Rare Minds, Rare Lives

Mental Health and Wellbeing Resources

This fact sheet aims to raise awareness of mental health and wellbeing resources that are available for people living with a rare disease in Western Australia (WA), including families and carers.

If you are in a crisis and need urgent assistance, please see the dedicated helplines on page 3 of this factsheet. **In an emergency, dial 000.**

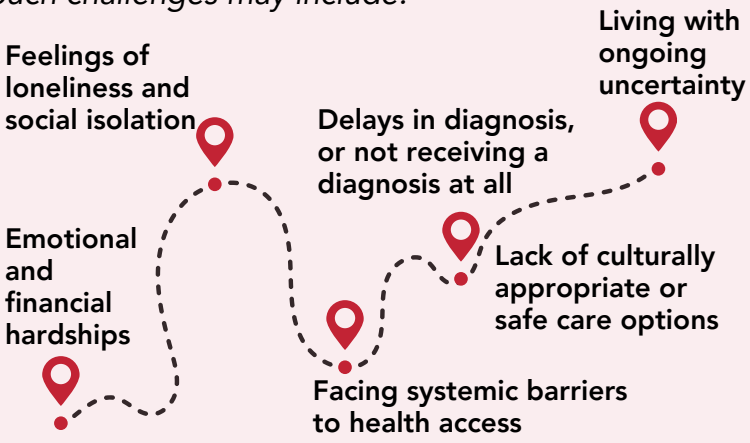
About Rare Diseases

An estimated 2 million Australians are living with a rare disease.[1] Living with a rare disease can be complex and vary from person to person. For example, a disease may be constant, or symptoms may change becoming easier or harder to manage. Some diseases are lifelong, while others may occur alongside disabilities or other diseases. Being diagnosed with a rare condition may take an average of 5 years and several doctors.[2] Some people may not receive a diagnosis at all. **These factors can have a big impact on people's mental health and wellbeing.**[3]

Mental health challenges are experienced more often for people living with a rare condition than the general population.[4]

The challenges that people living with rare disease face are complex and enduring.

Such challenges may include:[5, 6, 7]



If you experience any of these challenges, you are not alone.

Using a range of wellbeing resources can support people with their emotional, social, and mental health. **How is your mental health?** To check, see Beyond Blue's free online quiz.

What Types of Helpful Resources Are Out There?

Community and Peer Supports

Community support can include social media groups, peer counselling, online forums, as well as attending community meet ups or workshops.

One form of community support is **rare disease groups/organisations**. Groups like these may be local, based throughout Australia, or worldwide. These groups/organisations can be important for accessing information about a specific condition, and to connect with others living with a rare disease. However most groups/organisations do not provide professional mental health services.

Receiving peer support and accessing support networks can build feelings of belonging and connection, and improve access to information for people living with a rare disease.[8, 9]

Organisations offering a range of supports for those living with a rare disease are listed below.

Connect Groups assists support groups, including rare and undiagnosed disease groups in WA.

Kiind supports families with children living with disability, developmental delay, autism, genetic, rare, undiagnosed and/or chronic conditions. A range of supports such as practical assistance, emotional support and access pathways to services are available.

Neuromuscular WA: Pilot System Navigator Program for individuals living in WA with a neuromuscular condition. This service offers specialised system navigation support.

Rare Voices Australia's (RVA) Rare Awareness Rare Education (RARE) Portal can help with finding a support group/organisation for your rare disease. Assistance in finding a support group or organisation is available by contacting the RARE Helpline through the online form or by calling **+61 (0)499 549 629.** This helpline provides timely access to information and answers to key questions people living with a rare and complex disease often face.

RVA's Online Education Portal has free resources related to rare diseases for **multicultural communities,** people living **regionally, rurally, or remotely, and Aboriginal and Torres Strait Islander communities.**

Digital Mental Health

Digital mental health can relate to using mobile apps, online resources and information, online forums, social media groups, telehealth, fact sheets and e-learning modules that focus on mental health and wellbeing support. This may include learning at your own pace individually or can be completed with the assistance of a health professional.

These resources can be low or no cost and require an internet connection or phone service.

The following fact sheets for **people living with a rare disease** provide more information:

Download the Digital Mental Health Fact Sheet [PDF]

Download the Digital Mental Health Fact Sheet – Easy English [PDF]

Download the Digital Mental Health Fact Sheet – Plain Language [Word]

Crisis Lines

For immediate assistance **in an emergency, please call 000.**

24/7 Mental Health Crisis Response:
1300 555 788 (Metro)
1800 676 822 (RuralLINK)

Aboriginal and Torres Strait Islander people: 13 YARN (13 92 76)
Lifeline: 13 11 14

Finding a Mental Health Specialist

There are many different types of trained mental health professionals.

Your general practitioner (GP) can assist you with finding the right information, accessing treatment and with general support for your mental health in the long-term. Mental Health Treatment Plans can help with the costs of getting mental health support. Speak with your GP to learn more.

Organisations that can assist with mental health and counselling services are listed below.

Helping Minds offers free and confidential information on counselling and support groups for families, friends and carers of people living with mental health challenges.

Relationships WA provides mental health and counselling services to individuals, families and carers across WA, including supports for diverse population groups and specialist options.

The Samaritans WA provides anonymous emotional support and counselling for people across WA in times of need and during crisis.

Additional Resources

Support for Carers and Families

Carers WA offers a range of carer-focused services, including peer support groups, counselling and telehealth, self-guided coaching and access to emergency respite.

Siblings Australia provide resources and services for siblings of children and adults with chronic conditions, including disability, chronic illness and mental health challenges.

Ngala Parenting Line **08 9368 9368 (Metro) 1800 111 546 (Regional**) is a call-back service that provides free support and advice for parents and caregivers of children up to the age of 18 years old. Ngala can connect families to local community services.

Grief and Bereavement Supports

Griefline **1300 845 745**
Australia's national grief and loss support hub.

Grief Centre of WA is a grief and loss support centre, offering grief counselling, support groups and community connection, and creative workshops for people living with grief.

Palliative Care WA
WA's peak body for palliative care.

Disability Supports

People With Disabilities WA (PWdWA) offers non-legal advocacy services and information on peer supports for people living with a disability. Membership is free for WA residents who live with a disability.

Peer Connect shares a range of information, including pathways to connect with peer support networks, with a focus on disability. There is information for different states, including WA.

Community Pathways and Directories

The My Services Community Directory showcases a range of WA community and mental health services.

PeerPathways **(08) 9477 2809** is a state-wide service navigation helpline for individuals, families and carers seeking supports related to mental health.

For Health Professionals

For further reading for health professionals on rare disease and mental health, click here.

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Rare Voices Australia acknowledges Aboriginal and Torres Strait Islander people as the Traditional Owners of Country throughout Australia and as a priority population of the rare disease sector. We pay our respects to Elders–past, present and emerging.