

GP Connect

Keeping GPs informed in the changing primary health landscape



21 September 2022

Mystery patients and rare diseases: how will you help patients cope

Dr Elizabeth Palmer, Clinical Geneticist and investigator on the Australian Government funded Rare Disease Awareness Education Support, and Training (RArEST) Project.

In this GP Connect feature, Dr Palmer explores strategies for dealing with uncertainty when you and your patient have never encountered a rare condition.

Imagine receiving a diagnostic report for a condition you've never managed before. You feel uncertain about the best way to proceed. How will you deliver the news to your patient and their family? How will you treat this condition? Who will you refer this patient to? What if there are no treatments? Where will you find reliable evidence-based information?

Individually, rare diseases impact a small number of patients (less than five in 10,000 people). They are often life threatening and chronically debilitating. Examples include genetic conditions such as cystic fibrosis and rare autoimmune and oncological conditions like systemic lupus erythematosus (SLE) and mesothelioma.

But collectively, rare diseases impact an estimated two million Australians according to the [National Strategic Action Plan for Rare Diseases](#). Each Australian full-time equivalent GP will have an average of 74 patients living with a rare disease on their books at any one time.



Dealing with uncertainty

Rare disease patients and patient advocacy groups say it's ok not to have all the answers at your fingertips. Here are their top tips for quality rare disease care and support:

- Be honest: You may not have all the answers, and whilst that can be deeply frustrating for you as a healthcare professional, patients and families would rather you be frank and not pretend to have knowledge or expertise you don't have.
- Be open: Patients and caregivers affected by rare diseases often become 'patient experts'. Their research and insights can be incredibly useful. By working together, you are more effective.
- Check in: The early days after a rare disease diagnosis are a whirlwind. Once the dust begins to settle, patients will start to have more questions or require clarification about things they were told. Scheduling a follow up call in a few days can be a lifeline to patients and caregivers during an otherwise frightening and confusing time.
- Keep your patients informed: Silence can be alarming. Providing patients with regular updates, even to say you are still waiting for a test result, or expert opinion, can go a long way to alleviating the anxiety and sense of being alone felt by most rare disease patients and caregivers.

Continued page 2

Mystery patients and rare diseases: how will you help patients cope (cont)

- Be prepared: Consider 'calling a friend' before a results appointment, such as your local genetics specialist, an expert in an appropriate group of rare diseases, or a relevant support organisation.

Go-to rare disease resources

Patients and families generally want to know as much as possible, but a 'doctor Google' search can lead them down confronting and confusing rabbit holes without guidance. Have your 'go-to' quality rare disease resources at your fingertips.

The national peak body for Australians living with a rare disease, [Rare Voices Australia](#), is currently developing the [Rare Awareness Rare Education \(RARE\) Portal](#). The RARE Portal will be a dynamic repository of rare disease information, state-and territory-based care and [support services](#), and research and clinical trials information.

For clinicians, HealthPathways WA also provides locally relevant guidance on assessment, management and referral in the recently updated [Rare Diseases](#) pathway.

Other international resources include:

- The European [ORPHANET portal for rare diseases](#)
- The US portal [MedlinePlus](#) which has a large section from the Genetic Home Reference
- The Global Genes [RARE list](#)

What if there is no diagnosis?

Up to 40 per cent of Australian rare disease families have reported they needed to see more than six different doctors and spend over three years, undergoing countless tests, for a correct diagnosis to enable access to the right treatment. One in three patients will have at least one misdiagnosis. The challenges of a timely and accurate diagnosis are further compounded by Australia's geography, and the sparsity of rare disease experts and specialist centres.

Sadly, Aboriginal and Torres Strait Islander people, people from culturally and linguistically diverse backgrounds, those who have low socio-economic status and people with low health literacy experience the most challenges.

What do you do?

Treatments may not be available for a particular rare disease, but management of symptoms and person-centred care is always possible. The mental health impacts of rare diseases are immense: more than double that of the general population. Openly discussing mental health and wellbeing regularly, and offering support and mental health referrals, is important for patients, families and carers. There are even support groups for undiagnosed families such as [SWAN \(Syndromes Without a Name\) Australia](#). Carer respite might be appropriate. Some go to resources for family members including [Carer's Gateway](#) and [Siblings Australia](#).

Rare diseases are often chronic, impact multiple body systems, are progressive and life-limiting. GPs play an essential role in coordinating care, providing continuous support and patient education throughout a person's lifespan.

