Rare Disease Resources for Regional, Rural, and Remote Communities

Introduction

This collection of helpful links is for people who have rare diseases that live in regional, rural, or remote places in Australia. These links have been put together as part of the Australian Government's plan to help Australians with rare diseases. This plan is called the National Strategic Action Plan for Rare Diseases (the Action Plan). If you'd like to know more about the plan, or about Rare Voices Australia (RVA), visit RVA's website.

The links on this page aren't all about rare diseases. They also have information on things connected to rare diseases. This collection is meant to help people living with rare diseases in country or remote Australia. It will:

- Give you a place to start learning.
- Make it easier to get the help you may need for a rare disease.

Everyone, no matter where they live, should get the same good care and information about their health.

RARE Helpline

If you are looking for information about rare disease, you can contact the RARE Helpline on +61 (0)499 549 629. The RARE Helpline is open Monday to Friday 9:00am to 5:00pm (AEST). For more information, please visit the RARE Helpline webpage.

***Please note**: All links listed here are for services that can help people across Australia. If you want help that's more specific to where you live, you can use Ask Izzy and put in your postcode. If you are looking for information about rare diseases, please go to the Rare Awareness Rare Education (RARE) Portal.*

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Resources

Regional, Rural, and Remote Organisations

There are groups that help people living in regional, rural, and remote areas. We have listed two national organisations that may be able to support people living with rare diseases in country Australia.

National Rural Health Alliance

The National Rural Health Alliance (NRHA) speaks up for people who live and work in the country. The NRHA can provide information about disabilities, taking care of older people, mental health, and travelling to see doctors. If you want to know more, please visit NRHA's fact sheets page.

Consumers Health Forum of Australia

The Consumers Health Forum of Australia (CHF) speak up for people who use health care in Australia. CHF want everyone to get good, safe health care on time. They also want people to easily get information about health. The CHF has a special interest group that focuses on health in regional, rural, and remote areas. The special interest group is the first step to creating a bigger group that looks after people living with rare diseases in regional, rural, and remote areas.

Preconception and Pregnancy

When you're trying to have a baby, and when you are pregnant, getting tests and taking care of yourself is important. Finding and treating rare diseases fast helps to make sure babies don't get sicker or pass away. The links below provide information about the tests you can do before and during pregnancy that will help find rare diseases.

Rural and Remote Living - Pregnancy, Birth & Baby

> Pregnancy, Birth & Baby covers topics specific to pregnancy in regional, rural, and remote areas, including maternity services, eHealth, and financial support available.

Pregnancy Testing

The links below help you to understand the tests that you can do before you get pregnant and when you are pregnant.

- Reproductive Genetic Carrier Screening - Mackenzie's Mission
- Pregnancy - Centre for Genetics Education

These resources have been made for everyone.

Newborn Testing

The links below explain the tests that can be done to check your new baby for diseases.

- Newborn Bloodspot Screening - The Department of Health and Aged Care
- Newborn Screening - raisingchildren.net.au

Life Transitions

Moving from children's healthcare to adult healthcare or getting special care for serious illnesses can be hard. When someone has a rare disease, moving from one system to another can be even tougher. Your health care team may call these changes 'transitions'.

The disease and care needed might be complicated, and new doctors and nurses may know about the disease. This can make it tricky for people with rare diseases to think about the future and how it can make them and their families feel.[2]

These links can help with some of the big life changes people with rare diseases may face moving from one form of care to another.

raisingchildren.net.au

raisingchildren.net.au has helpful guides on taking care of children who have rare diseases. They also talk about what happens when children with rare diseases grow up and need different care.

This resource has been made for everyone.

Transition Care Network

Transition Care Network (the Network) is a New South Wales Department of Health program that provides information on transition care principles, fact sheets and a resource library.

This resource has been made for everyone.

Advance Care Planning Australia

Thinking ahead about your care when you're very sick and can't talk or decide for yourself is called Advance Care Planning. This information will help you understand how to plan and talk about the care you want.

This resource has been made for everyone.

