RArEST
Rare Disease Awareness,
Education, Support, and Training

What does it mean to live with a rare disease?

Opportunities for change

Accessing reliable information

Although no health professional can be an expert in all rare diseases, partnerships can be formed between health professionals and patients and patient support groups to learn more about the condition. You can do so via the QR code below to the RARE Portal.

Support for all people living with rare diseases

Rare diseases often impact people's mental health and wellbeing, and can result in out-of-pocket expenses.

Checking in on people's wellbeing and helping facilitate access to appropriate mental and socio-economic supports is important. You can do so via the QR code to the RARE Portal.

Scan to visit
the RARE Portal

What is a rare disease?

A rare disease is a chronic and complex condition that affects **less than five in 10,000** people.[1]

How many rare diseases are there?

Over **7,000 known rare diseases** exist with more yet to be named. Unknown or unclassified diseases are referred to as **undiagnosed diseases.**[1]

What are the types of rare diseases?

80% are of genetic origin, however, other non-genetic rare diseases include rare cancers, infections, and autoimmune disorders.[1]

How many Australians live with a rare disease?

An estimated two million Australians currently live with a rare disease which is **approximately 8% of Australians**.[1]

The health system and rare disease

Inequitable access to healthcare, **limited referral pathways**, and lack of **care coordination** make navigating the health system challenging.[1]

By virtue of being rare, rare diseases can often result in **delayed diagnosis and misdiagnosis.** Education and awareness are important factors in ensuring people living with a rare disease receive a quicker, more accurate diagnosis.[1]

Specialist clinicians, **health services**, **medicines** and **therapies** are often **not available** or **accessible**.[1]

Rare disease **data is not captured** in health information **systems or registries**, with no strategy to collect, measure and translate data.[1]

Scan the QR code
for more information.

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1. Australian Government Department of Health. National Strategic Action Plan for Rare Diseases. Canberra; 2020. 63 p. Accessed from: https://www.health.gov.au/resources/publications/national-strategic-action-plan-for-rare-diseases on 9 October 2023.

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