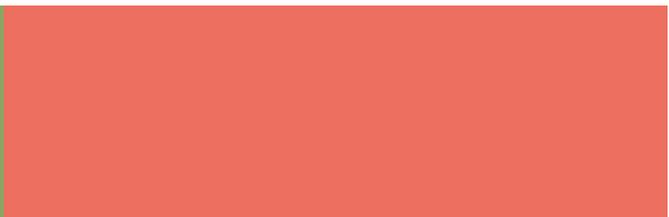




Resource Guide for Families



**GENETIC AND
RARE DISEASE
NETWORK**

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 after hours... 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. 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>LifeLine provides a 24 hour telephone counselling service. Online Crisis Chat hours: 7pm –4am (AEST) 7 days week</p>	<p>13 11 14 crischat.lifelinewa.org.au</p>

Can I get advice from other professionals?

<p>Physiotherapy can help with moving and breathing Australian Physiotherapy Association.</p>	<p>(08) 9389 9211</p>
<p>Speech Pathology can help with speech, swallowing and feeding. Speech Pathology Australia</p>	<p>(08) 9450 8281</p>
<p>Occupational Therapy can help with developing independence with everyday tasks. WA Occupational Therapy Association</p>	<p>(08) 9388 1492</p>
<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> <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>	<p>(08) 6458 1525 www.gswa.health.wa.gov.au</p>

I need more information... 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.healthinfonet.ecu.edu.au
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
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 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 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
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 and information and service referrals, support.	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
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. http://www.redcross.org.au/ladylawleycottage.aspx	(08) 9318 2160

How can I contact parents in similar situations?

<p>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.</p> <p>Website: www.gardn.org.au Email: hello@gardn.org.au</p>	(08) 9485 8999
<p>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.</p>	1800 066 413 (08) 9340 8094
<p>Activ's Parent Portal is an information service designed especially for parents of a child with a developmental disability.</p>	www.activ.asn.au (08) 9387 0474
<p>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.</p> <p>Website: www.geneticalliance.org.au Email: info@geneticalliance.org.au</p>	(02) 9295 8359
<p>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.</p> <p>Website: www.gsnv.org.au Email: info@gsnv.org.au</p>	(03) 8341 6315
<p>ConnectGroups – Support Groups Association WA (previously Western Institute of Self Help (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.</p> <p>Website: www.connectgroups.org.au</p>	(08) 9364 6909
<p>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.</p> <p>Website: www.rarevoices.org.au</p>	(02) 9967 5884

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

Translating and Interpreting Service (TIS) provides translations 24 hours a day, seven days a week. To access this service phone 131 450. Further information is available on the Website: www.tisnational.gov.au

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:

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.

Please visit: www.cancerwa.asn.au/resources/finding-information-on-cancer/#english



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: (08) 9485 8999

Email: hello@gardn.org.au

Web: www.gardn.org.au

Postal Address:

Genetic and Rare Disease Network

PO Box 1023

BOORAGOON WA 6954