Paediatric Palliative Care

Palliative care is a special kind of care for people who are very sick and may not get better. It's about helping people feel as comfortable as possible. Palliative Care Australia and Palliative Care New Zealand have worked together to create helpful facts and resources for young people who need palliative care and their friends, family, and carers.

This resource has been made for everyone.

Patients and Carers - Caresearch

Caresearch is a palliative care group that provides information, guides and tips on various aspects of palliative care. Caresearch also provides some information on palliative care in a regional, rural, and remote context.

This resource has been made for everyone.

Palliative Care Australia

Palliative Care Australia (PCA) works with people who use medical services and health care to make sure good palliative care is there for everyone and is easy to get.

PCA has information on palliative care for patients, carers, and health care professionals.

This resource has been made for everyone.

Disability and the National Disability Insurance Scheme (NDIS)

"While not every person with a rare disease will have an associated disability, those who do will often require assistance in activities of daily living. However, unlike many other conditions that cause disability such as intellectual disability or paraplegia, rare diseases often progress over time and change the nature of an individual's needs."

- Angela Jackson, 'Disability & Rare Disease: Towards Person Centred Care for Australians with Rare Diseases', 2019[3]

People living with a rare disease who have a disability should be able to get help for their disability. These tools can provide information about the help you can get for your disability and explains how you can get it.

NDIS Support and Services for Rural or Remote Families: Tips - raisingchildren.net.au

raisingchildren.net.au talks about the challenges of getting help for disability when you live in the country and explains how you can get the best possible support from the National Disability Insurance Scheme (NDIS).

Disability Gateway

Disability Gateway lists lots of places you can get disability help across Australia. It has information guides and fact sheets about all different parts of life with a disability and explains the NDIS.

This resource has been made for everyone.

Aged Care

Because rare diseases are complicated, people who have them may need extra help when they get older. These tools give you details about the help available for older people who don't live in major cities.

myAgedCare

The Department of Health and Aged Care has information about care for older people. You can find information about tests, your rights, programs, and help that you can get on myAgedCare. myAgedCare also has special information for older people in rural and remote areas.

Aged Care Quality and Safety Commission

The Aged Care Quality and Safety Commission (the Commission) makes sure that care for older people in Australia is good, fair, and easy for everyone. You can get in touch with the Commission if you want to share your thoughts, worries, or if you're not happy with your care.

The Commission has a page on their website for people who get care that tells them about their rights and how they are kept safe when they are getting care.

This resource has been made for everyone.

Advocacy and Self-Advocacy

Speaking up for others is called advocacy. Speaking up for yourself is called self-advocacy. People who help those with rare diseases, like doctors and carers, might not know much about these diseases and how they affect people. That's why people living with rare diseases might need to advocate for themselves or their family to make sure they get what they need.[4]

These links have information and tools that help you learn to speak up for yourself and others. The links also tell you about help you can get advocating for yourself if you live in regional, rural, or remote areas.

Voices Together

Voices Together is an Australian website where you can learn about speaking up for yourself. It has information to help you understand and get better at self-advocacy.

This resource has been made for everyone.

Speak Up – Aged and Disability Advocacy Australia

Aged and Disability Advocacy Australia is a group in Queensland that helps people speak up for themselves. They have a large collection of information about self-advocacy.

This resource has been made for everyone.

Self Advocacy Kit

Advocacy for Inclusion (AFI) have made a four-part toolkit on learning to speak up for yourself. The kit has videos, things to think about, and guides you can download.

This resource has been made for everyone.

Chronic Disease Management

Most rare diseases last all a person's life and are hard to understand. People living with rare diseases may need more help and planning for their health than others.[1] The government provides support for people with long lasting and complicated conditions to get extra help. This information is for people with rare diseases who would like to know what additional support may be available to them.

My Health Record in Rural Australia

The National Rural Health Alliance explains what My Health Record is, and how it can specifically benefit people living in regional, rural, and remote Australia.

Digital Health Learning

Learning how technology can help with a long-lasting condition may make you feel better and reduce stress. Australian Digital Health Agency's Online Learning Portal has lessons on My Health Record, the My Health App, and electronic scripts for people to use.

