACC program), Registered Nurses, Doctors, Case Workers, Podiatrists, Physiotherapists, Dentists and Stolen Generation, Welfare, Ear and Eye Health Workers.	Bayswater: 9370 1044 East Perth: 9421 3801 Maddington: 9452 5333 Midland: 9374 1400 Mirrabooka: 9344 0444 www.derbarlyerrigan.com.au
Australian Indigenous HealthInfoNet provides information, resources and a referral service relating to agencies and services for the community.	(08) 9370 6336 www.healthinonet.ecu.edu.au
SANE Australia is an independent national charity working for a better life for people affected by mental illness and their carers. Helpline operates Monday to Friday 9-5 AEST	1800 18 7263 www.sane.org
Better Start Early Days workshops & webinars are for parents who are in the early days of the journey with their child with a disability.	www.betterstartearlydays.net.au
Inclusion WA works alongside community groups, sports associations and local Government to make them more accessible for people living with disabilities and provides tailored information to people (and family members on their behalf) who want to get involved in their communities.	(08) 9201 8900 www.inclusionwa.org.au
Kalparrin assists families and carers of children, of any age, with any disability or special need by providing practical and emotional support.	1800 066 413 (08) 9340 8094

I need specialised equipment to make my home more liveable..

Technology Assisting Disability WA Inc. (TADWA) provide services to improve quality of life through the application of technology and skills, including modified/adaptive equipment and technology, home visits and Advocacy.	(08) 9379 7400
The Occupational Therapy Department at Perth Children’s Hospital for Children and Sir Charles Gairdner Hospital can assist independent living. A referral is required at both these places.	(08) 9340 8222 (08) 9346 2855
The Physiotherapy Department at Perth Children’s Hospital for Children (referral is required) and Sir Charles Gairdner Hospital can assist with movement and independent living (referral is required when seeing the senior physiotherapist, but not if seeing Curtin physio students).	(08) 9340 8222 (08) 6457 2337
Variety helps families with financial support for things like wheelchairs and specialist equipment.	(08) 9355 3655 variety.org.au
The WA Home and Community Care Program (HACC) is a joint funding initiative of the Commonwealth and WA State Governments which provides basic support services for eligible people of all ages with a disability and their carers to assist them to continue living independently at home.	1300 785 415
The Assistive Equipment & Technology Service area of Independent Living Centre provides specialised equipment assistance to meet the needs of Western Australians of all ages experiencing reduced independence or mobility resulting from a disability, aging or health related condition. Types of equipment on display include wheelchairs, scooters, walking aids, eating and cooking equipment, hoists, chairs, cushions and specialised seating, telephones, dressing aids, beds, mattresses, aids to assist with personal hygiene and much more. The Assistive Equipment Services (AES) employs Occupational Therapists to provide FREE expert advice on a large range of assistive equipment and resources to people with disabilities of all ages, seniors, carers, health professionals and service providers.	(08) 9381 0600 1300 885 886 www.ilc.com.au

How do I make future plans for education?

Disability Services Commission advances quality of life for people with Disabilities by providing a range of services and supports.	(08) 9426 9200 Country 1800 998 214 TTY: 9426 9315
Resource Unit for Children with Special Needs (RUCSN) provides support services, resources and training to help carers, parents, families and students to understand and meet the needs of children with special needs.	(08) 9249 4333 www.ruscn.org.au
The Ronal McDonald Learning program provides comprehensive assessment to determine each child's learning strengths and needs. From the results, an individual education plan is developed which includes tuition and speech or occupational therapy if required.	(08) 9388 8607
The WA Department of Education Statewide Specialised Services provides visiting teachers and support officers from varied educational institutions for students with disabilities and diverse learning needs. Please visit: www.det.wa.edu.au/studentsupport/detcms/portal/	(08) 9264 4111
Your local Child Development Service provides a range of assessment, early intervention and treatment services to children with, or at risk of, developmental conditions or delay. Child Development Services in WA are important referral points for universal and specialist health service providers. Please visit: www.pmh.health.wa.gov.au/general/CACH/child_development_centres.htm	(08) 9426 9444

I need financial support and advice..