The RArEST Project

A three-year Australian Government Department of Health and Aged Care grant for the national Rare Disease Awareness Education Support, and Training (RArEST) Project has been awarded. The RArEST team is working to deliver rare disease mental health and wellbeing resources, disease-agnostic clinical guidelines, support and tools to help you identify the possibility of a rare disease, provide advice on referral pathways, reliable evidence and regular non-hierarchical case-based learning (complete a [short anonymous survey](#) about your needs as a healthcare professional) and more. You can also [leave your details](#) to learn more about the RArEST Project.

Alternatively, email the team at rarest@unsw.edu.au to get involved in the research in a number of ways—from being a researcher, to being interviewed by a PhD student, participating in case-based education sessions, viewing online training in your own time or by accessing rare disease resources. We are here to help you take care of your patients.

WA Primary Health Alliance in partnership with the Rare Care Centre is presenting a Rare Diseases in General Practice education event on 12 October 2022.

Read more on p.7 or visit the [online events calendar](#) to find out more.

We challenge you to #DaretothinkRare!

Hospital Liaison GP Updates

Royal Perth Bentley Group: Referrals to named consultants

Please avoid addressing referrals to specific RPH and Bentley Hospital consultants by name wherever possible. Referring to the speciality without naming a consultant allows the referral to be allocated to any suitable qualified specialist within the speciality so that your patient receives the first available appointment for their clinical triage urgency (urgent, semi-urgent, routine).

Referrals to named consultants follow these same booking principles however as they are limited to only one consultant's clinic, patients often end up waiting longer to be seen as some RPH consultants only provide a fortnightly or monthly clinic.

However, if you have discussed a case with a particular consultant or registrar, please include the name of the doctor you spoke with on the referral.

Dr Jacquie Garton-Smith
Hospital Liaison GP, Royal Perth Bentley Group
Jacquie.Garton-Smith@health.wa.gov.au

Rehabilitation Aged care Intervention Liaison Service (RAILS) at OPH and SCGH

The multidisciplinary RAILS team provides a rapid response service for people over the age of 65 through home visits and phone consultations. Under Emergency Department Innovation funding, RAILS has been expanded from servicing OPH catchment to now include SCGH catchment area. The RAILS team aims to initiate contact with clients within 48 hours.

RAILS accepts referrals via HealthLink Connect: railsrrt or Fax: 6457 8263 / 6457 8405.

Case Study – how RAILS can support your vulnerable patients in the community:

Annie is a 78-year-old grandmother living alone in her home and is socially isolated with little contact with her children. She has been receiving visits from support workers through a Commonwealth Home Support Program. Over the last few months, her support workers have been concerned by her declining cognition, dietary intake and hygiene.

While she had been approved for a higher level of care through a Home Care Package, she was not accessing the care as she did not understand what was being offered or how to accept it.

The support workers referred her to the SCGH Rehabilitation Aged care Intervention Liaison Service (RAILS) – which is now available throughout the North Metropolitan area catchment. A social worker from RAILS arranged to visit Annie at her home. When she arrived, she found that her front door was unlocked and Annie had forgotten about the visit. Her fridge was overflowing with food and found that she had not been taking her medications.

Following the initial visit, a physiotherapist and occupational therapist visited Annie and conducted a range of assessments (mobility, falls, functional and cognitive). Based on the assessments and risks of her ongoing situation, the team arranged for her to be seen by a geriatrician in the Frailty Rapid Access Clinic (FRAC) for further cognitive assessment.

The social worker worked with Annie, her next of kin and the service provider to negotiate commencement of a level 3 Home Care Package. Annie's services increased to include domestic assistance, transport, social support, gardening, home maintenance / modifications, shopping and management of incontinence.

With the commencement of the Home Care Package Annie progressed very well and started to appreciate the services coming in to support her. Annie's cognition greatly improved with the new supports, and demonstrated an improvement with insight into her care needs at home.

Education was provided to Annie's next of kin with regards to Enduring Power of Attorney and Guardianship to support Annie now and in the future. Annie will continue to be reviewed by the Memory Clinic at SCGH.

Dr Cory Lei
Hospital Liaison GP, Sir Charles Gairdner Osborne Park Health Care Group
Cory.Lei@health.wa.gov.au

Clinical Updates



WA Health - Specialist Referral Access Criteria update

The WA Department of Health has advised from 27 September 2022, the new Adult Direct Access Gastrointestinal Endoscopy RAC and Referral form applies to all referrals, submitted via the Central Referral Service, for public Direct Access Gastrointestinal Endoscopy services in WA.

The updated criteria are available via the [WA Health RAC webpage](#). The NEW Direct Access Gastrointestinal Endoscopy Referral form is available via the WA Health CRS [Referral form templates webpage](#).

Referrals to regional (WACHS) sites are to be sent directly to the relevant site as per current process.