This set of videos from My Health Record explains how to use your record.

This resource has been made for everyone.

Question Builder

healthdirect has a checklist that helps people build a set of questions about their health worries that they can take to their doctor or specialist. Using a checklist will help you to make the most of your medical visits.

This resource has been made for everyone.

Easidose

Easidose helps you to understand your medicines if you struggle to read English. Easidose uses colours for different medications and pictures to show how much to take, how often and for how long. It can also tell you other special things you need to know about the medications you're taking.

Mental Health and Wellbeing

Living with a rare disease can affect how someone feels and their overall wellbeing. The stress can also affect the people who are caring for them. When someone has a rare disease, it may take a while to find out what's wrong and get proper help, and this can make people living with rare diseases feel unsure and alone.[5]

Getting help for how you feel is important. The links below may connect you with the right resources. These resources are not for emergencies but can still be helpful.

If you need help right now for your feelings and wellbeing, you can call Lifeline for free at any time on 13 11 14.
If your life is in immediate danger, please call 000.

Centre for Rural and Remote Mental Health

The Centre for Rural and Remote Mental Health have many resources that focus on mental health and wellness in rural and remote communities. The resources and support section of their website includes a podcast, videos, and downloadable guides and fact sheets, all focusing on different ways to care for your mental health.

Rural Adversity Mental Health Program

The Rural Adversity Mental Health Program (RAMHP) helps people in New South Wales (NSW) and provides online resources and programming for people outside of NSW. RAMHP's offerings include self-assessment checks, fact sheets, the 'let's talk' podcast and self-help tip videos.

You Got This Mate

You Got This Mate has been developed by RAMHP to help rural men achieve their best mental health and wellbeing.

ifarmwell

Created together with rural farmers, ifarmwell is made by the Department of Rural Health at the University of South Australia. This online toolkit helps farmers deal with their mental health and wellbeing in country areas. ifarmwell offers free online learning and resources to use.

This Way Up

This Way Up provides online tools to learn about ways to deal with your mental health and feeling good. This Way Up has programs to help you learn about different mental health topics, fact sheets and guides, and quizzes that can help you check how you're doing.

Carer Resources

Caring for someone living with a rare disease can often be tough physically, mentally, and emotionally.

Carers are often involved in:

- Making and going to medical appointments.
- Giving medicine and helping with therapy.
- Providing personal care.
- Advocating for the person with the condition.[6]

Many carers for people living with a rare disease often experience impacts on their quality of life and mental wellbeing.[5] Carers living in a regional, rural, or remote area often experience extra barriers when providing care.

These resources are for people who provide informal support and care to someone with a rare disease.

Carer Gateway

Carer Gateway is run by the Department of Social Services for all carers. Information on different supports, counselling, skill development and caring tips are covered.

This resource has been made for everyone.

Carers Australia

Carers Australia is a group for all unpaid carers. They provide information on various topics important to caring, programs, projects, resources, and updates on things that affect carers.

This resource has been made for everyone.

Caring for Someone – Services Australia

Services Australia tells you about payments and supports available to unpaid carers. This information can help unpaid carers to get carer's allowance and services if people are eligible.

This resource has been made for everyone.

Carer Help

Carer Help is a website that provides information, resources, and support for carers.

This resource has been made for everyone.

Government Services

The Australian and State Governments offer different kinds of help for people living with rare diseases. This can be money to help live, help for carers, and other kinds of support.

The resources below have information about government help available to those that live in regional, rural, or remote areas.

Health and Disability

Services Australia explains the programs and payments for those who are currently managing their health and disability.

This resource has been made for everyone.

Living in a Rural or Remote Area

Services Australia identifies programs and payments for people living in a rural or remote area.

National Disability Insurance Scheme (NDIS)

The NDIS provides funding to eligible people with a disability to help them connect better to health, social and community groups.

Medicare Services for Rural and Remote Australians

Medicare outlines the services and supports available to people living in rural and remote Australia.

Government Health Services

Each state has a health care service that oversees regional, rural and remote areas.

