RArEST Rare Disease Awareness, Education, Support, and Training
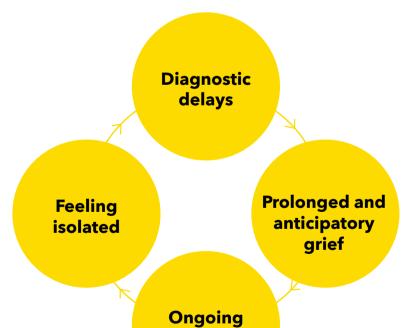
Living with a rare disease
Digital mental health resources

This fact sheet is for Australians living with a rare disease, including their families and carers.

The content is based on consultations with people living with rare diseases* (see page 2). Digital mental health resources can help overcome commonly experienced barriers people living with a rare disease report experiencing when accessing mental health supports. This fact sheet assists with learning about digital mental health information.

Rare disease and mental health

The experience of living with a rare disease can be complex and life altering, which may significantly impact wellbeing and quality of life.[1,2] A range of difficult and distinct circumstances that people living with a rare disease face can impact mental health. Situations include the significant life upheaval associated with a rare disease diagnosis, and difficulties prioritising emotional wellbeing due to the burden of medical needs. It has been reported by people with lived experience of rare disease* that stigma surrounding mental health is an additional barrier that may arise for some community members.

Unique challenges of living with a rare disease

- Diagnostic delays
- Prolonged and anticipatory grief
- Ongoing uncertainty
- Feeling isolated

A large-scale survey[3] looked into the impact on mental health and living with a rare condition.

It was reported that:

88%
of people living with a rare disease report feeling emotionally exhausted.

95%
of people living with a rare disease feel anxious some or all the time.

The experience of rare disease can also have a substantial impact on families. An Australian study[4] found:

90%
of Australian families report that the psychosocial impact of rare disease is moderate to high.

>75%
of Australian families reported high levels of psychological and financial stress, indicating an unmet need for psychological support.

This resource does not provide advice on mental health and wellbeing. Individuals are encouraged to consult with relevant health professionals when accessing or utilising mental health and wellbeing resources.

For mental health assistance, please go to **Head to Health**. For those seeking immediate assistance, please follow the information on page 4. In the case of an emergency, dial 000.

RArEST

Rare Disease
Awareness, Education,
Support, and Training

Having a rare or undiagnosed disease may impact the emotional and mental wellbeing of both the individual and those who care and support them.[3]

> "
> **The grief attached to not leading the life you imagined or planned for – restructuring what having a full and good life means.***

> "
> **The journey is unpredictable, always challenging and never out of mind.***

> "
> **It does not mean I have a mental health problem to say my life is difficult. It's a struggle, it's an everyday battle which is not part of the everyday existence for most people.***

Members of the rare disease community* have highlighted the benefits of accessing information and support for emotional wellbeing soon after diagnosis to support their coping and ability to adjust.

These community members told us they want mental health supports that:

1 **Understand** the unique challenges of people living with rare disease.

2 Are **accessible** for people with limited time for appointments and who may be living in regional, rural and remote locations.

3 **Respond** to the mental health and wellbeing experiences of both people diagnosed with a rare disease and those who care for them.

4 Are **sensitive** to the needs of diverse groups.

5 Are **affordable, flexible** and **accessible**.

![RArEST — Rare Disease Awareness, Education, Support, and Training]

About digital mental health resources

How can digital mental health resources support people living with rare disease?

Digital mental health resources can assist people living with rare disease by providing useful information, support and skills. This can be helpful in managing some of the wellbeing challenges typically faced by people living with a rare disease.

Features of digital mental health supports

1 Many families living with a rare disease may feel financial pressure. This can be due to costs associated with disease management. There are several Australian Government funded options for mental health supports. These evidence-based supports are free of charge.

2 Supports and resources can be accessed wherever internet or phone coverage is available. This is ideal for families who may have many medical appointments or find it hard to attend sessions in-person.

3 Most services have little to no waiting period.

4 Many resources can be used to complement in-person care. This looks like tools and strategies that can be used to support in-person sessions. This is helpful when sessions might be limited. Resources can also be used alongside other types of mental health supports.

5 Informal digital mental health resources, such as social media and podcasts, can be a way to connect with others with lived experience of rare disease. This can bring about community and social connection and lead to the exchange of shared experiences and information.

6 Specialised digital mental health resources are available for priority populations, including Aboriginal and Torres Strait Islander people and those from culturally and linguistically diverse backgrounds.