Specialist RAC are standardised referral criteria that provide guidance around:

- What conditions will be seen in a public outpatient specialty (and what is excluded).
- What investigations are required to be included with referrals to facilitate patient preparedness and appropriate clinical triage.

The Central Referral Service will ensure that all mandatory information as outlined in the RAC has been provided before allocating the referral to the appropriate hospital.

Providing the required information as outlined in the RAC will ensure referrals are processed in a timely, consistent manner.

The RAC project is part of the broader WA Outpatient Reform Program being led by the System Improvement Unit - Department of Health, which aims to improve outpatient access for those most in need and streamline the outpatient journey. To date the following RACs have been implemented:

- Urology (Adult)
- Neurology (Adult)
- ENT (Adult)
- ENT (Paediatric)

The Adult Ophthalmology RAC and Adult Plastic Surgery RAC are in development and will be implemented over the coming months.

The Central Referral Service will ensure that all further information, including a series of FAQs, is available on the WA Department of Health [Referral Access Criteria webpage](#) or for specific questions email the project team at DOHSpecialistRAC@health.wa.gov.au.

National Suicide Prevention for Seniors Program

Anglicare's Suicide Prevention for Seniors Program equips those who support older people with the knowledge to help prevent suicide.

The free program has expanded nationally and includes a general suicide prevention online course followed by a workshop contextualising the training for older people. The two parts should only take a total of three hours to complete.

The program is funded by the NSW and Australian governments. To be eligible, you need to be working with older people and have internet access.

If you are interested, please email Anglicare at suicide.prevention@anglicare.org.au or visit the [Anglicare website](#).



Australian Immunisation Handbook – updated Tuberculosis chapter now available

The chapter has been updated to include revised recommendations for skin testing before BCG vaccination.

A tuberculin skin test before BCG vaccination is now only recommended in limited circumstances, based on a risk assessment.

All other sections of the chapter have also been updated.

Access [here](#)

MindSpot GP: A free digital mental health clinic

MindSpot GP provides the community with free online and telephone-based assessment and treatment for anxiety, depression, OCD, PTSD, substance use, and coping with chronic pain and chronic health conditions. If online or telephone treatment is not suitable, patients can also be referred to ORS Psychology for up to six free face-to-face sessions.

MindSpot GP supports people who are referred by GPs and health professionals from across Western Australia. No mental health treatment plan is required for patients to access our services.

Referral options:

- [Online referral form](#)
- **Secure messaging** - For help setting this up, call 1800 61 44 34
- Practice management software: Right click and download to add to your software: [Best Practice rtf form \(v13.0\)](#) or [Medical Director rtf form \(v13.0\)](#)

GPs in Country WA can refer patients to MindSpot GP via their Integrated Mental Health Care Provider (Mental Health portal). Please refer to [HealthPathwaysWA](#) for your local Mental Health Portal provider or for more information, please contact us.

To find out more about MindSpot GP and how practices can use this service, visit www.mindspot.org.au/mindspot-gp/ or call 1800 61 44 34.

Peel Mental Health Service Directory Release

General practices in the Peel region can now benefit from the release of the [Peel Mental Health Service Directory](#). The resource provides an easy way to see all the available mental health, alcohol and other drugs, and psychosocial support services in the Peel region. The directory contains over 150 listings of services delivered primarily in the Mandurah, Waroona and Murray areas.

The directory can be used alongside [Health Pathways WA](#) to navigate people through services and guide referrals. To access the Peel Mental Health Service Directory please download the latest version [here](#) (it will auto download). Information is updated regularly, so it is important to download the latest version of the PDF via the online link regularly.

The service directory has been created with members of the services sub-group of the Peel Mental Health Taskforce. It has been initially launched to service providers and clinicians. A public launch will coincide with a model of care at a later date. The Peel Mental Health Program is jointly funded by South Metropolitan Health Service, WA Primary Health Alliance and Mental Health Commission. For further information please contact simone.kerrigan@health.wa.gov.au.

Health Care Guide for people who need extra support

A comprehensive health literacy guide to support the health of people with a cognitive impairment or intellectual disability has been developed by the University of Notre Dame Australia with funding from the Western Australian Department of Health Research Translation Project.