- Australian Capital Territory (ACT) Department of Health
- New South Wales (NSW) Regional Health Services
- Northern Territory (NT) Remote Health
- Queensland (QLD) Rural and Remote Health
- South Australian (SA) Regional Health Services
- Tasmanian (TAS) Department of Health
- Victorian (VIC) Rural Health Service
- Western Australia (WA) Country Health Service

Patient Assisted Travel Schemes

People living in regional, rural and remote areas often need to travel to get to doctors and other services. All state governments have programs to help with some travel costs associated with health care:

- Federal - Medical Treatment Overseas Program
- ACT - Isolated Patients Travel and Accommodation Assistance Scheme and ACT Interstate Patient Travel Assistance Scheme

- NSW - Isolated Patients Travel and Accommodation Assistance Scheme
- NT - Patient Assistance Travel Scheme
- QLD - Patient Travel Subsidy Scheme
- SA - Patient Assistance Transport Scheme
- TAS - Patient Travel Support
- VIC - Patient Transport Assistance Scheme
- WA - Patient Assisted Travel Scheme

The National Rural Health Alliance provides a Guide to Patient Assisted Travel Schemes.

Genetics and Genomics

Around 80% of all rare diseases are believed to come from genes.[7] Knowing about genes and how they work can help people with rare diseases to:

- Ask for tests that look at genetics and talk about genetic medicines that may help them.
- Talk to their family about conditions that run in the family and the chance they may also have a rare disease too.[7]

There are not many resources on genomics and genetics written specifically for regional, rural and remote communities in Australia. This makes it harder for people in the country to get help with genetics. Below are links to general information on genetics and genomics.

Genomic Information for You and Your Family

Australian Genomics presents a series of easy learning materials for people to learn more about DNA, genes and genomics. Resources include a video on what the patients go through, booklets introducing reading genes (called gene sequencing) and telling others about your genes.

This resource has been made for everyone.

Genomics Resources for Consumers

The National Health and Medical Research Council has lots of fact sheets that explore different things, including an introduction to the human genome; genome sequencing; how things affect your genes; personalised medicine and genetics; and genetic tests you can do yourself.

This resource has been made for everyone.

Genes and Genetics Explained

Better Health Channel uses plain English to explain genes, chromosomes, and how genetics and changes in genes can make conditions run in a family.

This resource has been made for everyone.

Research and Clinical Trials

Clinical trials are important to people living with rare diseases. About 95% of rare diseases don't yet have a treatment.[1] For people living with rare diseases, joining a clinical trial may be the only way they can try treatment.

What clinical trials are, how they work, and how to get involved can be confusing. These resources provide a good starting point for learning more about clinical trials and how to access them.

Australian Teletrial Program

The Australian Teletrial Program wants to make it easier for people living in the country to join clinical trials. The website includes sections written for patients, doctors, and the people organising the trials, in addition to other resources.

Australian Clinical Trials – For Consumers

The Department of Health and Aged Care shares information on clinical trials for consumers. Topics covered include what is a clinical trial?, phases of clinical trials; how clinical trials work; who can be part of a clinical trial; and what happens when a trial is complete.

This resource has been made for everyone.

Australian Clinical Trials Alliance - Consumers

The Australian Clinical Trials Alliance explains research and clinical trials for consumers in plain English using videos, stories and consumer guides.

This resource has been made for everyone.

Data Sovereignty (Data Ownership)

When people go to the doctor and access services, a lot of information is collected about them.[8] Understanding who owns the data that is collected, and how this knowledge is used or could be used, will help people living with rare diseases make smart choices around their data and safety.

Data Sovereignty - You Decide How Your Data Gets Used

The International Data Spaces Association discusses data sovereignty in a way that is easier to understand.

This resource has been made for everyone.

Collaboration

The National Rural Health Alliance (NRHA) were consulted when RVA was working on this collection of resources.

Suggestions and Feedback

We invite people to provide suggestions and feedback about this page and the resources listed by using our Suggestions and Feedback form.

Disclaimer

RVA provides this information to consumers for educational purposes only. Please see our Terms of Use for further information.

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