



**INFORMATION  
RESOURCE  
TO SUPPORT  
INDIVIDUALS,  
FAMILIES AND  
CARERS LIVING  
WITH GENETIC,  
RARE AND  
UNDIAGNOSED  
CONDITIONS**

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## NEED ADVICE OR SUPPORT ...

### Who can I call?

Here is a selection of organisations you can reach out to in an emergency for immediate support with mental health concerns and emotional support, and health

#### **BEYOND BLUE**

Phone: 1300 22 4636

Provides information and support to whoever and wherever to improve their mental health.

<https://www.beyondblue.org.au/>

#### **CRISIS SUPPORT**

Advice on care planning, phone numbers and relevant contacts.

<https://www.betterhealth.vic.gov.au/health/servicesandsupport/emergency-or-crisis-support-for-carers>

#### **HEALTHDIRECT**

Phone: 1800 059 059

Emergency respite support outside standard business hours

<https://www.healthdirect.gov.au/>

#### **KIDS HELP LINE**

Phone: 1800 55 1800 (counselling line)

Free and confidential, 24-hour telephone counselling and online service for 5-25-year old's in Australia

[www.kidshelp.com.au](http://www.kidshelp.com.au)

#### **LIFELINE**

Phone: 13 11 14

Provides a 24-hour telephone counselling service

<https://www.lifeline.org.au>

**NURSE ON CALL**

phone: 1300 60 60 24

Free 24/7 medical advice given by a registered nurse

**NATIONAL RELAY SERVICE**

TTY 133 677

Phone: 1300 555 727

Australian-wide phone solution for people who are deaf or have a hearing or speech impairment. 24 hours, 7 days a week.

**PANDA**

Phone: 1300 726 306

PANDA supports women and their families who are suffering from perinatal anxiety or depression.

<https://www.panda.org.au>

**PARENTLINE VICTORIA**

Phone: 13 22 89

Provide support, understanding and strategies to address parenting concerns.

<https://www.betterhealth.vic.gov.au/health/serviceprofiles/parentline-service>

**PATIENT PATHWAYS GENETIC AND RARE DISEASE TELEHEALTH NURSE**

Phone: 1300 75 50 50

Telehealth Patient Pathways Nurse is a free, confidential information and support service which provides information and links to practical support to our Genetic, undiagnosed and rare disease communities within Australia. A booking form can be accessed via this link :

<https://www.gsnv.org.au/patient-pathways-program/>

**VERY SPECIAL KIDS**

Phone: 1800 888 875

Very special kids can provide support for those with the life threatening disease as well as those in the family who may need support this number is for their support line.

<https://www.vsk.org.au>

## I NEED MORE SUPPORT AND COUNSELLING ...

### Who can I ask?

**These organisations will assist by providing emotional and practical support**

#### **ANGLICARE VICTORIA**

Phone: 1800 809722

Counselling can be provided to individuals, couples or whole families if necessary. Anglicare offer telephone counselling for people who cannot attend a session, including those who live in rural or remote regions.

<https://www.anglicarevic.org.au/>

#### **ASSOCIATION FOR CHILDREN WITH A DISABILITY**

Phone: 9880 7000

Offers workshops and peer support. The association also provides advocacy for those with a disability as well as education and fact sheets.

<https://www.acd.org.au/workshops-and-peer-support/>

#### **AUSTRALIAN COUNSELLING ASSOCIATION**

Phone: 1300 784 333

Australia's largest body of counsellors and psychotherapists.

<https://www.theaca.net.au/>

#### **BETTER START EARLY DAYS**

Runs workshops & webinars are for parents who are in the early days of the journey with their child with a disability.

[www.betterstartearlydays.net.au](http://www.betterstartearlydays.net.au)

#### **BEYOND BLUE - MULTICULTURAL PEOPLE**

Supporting mental health in culturally and linguistically diverse people.

<https://www.beyondblue.org.au/who-does-it-affect/multicultural-people>

#### **FIRST PEOPLES DISABILITY NETWORK AUSTRALIA**

Phone: +61 (2) 9267 4195

FPDN is a national organization of and for Australia's first peoples with disability, their families and communities.