Digital mental health resources include a range of services, programs, information and interventions provided online and via phone or mobile devices. Several examples are listed below.

Apps

Fact Sheets

Telehealth

Programs

Webpages

Online Activities

E-Learning

Services may be self or practitioner guided. They can also be used in combination with in-person care. Mental health professionals recommend advising your GP or other health professionals when accessing digital mental health resources as they may be able to assist you.

Digital mental health supports are just one type of support. Should you need specific advice, please speak to your GP or clinician.

Where can I access digital mental health resources?

Digital mental health resources are readily accessible in Australia. Below is a list of trusted providers of digital mental health resources that offer inclusive mental health information and supports that can be accessed by individuals living with a rare disease, their families and carers.

Immediate assistance: If you or someone you know is in immediate danger, please call 000.

If you need mental health support immediately, please call Lifeline on 13 11 14. For crisis support for Aboriginal and Torres Strait Islander people, please call 13 YARN (13 92 76).

Digital mental health and wellbeing resources

Head to Health (headtohealth.gov.au)

Head to Health is a free confidential service from the Australian Government. They offer a digital mental health services directory that includes apps, online programs, helplines and other resources, including information tailored to particular groups. Use this questionnaire to help identify the most appropriate type of support for your unique needs.

MindSpot (mindspot.org.au)

- Free assessment and treatment for adults experiencing anxiety, stress, depression and low mood.
- Clinically proven treatment options, including teletherapy and online treatment courses either as self-directed or with therapist support.
- The Chronic Conditions Course is available and may be suitable for some people living with a rare disease.
- MindSpot is working with Rare Voices Australia to provide rare disease awareness and education training to MindSpot staff.

Beyond Blue (beyondblue.org.au)

- Online mental health information available across forums, web chat services and resources.
- A range of services, including connecting with a counsellor via phone, video link or webchat or access to support from a mental health coach.

Black Dog Institute (blackdoginstitute.org.au)

- Online programs, mobile apps and digital tools and fact sheets focused on specific mental health conditions.

Carer Gateway (carergateway.gov.au)

- Carer Gateway is a free government program that offers emotional and practical supports for carers. This includes counselling, peer support, online skills courses and coaching options. These may be delivered in-person, online and over the phone.

Mental Health Online (mentalhealthonline.org.au)

- Mental health self-assessment and help, including information and resources, and a free 12-week online treatment program. Therapy assisted options include the Therapist Assisted Program.

E-couch (ecouch.com.au)

- Free for all Australians, e-couch offers self-directed training and e-learning modules that aim to help people manage mental health symptoms through evidence-based strategies.

Wellmob (wellmob.org.au)

- Wellmob shares a range of online resources to support the social, emotional and cultural wellbeing for Aboriginal and Torres Strait Islander people.

This fact sheet provides a general overview of a selection of available resources only and is not intended for the purposes of providing advice or recommendations on mental health diagnoses or treatment.

Please see a health professional for support in navigating mental health services, resources and treatment.

Resources for young people

Headspace (headspace.org.au)

- Free and confidential online counselling support for young people aged 12 to 25 years through webchat, email, or via phone. People have the option to connect with a mental health clinician with no referral required.

ReachOut (au.reachout.com)

- Anonymous, confidential and free online mental health and wellbeing support for young people, with information also available for parents and carers.
- Self-help tools, articles, personal stories and forums and an option to connect with a peer worker.

For information about rare diseases

RARE Portal (rareportal.org.au)

If you are interested in more information specific to rare disease and supports for people living with rare disease, please check out the Rare Awareness Rare Education (RARE) Portal.

RARE Helpline (rareportal.org.au/rare-helpline)

If you are living with a rare or complex disease, you can contact the RARE Helpline if you wish to discuss the information outlined in this fact sheet or have any other questions about navigating living with a rare or complex disease.

Hours: Monday to Friday 9.00am–5.00pm (AEST)

References

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3. Spencer-Tansley R, Meade N, Ali F, Simpson A, Hunter A. Mental health care for rare disease in the UK - recommendations from a quantitative survey and multi-stakeholder workshop. BMC. Health. Serv. Res. 2022;22:648. doi: 10.1186/s12913-022-08060-9

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5. eMHPrac (e-Mental Health in Practice) Project. What are digital mental health programs? 2023. Accessed 14 December 2023. https://www.emhprac.org.au/about/