ConcessionsWA is an easy to use online resource which provides details on more than 100 rebates, concessions and subsidy schemes provided by the Government of Western Australia.	www.concessions.wa.gov.au
Centrelink Financial Information Services assists people to make informed decisions regarding financial matters.	132 300
Communicare offers financial counselling to assist families and enable them to gain financial stability in their lives.	(08) 9251 5777
Be Inspired Foundation provides scholarships for active rehabilitation treatment plans to disadvantaged Western Australian youth living with chronic disease, cancer, disabilities or major trauma. www.beinspiredfoundation.com.au	1300 799 915
The WA Companion Card Program is a card issued to people with a significant and permanent disability who require attendant care support from a companion to participate at most venues and activities.	(08) 9443 3107 wa@companioncard.asn.au
Contact Centrelink and ask to make an appointment with their social worker, for support, information and refer you to other relevant support services. Please visit: www.humanservices.gov.au/customer/services/social-work-services#a5	132 850

I need time out! How do I arrange this?

Carers' Association of WA provides support and services to family carers through information and resources, education, training, counselling, social support, advocacy and representation. 300 CARERS (1300 227 377) 8.30am – 4.30pm	1800 242 636
Carers WA has a Young Carers program which offers young carers access to specific counselling, support and information and service referrals	1300 227 377 https://www.carerswa.asn.au
Commonwealth Respite and Carelink Centre provides free and confidential information on local carer support, disability and community services.	1800 052 222
Intelife offers flexible, individualised respite services for carers of people living with mental illness, autism or an intellectual disability.	(08) 6169 1100 www.intelife.org
Avivo support family and carers in the disability, aged and mental health areas. The crisis support service is available 24 hours a day, seven days a week.	1300 428 486 Crisis Support (08) 9204 7801
Alkira Care Respite Services provides community based respite care with innovative, flexible and individualised services 24 hours, 7 days a week. The facilities in South Lake Western Australia, is providing Short to Long Term Respite for children up to 18 years of age with Multiple and Complex needs requiring nursing care and support. Support in your home and community is available.	(08) 9417 3015 www.alkiracarerespiteservices.com.au
IdentityWA Children's Houses (Riverton & Nollamara) supports families and carers to have regular, planned breaks from their caring role. While families and carers have a break, children can stay in one of their where they can take part in activities of their choice at the home and in the community.	(08) 9474 3303 www.identitywa.com.au
Do you and your family need some time away to reconnect, have some fun and create some family memories? Have you considered staying at our Ronald McDonald Family Retreat in Bunbury? As you have stayed at our House or you're currently on our Ronald McDonald Learning Program you are eligible to stay for up to one week and the best thing is the accommodation is absolutely FREE!	(08) 9346 9000 Courtney.kennedy@rmhc.org.au
Lady Lawley Cottage: Day care, residential respite and home support for children with disabilities in Perth. They support children and young adults with a wide range of multiple and complex needs.	(08) 9318 2160 http://www.redcross.org.au/ladylawleycottage.aspx

How can I contact parents in similar situations?

Genetic and Rare Disease Network provides practical support and information for individuals and families living with a genetic and rare condition including referral and links to patient support organisations in WA and across Australia.	1300 770 995 www.gardn.org.au
Kalparrin assists families and carers of children, of any age, with any disability or special need by providing practical and emotional support and can connect families in similar situations through their Parent Link service. http://kalparrin.org.au	1800 066 413 (08) 9340 8094
Activ's Parent Portal is an information service designed especially for parents of a child with a developmental disability.	(08) 9387 0474 www.activ.asn.au
Genetic Alliance Australia (GAA) - is a peak umbrella group for rare genetic conditions/ diseases, so rare they don't have their own support group. AGSA will endeavour to facilitate contact with another family/individual affected by the same, or similar condition, and/or provide information about an overseas support group. www.geneticalliance.org.au	(02) 9295 8359
Genetic Support Network Victoria (GSNV) is an organisation committed to promoting the interests and well-being of people affected by genetic conditions. GSNV facilitates access to services, connecting with others, education, advocacy, support and information.	(03) 8341 6315 www.gsnv.org.au
ConnectGroups – Support Groups Association WA (previously Western Institute of SelfHelp (WISH) Inc) is a unique not-for-profit, community-based organisation that provides support and assistance for individuals and support groups with start-up, ongoing development, advocacy and networking.	(08) 9364 6909 www.connectgroups.org.au
MyTime peer support groups provide support for mothers, fathers, grandparents and anyone caring for a child with a disability or chronic medical condition. It's a place for you to unwind and talk about your experiences. It's a world away from appointments and therapy.	(08) 9368 9368 www.mytime.net.au
Rare Voices Australia (RVA) is a national organisation advocating for those who live with a rare disease. RVA provides a strong common voice to promote for health policy and a healthcare system that works for those with rare diseases. RVA works with governments, researchers, clinicians and industry to promote research, diagnosis, treatment and services for all rare diseases in Australia.	(02) 9967 5884 www.rarevoices.org.au

English is not my first language... who can help me understand?