<https://fpdn.org.au/>

#### **KALPARRIN**

Phone: 9435 8311

Assists families and carers of children, of any age, with any disability or special need by providing practical and emotional support.

<https://www.kalparrin.com.au/>

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<https://www.gsnv.org.au/patient-pathways-program/>

**RELATIONSHIPS AUSTRALIA**

PHONE: 1300 364 277

RELATIONSHIPS AUSTRALIA PROVIDES SUPPORT AND ADVICE TO ANY AUSTRALIAN TO AID IN THEIR RELATIONSHIPS VIA SERVICES SUCH AS COUNSELLING AND FAMILY DISPUTE PROGRAM.

<http://www.relationships.org.au/>

**SANE**

Phone: 1800 18 7263

Australia is an independent national charity working for a better life for people affected by mental illness and their carer's. Helpline operates Monday to Friday 9-5 PM

<https://www.sane.org/services/help-centre>

**SCOPE**

Phone: 1300 4 72673

Short term accommodation at Scope

[www.scopeaust.org.au/](http://www.scopeaust.org.au/)

**THE COMPASSIONATE FRIENDS VICTORIA (TCFV)**

Phone:1300 064 068 ( 24 /7)

The Compassionate Friends Victoria (TCFV) is dedicated to supporting grieving parents, siblings and grandparents in the event of the death of a child – of any age or from any cause

<https://www.compassionatefriendsvictoria.org.au/>

**VICTORIAN ABORIGINAL HEALTH SERVICES**

Phone: (03) 9419 3000

Offers health services for first peoples.

<https://www.vaahs.org.au/>

**VICTORIAN INCLUSION AGENCY**

Phone: 1800 177 017

Offers inclusion support and other disability services.

<https://www.viac.com.au/>

## CAN I GET ADVICE FROM OTHER PROFESSIONALS? (EARLY INTERVENTION SERVICES)

Many children with a disability can benefit from some type of early therapy. For example: Occupational Therapy can help with motor skills such as playing, dressing and going to the toilet. Physiotherapy can help with balance, sitting, rolling, crawling and walking. Speech therapy can help with speech and language, as well as eating and drinking skills. Early intervention often combines specialist support and therapies. These organisations can link you to services in your local area

### AUSTRALIAN PHYSIOTHERAPY ASSOCIATION

PHONE: (03) 9092 0888

.A Paediatric Physiotherapist offers early intervention for children who may have neurological and developmental delays as well as sensory impairments .Physiotherapy also helps children with biomechanical, positional and sports injuries. Some children may present with multiple issues that can be helped by seeing a Paediatric Physiotherapist.

<https://australian.physio/>

### EVERYDAY INDEPENDENCE

A therapy organisation that supports people of all ages to live to their full potential with disability. Their team consists of occupational therapists, speech pathologists and physiotherapists and are support patients on the NDIS

<https://www.everydayind.com.au/>

### OCCUPATIONAL THERAPY ASSOCIATION

PHONE: 1300 682 878

Occupational Therapy can help with developing independence with everyday tasks.

<https://www.otaus.com.au/>

### SPEECH PATHOLOGY AUSTRALIA

PHONE:: 1300 368 835

Speech Pathology Australia (the Association) is the national peak body for the speech pathology profession in Australia. .Speech pathologists study, diagnose and treat communication disorders, including difficulties with speech, language, fluency and voice.

<https://www.speechpathologyaustralia.org.au/>

## I NEED SPECIALISED EQUIPMENT TO MAKE MY HOME MORE LIVEABLE...

### **ASSISTANT DOGS AUSTRALIA**

Phone: 1800 688 364

Provides assistant dogs to those with a disability aiding in a variety of tasks.

<https://www.assisteddogs.org.au/>

### **EVERYDAY INDEPENDENCE**

Supporting children with a disability through a range of therapies.

<https://www.everydayind.com.au/who-we-support/children/>

### **GUIDE DOGS VICTORIA**

Phone: 100 804 805

Provides support to Victorian's with low vision or blindness.

