

Is Your Patient Living With a Rare Disease?



A fact sheet for healthcare professionals to increase awareness of the mental health impacts of living with a rare disease.

Rare diseases are collectively common, with **8% of the Australian population** and an estimated **2 million Australians** living with a rare disease.^{1,2}

There are more than 7,000 different rare diseases.³ As the Australian Government's [National Strategic Action Plan for Rare Diseases](#) highlights, diagnostic delays are common, with 30% of Australians living with a rare disease experiencing a diagnostic delay of more than 5 years.³ Many rare diseases have no known cures available.

Why Is Mental Health and Wellbeing Awareness Important for People Living With a Rare Disease?

An individual living with or caring for someone with a rare disease is at a higher risk of experiencing mental health and wellbeing challenges.⁴

People living with a rare disease experience **stress, depression and anxiety at higher rates than the general population.**⁵

In a 2013 study, **90% of Australian families** reported that the psychological impact of living with a rare disease is high.⁶

The often complex, progressive, and life limiting nature of rare diseases have a **significant impact on people's mental health and wellbeing.**⁷



Findings indicate Australians living with a rare disease often do not receive adequate mental health and wellbeing support.

In a 2017 study, **47.5%** of Australians living with a rare disease stated they were offered referrals to counselling or therapists at the time of their diagnosis.⁸

A further **79.4%** of Australian adults living with a rare disease felt they did not receive enough psychological support, compared to 66.4% reporting they received adequate medical support in a 2019 survey.⁹

*Mental health assessment and treatment is not routinely included in rare disease care.*¹⁰

People living with a rare disease often do not have access to mental health and wellbeing support or psychosocial supports. Mental health and wellbeing support is important for everyone living with a rare disease, including families and caregivers.

i What Can You Do to Help Your Patients?

When a patient sees you, they may need your help to access appropriate mental health and wellbeing support for themselves and their families.

Australia's first-ever [National Recommendations for Rare Disease Health Care](#) includes direction to recognise and support mental health, social and emotional wellbeing needs - as living with a rare disease affects all facets of people's lives!¹¹

As a clinician you can:

1 BE AWARE



Be aware of the mental health and wellbeing impacts of living with a rare disease.

2 ASK



Ask about mental health and wellbeing at all appointments.

3 ACT



Recommend appropriate resources, support, and referrals.

4 APPLY



Deliver trauma-informed and strengths-based care.



Resources Available

Rare Disease Information

The [RARE Helpline](#) (available via the online form or by phone +61 (0)499 549 629) is a national helpline that assists people living with rare diseases and complex conditions. Clinicians are also able to ring the helpline to ask questions on behalf of patients with rare and complex diseases.

The [Rare Care Clinic](#) is a Clinical Centre of Expertise in Perth for rare and undiagnosed diseases, supporting patients and families through cross sector care coordination services, and can assist health professionals with related enquiries.

For People Living With a Rare Disease

People living with a rare disease means: Patients who have a diagnosed or undiagnosed rare condition, their families and carers.

[RVA's Online Education Portal](#) has free resources customised for **Aboriginal and Torres Strait Islander and multicultural communities**, and people living regionally, rurally, or remotely.

- [Rare Minds Rare Lives: Mental Health and Wellbeing Resources \(WA\) Fact Sheet](#)
- [Living With a Rare Disease Digital Mental Health Resources Fact Sheet](#): A range of wellbeing and digital mental health services for individuals, families and carers are provided.

Community Supports

Many people living with a rare disease have found it helpful to connect with others with lived experience.^{12,13}

Linking patients to a rare disease group or organisation can improve access to tailored information and be a pathway to peer support and feelings of belonging.

Rare Voices Australia's (RVA) [Rare Awareness Rare Education \(RVA\) Portal](#) has a large directory of rare disease [patient support groups/organisations](#) based in Australia, listed by condition. [RVA](#) is the national peak body for Australians living with a rare disease.

For Health Professionals

E-Learning for health professionals:

- ['Rare Disease 101 - Australia'](#): A free online course co-designed with people living with a rare disease. This course provides education to health professionals and includes a module on mental health and wellbeing.
- [Rare Disease Project ECHO®](#): A free, innovative video conferencing model that connected providers to the multidisciplinary [Rare Disease Awareness, Education, Support and Training \(RAREST\)](#) Project team. Two series of this Clinical Community of Learning Practice were held in 2022 and 2023 with resources available online, including a module on mental health and wellbeing.

[Register to remain up to date](#) with news on future series or relevant resources/events.

Information and further resources:

- [National Recommendations for Rare Disease Health Care](#)
- [Helpful resources for health professionals, and lived experience videos.](#)

References

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A print-friendly page with resources for healthcare professionals in Western Australia to increase awareness of the mental health impacts of living with a rare disease.

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For Health Professionals

[Is Your Patient Living With a Rare Disease? Resource for Clinicians \(WA\)](#)



Helpful resources for health professionals, and lived experience videos



For People Living With a Rare Disease, Carers and Families



[National Recommendations for Rare Disease Health Care](#)



E-Learning for health professionals:

[Living With a Rare Disease Digital Mental Health Resources Fact Sheet](#)



[Rare Disease Project ECHO®](#)



[Rare Minds, Rare Lives Mental Health and Wellbeing Resources Fact Sheet \(WA\)](#)



['Rare Disease 101 - Australia' free online course](#)