<p>The Translating and Interpreting Service (TIS National) provides interpreting services 24 hours a day, every day of the year.</p>	<p>131 450 www.tisnational.gov.au</p>
<p>If English is your second language (ESL), and you would like to speak with someone about cancer in your own language, you can connect with an interpreter from the Cancer Council Helpline by following these steps:</p>	<p>www.cancerwa.asn.au/resources/finding-information-on-cancer/#english</p>
<ol style="list-style-type: none">1. Call 131 450 between 9am and 5pm Monday to Friday.2. Say the language that you need.3. Wait for an interpreter - this could take up to 3 minutes.4. Ask the interpreter to call the Cancer Council Helpline on 131 120.5. Speak with the Cancer Council Helpline with the help of your interpreter	

I have a hearing/speech impairment... who can help me understand?

<p>National Auslan Interpreter Booking and Payment Service (NABS) provides interpreters for Deaf, Deafblind and hard of hearing people who use sign language and would like an interpreter for private health care appointments.</p> <p>Sign language services to Deaf Indigenous people are provided for both public and private health care appointments.</p> <p>An interpreter can be booked if the appointment is for a Deaf adult or a Deaf child. This includes situations where there is a Deaf adult and a hearing child or a hearing adult and a Deaf child attending a private health care appointment.</p> <p>Services include face to face interpreting (onsite) and Video Remote Interpreting (online). NABS services are not free for people who have an NDIS Plan or who are eligible for NDIS.</p>	<p>1800 24 69 45 www.nabs.org.au</p>
<p>Telethon Speech and Hearing Centre for Children is a not-for-profit, charitable organisation based in Wembley, Western Australia. Telethon Speech & Hearing (TSH) exists to support families, children, adults and carers</p>	<p>(08) 9387 9888 www.tsh.org.au/programs-services/audiology-ear-health</p>
<p>National Relay Service (NRS): If you are deaf, or have a hearing or speech impairment, you can make calls through the National Relay Service.</p>	<p>1800 555 660 www.relayservice.gov.au</p>

I need support with transport..

The ACROD Parking Program aims to support Western Australians with a significant mobility restriction to access the community. No payment required. For more information visit: www.app.org.au	(08) 9242 5544
Angel Flight Australia co-ordinates non-emergency flights, free of charge, for financially and medically needy people. Flights may involve patients or compassionate carers travelling to or from medical facilities anywhere in Australia. For more information visit: www.angelflight.org.au	(07) 3620 8300 or toll free: 1300 726 567
Interstate Patient Travel Scheme: Patients who need to travel interstate to obtain essential specialist medical treatment not available in WA may be eligible for assistance under the Interstate Patient Transfer Scheme (IPTS).	(08) 9222 2474
Patient Assisted Travel Scheme provides a subsidy towards the cost of travel and accommodation for eligible Regional patients travelling long distances to seek certain categories of specialist medical services.	www.wacountry.health.wa.gov.au/pats
Royal Flying Doctors Service: Using the latest in aviation, medical and communications technology, they deliver extensive primary health care and 24-hour emergency service to those who live, work and travel throughout Australia.	www.flyingdoctor.org.au
Wheelchair Accessible MAXI Taxi: Black & White Cabs currently has a fleet of over 150 Wheelchair Accessible Maxi Taxis.	13 MAXI (136 294) www.blackandwhitecabs.com.au

Notes

About the Genetic and Rare Disease Network

The Genetic and Rare Disease Network provides information and support to individuals and families living with a genetic and/or rare condition.

Our services include:

- Information on the services provided by genetic and rare support groups. In Australasia, there are hundreds of such groups, each focusing on a specific genetic condition. We can help put you in contact with these groups or provide support and guidance to help you establish a new support group
- A Education & Resource Coordinator who can assist with enquiries and facilitate ongoing support for individuals, families, health professionals and other interested groups
- Resources relating to education, parenting, respite care, medical services and other community support organisations
- Information seminars
- Regular newsletters

GaRDN may also be able to provide information and support for conditions so rare that there is no specific support group.

Visit our website at www.gardn.org.au or call 1300 770 995 for further information or assistance.



Genetic and Rare Disease Network (GaRDN)

ABN: 63 614 315 270

GaRDN works to empower individuals and their families to reach positive health outcomes.

We inform health professionals and the wider community on the perspectives and experiences of those affected by genetic and rare diseases.

We connect key stakeholders and service providers with people affected by genetic and rare diseases.

For further information

Please contact us.

Phone: 1300 770 995

Email: hello@gardn.org.au

Web: www.gardn.org.au

Postal Address:

Genetic and Rare Disease Network

PO Box 1023

BOORAGOON WA 6954