<https://www.guidedogsvictoria.com.au/>

### **INDEPENDENT LIVING CENTRES AUSTRALIA**

Phone: 1300 885 886

Provide professional advice by occupational therapists and speech pathologists on the functional application of assistive technology, which enables informed decision making about communication, computer and technology options for people with disabilities.

[https://ilcaustralia.org.au/contact\\_us/victoria](https://ilcaustralia.org.au/contact_us/victoria)

### **PHYSIOTHERAPY AT THE ROYAL CHILDREN'S HOSPITAL**

Phone: 9345 5522

Pediatric Physiotherapists are trained to work with infants, children and adolescents. They have an expert understanding of child development and how this relates to neurological, cardio-respiratory and musculoskeletal health. Pediatric Physiotherapists assess each child individually and develop programs with a child and family-centred focus. They provide treatment, management and education to enhance the health and wellbeing of children and maximise their participation in everyday activities. Referral required.

[https://www.rch.org.au/physio/contact\\_us/](https://www.rch.org.au/physio/contact_us/)

### **SOLVE DISABILITY SOLUTIONS**

Phone: 1300663243

Solve is a not for profit organization providing a Victoria wide occupational therapy service and custom Assistive Technology for people of all ages living with a disability.

<https://solve.org.au/assistive-technology/>

### **Variety**

Phone: (03) 8698 3900

Variety helps families with financial support for things like wheelchairs and specialist equipment.

[www.variety.org.au](http://www.variety.org.au)



## HOW DO I MAKE FUTURE PLANS FOR EDUCATION?

### **DISABILITY SERVICES COMMISSION**

Phone: 1300 728 187

Advances quality of life for people with disabilities by providing a range of services and supports.

<https://services.dhhs.vic.gov.au/education>

### **VISITING TEACHER SERVICE**

Comes to the school to help with children's special needs.

<https://www.education.vic.gov.au/school/teachers/learningneeds/Pages/visiting-teachers.aspx>

For your regional office number follow this link-

<https://www.education.vic.gov.au/about/department/structure/Pages/regions.aspx>

### **YOUR LOCAL CHILD DEVELOPMENT SERVICE**

Phone: 98901062

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.

<https://services.dhhs.vic.gov.au/concessions-and-benefits>

### **STATEWIDE VISION RESOURCE CENTRE (SVRC)**

Phone: (03) 9841 0242

State Wide Vision Resource Centre. Education resource for school aged children with a vision impairment.

<https://svrc.vic.edu.au/about/the-role-of-visiting-teachers-vision/>

### **ASSOCIATION FOR CHILDREN WITH A DISABILITY**

When schools are working with families that have enrolled students with a disability they are required to make reasonable adjustments so those students can participate on the same basis as other students. This organisation will provide resources that will help you support your child's education.

<https://www.acd.org.au/workshops-and-peer-support/>

## NEED FINANCIAL SUPPORT AND ADVICE...

### **BETTER PLACE AUSTRALIA**

Phone: 1800 632 523

Free financial counselling over the phone or by video chat.

<https://www.betterplaceaustralia.com.au/video-counselling>

### **CENTRELINK FINANCIAL INFORMATION**

Phone: 132 300

Service assists people to make informed decisions regarding financial matters.

<https://www.servicesaustralia.gov.au/individuals/services/financial-information-service>

### **COMPANIONSHIP CARD PROGRAM**

Phone: 1800 650 611

The State Government provide this service for those who qualify. Companionship cards allow you or a carer complimentary access accompanying your child with a disability.

Email Address: [companioncard@dhhs.vic.gov.au](mailto:companioncard@dhhs.vic.gov.au)

<http://www.companioncard.gov.au>

### **CYDA (Children and Young People with Disability Australia)**

Phone: (03) 9417 1025

Advocates for people with disability a disability and can also provide bursaries to eligible carers.

<https://www.cyda.org.au>

### **RONALD MCDONALD HOUSE CHARITY**

Phone: 1300 307 642

Provides free accommodation for families who are staying away from home for their child's medical needs.