This comprehensive guide can be used by health professionals who are supporting the health of a person with an intellectual disability, and includes a section on 'Primary Care in the Community'. Access the full guide [here](#)

Mental Health Week 2022

As a proud sponsor of the annual WA Mental Health Week WA Primary Health Alliance is committed promoting awareness, reducing stigma and encouraging people to get the support they need to improve their mental health and wellbeing. There are lots of ways your practice can get involved. Access resources for support, strategies and self care and downloads to promote Mental Health Week, 8-15 October 2022 at mentalhealthweek.org.au/resources. And if you are looking for strategies to look after your own mental health, visit mentalhealthweek.org.au/support

GP referral for private COVID testing

Recent changes to COVID testing arrangements reflects reduced demand for PCR testing and high uptake of rapid antigen tests (RATs). In most circumstances, a RAT is suitable to test for COVID-19, however access to PCR testing will remain.

From 1 October, people seeking PCR testing by private pathology providers will need a referral from their GP or medical practitioner. The usual fees for GP clinics will apply. This new approach to COVID-19 testing aligns with existing testing for other respiratory illnesses, such as influenza. Public COVID clinics will offer PCR testing without a referral for people with COVID-like symptoms and asymptomatic close contacts to meet their testing requirements during isolation.

Learn more at [health.wa.gov.au COVID-19 information for health professionals](https://health.wa.gov.au/COVID-19/information-for-health-professionals)

Working to support the future GP workforce

WA Primary Health Alliance will provide advice on the priority locations for GP training placements to meet current and future GP workforce needs, through the Australian General Practice Training Program GP Workforce Planning and Prioritisation grant.

This work will make a vital contribution to the future of GP training that will be delivered by the Australian College of Rural and Remote Medicine and the Royal Australian College of General Practitioners from February 2023.

Read more on the online [News Hub](#).

Help save lives through increasing early detection of hepatocellular carcinoma

Hepatocellular carcinoma (HCC) is increasing in Australia, with the age-standardised mortality rate increasing greater than any other cancer over the past four decades. The University of Melbourne and University of Western Australia, together with GPs, hepatologists and consumers, have designed a comprehensive liver screening program to help identify cirrhosis and HCC in primary care.

Participating general practices will consent for potential patients aged 45-75 years old, with at least one risk factor for chronic liver disease to be a part of the Identifying Cirrhosis and Liver Cancer in primary Care (IC3) Liver Health Trial.

Email trial@unimelb.edu.au if you would like to get involved.

GP Education & Training

Rare Diseases in General Practice

In WA, it is estimated that 63,000 children are affected by a rare disease and every full time GP has at least 70 patients with a rare disease on their books. Presented by WA Primary Health Alliance and the Rare Care Centre, this online education event will feature expert speakers covering:

- The commonality of rare diseases
- The Rare Diseases Diagnostic Odyssey
- Available referral pathways
- Resources for health professionals

Presenters:

- Dr Gareth Baynam, Clinical Geneticist and Medical Director, Rare Care Centre, Perth Children's Hospital
- Sian Gannon, Clinical Nurse Specialist, Rare Care Centre

Date: Wednesday 12 October 2022

Time: 6.00pm - 7.00pm

Venue: Online

More information and register [here](#)

A Trauma-Informed Approach in Relation to Self-Care

This interactive training session by the Training Centre in Subacute Care WA in collaboration with WA Primary Health Alliance is open to all WA general practice staff. The event will explore the role of self-care for health clinicians experiencing stressful situations and will equip participants with the tools and strategies to manage your individual response to patients/colleagues who are experiencing stress/trauma.

Date: Thursday 12 October 2022

Time: 5.00pm - 7.00pm

Venue: Online

More information and register [here](#)

TONIC MEDIA NETWORK + GENERAL PRACTICE IN A RAPIDLY CHANGING WORLD

A WEBINAR SERIES FOR GPs

In association with



Mark Butler & the future of General Practice -
What can GPs expect from the new Federal Government

Dr Norman Swan

Hon. Mark Butler MP

RACGP CPD Activity 2020/22 2 points

Join multi-award-winning broadcaster and journalist, Dr Norman Swan, and Hon. Mark Butler MP, Federal Minister for Health and Aged Care, for a one on one webinar, exclusively for GPs.

This live discussion will provide insights into the challenges facing General Practice today, Medicare reform, and the strategic priorities facing one of Australia's most influential ministers. It will also allow you to ask questions of the minister.

Tuesday 27 September

7:00 - 8:00 PM AEST
(5:00 PM - 6:00 PM AWST)

REGISTER NOW

Produced by Tonic Media Network in association with WA Primary Health Alliance and the PHN Cooperative

Annual Review of Metabolism, Endocrinology and Diabetes

Join WA Primary Health Alliance in partnership with South Metro Health Service, Fiona Stanley Hospital and Diabetes WA for an interactive day featuring practical demonstrations and a forum for discussion and debate on topical aspects of endocrine care.

Date: Thursday 15 October 2022

Time: 8.30am - 2:30pm

Venue: Online

More information and register [here](#)