<https://www.rmhc.org.au>





## **NEED TIME OUT... How do I arrange this?**

**Respite care is when someone looks after you as the patient, or your child with additional needs. Respite care can be for a few hours during the day. It can also be overnight or for longer periods like a few weeks. You might use respite care occasionally or on a regular basis. The respite care can take place in your home or somewhere else.**

### **CARERS AUSTRALIA**

Phone: 1800 242 636

We work to improve the health, wellbeing, resilience and financial security of carers and to ensure that caring is a shared responsibility of family, community and government.

<https://www.carersaustralia.com.au>

### **CARER GATEWAY - RESPITE**

Phone: 1800 422 737

If you need time of to recharge or rest for yourself, carers gateway can arrange for someone to look after the individual you care for.

<https://www.carergateway.gov.au/respite>

### **COMMONWEALTH RESPITE**

Phone: 1800 052 222

Carer respite and support services, office hours counselling.

### **DISABILITY INTAKE AND RESPONSE SERVICES**

Phone: 1800 783 783

The interchange program provides the opportunity for short breaks by matching a family with a child or adolescent with a disability with a host family.

<https://services.dhhs.vic.gov.au/disability-supports-and-services-contacts>

### **EMERGENCY SHORT-TERM STAYS AND RESPITE**

If an emergency short-term stay or in-home support is needed, the Commonwealth Respite and Carelink Centre can offer emergency short-term stays or support in the home. The centre will assess care requirements and help to arrange short-term stays and emergency support in the local area. For information about after-hours emergency support call the Commonwealth Respite and Carelink Centre

Phone: 1800 059 059

### **EMERGENCY CARE**

Phone: 1800 059 059

Can get you after hours emergency respite 24/7

### **YOUNG CARERS**

Young Carers program which offers young carers access to specific counselling, support and information and service referrals

<https://www.carersvictoria.org.au/be-informed/young-carers>

### **YOORALLA**

Phone: 9666 4500

Respite for children and young people

<https://www.yooralla.com.au>

## HOW CAN I CONTACT INDIVIDUALS/PARENTS IN SIMILAR SITUATIONS?

### **ACD (Association for Children with a Disability)**

Phone: (03) 9880 7000

Offers workshops support groups and a support line.

<https://www.acd.org.au>

### **GENETIC ALLIANCE AUSTRALIA (GAA) CONTACT CORNER**

Phone: (02) 9295 8359T

GAA facilitate support for those affected directly or indirectly by genetic conditions throughout Australasia. Peak umbrella group for rare genetic diseases, GAA will endeavor to facilitate contact with another family/individual affected by the same, or similar condition, and/or provide information about an overseas support group.

[http://www.geneticalliance.org.au/contact\\_corner.php](http://www.geneticalliance.org.au/contact_corner.php)

### **GENETIC AND RARE DISEASE NETWORK (GARDN WA)**

Phone: 1300 770 995

The Genetic and Rare Disease Network (GaRDN) is a not for profit organisation that acts as a peak body for genetic and rare disease support groups in Western Australia, working to empower individuals and their families to reach positive health outcomes

<https://gardn.org.au>

### **GENETIC SUPPORT NETWORK VICTORIA (GSNV)**

Phone: (03) 8341 6315

The organization is committed to promoting the interests and well-being of people affected by genetic conditions. GSNV facilitates access [www.gsnv.org.au](http://www.gsnv.org.au) to services, connecting with others, education, advocacy, support and information.

<https://www.gsnv.org.au/>

### **SWAN Australia (Syndromes Without a Name)**

Phone: 0404 280 441

Peak national organisation supporting families who care for a child with an undiagnosed or rare genetic condition. Peer to peer support

<https://swanaus.org.au>

### **MY TIME**

Support for parents with children with a disability. My time helps you connect with other parents who really understand what it's like to have a child with a disability, as well as skilled guidance from facilitators to help you access information and services in your area.

<https://www.mytime.net.au/>

### **RARE VOICES AUSTRALIA (RVA)**

Phone: (02) 9967 5884

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.

[www.rarevoices.org.au](http://www.rarevoices.org.au)

**ENGLISH IS NOT MY FIRST LANGUAGE... Who can help me understand?**

**MEDICAL TRANSLATION**

Phone: 131 450

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.

<https://www.betterhealth.vic.gov.au/health/ServiceProfiles/translating-and-interpreting-service>

**THE TRANSLATING AND INTERPRETING SERVICE (TIS NATIONAL)**

Phone: 131 450

Provides interpreting services 24 hours a day, every day of the year.

[www.tisnational.gov.au](http://www.tisnational.gov.au)



## I HAVE A HEARING/SPEECH IMPAIRMENT...

### Who can help me understand?

#### **AUSLAN INTERPRETER (NABS)**

Phone: 1800 24 69 45

Booking and Payment Service provides interpreters for Deaf, Deafblind and hard of hearing people who use sign language and would like an interpreter for private health care appointments. Sign language services to Deaf people are provided for both public and private health care appointments. 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. 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.

[www.nabs.org.au](http://www.nabs.org.au)

#### **AUSLAN SIGNBANK**

Signbank resource is a dictionary for the deaf language Auslan, you can find interpretations, videos and classes in the link below.

<http://www.auslan.org.au>

#### **DEAF CHILDREN AUSTRALIA**

Phone: 1800 645 916

Aids children/young people with hard hearing of deafness as well as support for the whole family.

<https://www.deafchildrenaustralia.org.au>

Deaf friendly schools Victoria:

<https://www.aussiedeafkids.org.au/vic.html>

#### **KEY WORD SIGN VICTORIA**

Key word sign Victoria runs workshops and training sessions to help people learn sign language.

<https://keywordsignvictoria.org>

#### **NATIONAL RELAY SERVICE (NRS)**

Phone: 1800 555 660

If you are deaf, or have a hearing or speech impairment, you can make calls through the National Relay Service.

[www.relayservice.gov.au](http://www.relayservice.gov.au)

#### **RIDBC**

Phone: 1300 581 391

Royal Institute for Deaf and Blind Children support children who are vision and hearing impaired and their families across Australia

<https://ridbc.org.au/contact-ridbc>

## I NEED SUPPORT WITH TRANSPORT...

### **ANGEL FLIGHT AUSTRALIA**

Phone: 1300 726 567

Co-ordinates non-emergency flights, free of charge, for (07) 3620 8300 or toll financially and medically needy people. Flights may involve patients or free: 1300 726 567 compassionate carers travelling to or from medical facilities anywhere in Australia.

For more information visit:

[www.angelflight.org.au](http://www.angelflight.org.au)

### **AUSTRALIANS DISABILITY PARKING SCHEME**

The scheme allows individuals to hold a disability parking permit allowing them to park in the nationally recognised disability parking spaces.

<https://www.dss.gov.au/our-responsibilities/disability-and-carers/programmes-services/for-people-with-disability/australian-disability-parking-scheme>

### **MULTIPURPOSE TAXI PROGRAM**

Phone: 1800 638 802.

Program designed for those with severe and permanent disabilities, member of the program can receive subsidised taxi fares. Online application below.

<https://cpv.vic.gov.au/passengers/mptp/doctors-online-form>

### **Royal Flying Doctors Victoria**

Phone: (03) 8412 0400

Assists in getting rural and remote Australians the medical assistance they need when the need it.

<https://www.flyingdoctor.org.au/>

### **VPTAS- VICTORIAN PATIENT TRANSPORT ASSISTANCE SCHEME**

Phone: 1300 737 073

Victorian Patient Transport Assistance Scheme covers some of the travel and accommodation costs incurred by rural Victorians when they must travel more than 100 kilometres one way for specialist medical treatment.

<https://www2.health.vic.gov.au/hospitals-and-health-services/rural-health/vptas-how-to-apply>

### **VTCTA- VICTORIA AND TASMANIA COMMUNITY TRANSPORT ASSOCIATION**

Phone: 0438 780 911

Transport support for the disabled.

<https://www.vtcta.org.au/>

### **WHEELCHAIR ACCESSIBLE MAXI TAXI**

Phone: 136 294

Black & White Cabs currently has a fleet of 13 MAXI over 150 Wheelchair Accessible Maxi Taxis.

[www.blackandwhitecabs.com.au](http://www.blackandwhitecabs.com.au)