

COVID-19 pandemic: critical care guidelines for Australians living with a rare disease

This position statement has been developed in conjunction with RVA's Scientific and Medical Advisory Committee following the COVID-19 press release issued by EURORDIS on 31 March 2020.

Rare Voices Australia (RVA) calls for the urgent development and use of critical care guidelines for people living with a rare disease to inform Australian hospitals and clinicians during the COVID-19 pandemic. RVA supports the State and Federal Government's coordinated implementation of COVID-19 control measures across the country. People living with a rare disease require heightened preventative measures and personalised, collaborative and consultative approaches to treatment and care. It is imperative that these patients have continued access to their ongoing treatment during this crisis, and that special requirements are considered for rare disease patients diagnosed with COVID-19.

On 26 February 2020, the Federal Minister for Health, the Hon Greg Hunt MP, formally launched the National Strategic Action Plan for Rare Diseases (the Action Plan). RVA led the collaborative development of the Action Plan with its vision being to achieve the best possible health and wellbeing outcomes for Australians living with a rare disease. The priorities underlying this policy framework, including awareness and education, care and support and research and data, are all highly relevant to Australia's response to the COVID-19 pandemic. RVA urges policy makers and authorities to specifically consider people living with a rare disease during the COVID-19 crisis, and to take action to ensure their individual clinical needs are met.

RVA fully supports the efforts of all healthcare professionals on the frontline and behind the scenes who are caring for Australians during these challenging times. The Australian Government has identified people with chronic medical conditions and compromised immune systems as being most at risk to contracting COVID-19¹. People living with a rare disease form part of this at risk population. Rare diseases are often serious, typically chronic diseases that can cause disability. Due to the complex and often progressive nature of rare diseases, people require multi-disciplinary and flexible approaches to care and support.

The COVID-19 pandemic is exacerbating the challenges that people living with a rare disease face daily. Those with certain diseases such as rare immunodeficiency, respiratory and neuromuscular disorders are at particular risk, as are those whose treatment includes immunosuppressants (e.g. rare cancer patients and organ transplant recipients).

Approximately eight per cent of Australians live with a rare disease². As COVID-19 increasingly puts pressure on our hospital and health systems, we must take steps to ensure that care and support, as well as equitable access to medicines for people living with a rare disease, are not compromised. For key decision-makers at all levels, greater knowledge of rare diseases can facilitate more responsive and appropriate services for people living with a rare disease and their families and carers³. Now, more than ever, decision-makers must be informed about the rare disease community's needs and priorities.

Frontline health professionals and ICU doctors in particular should seek advice on a given rare disease, and involve a patient's carers and regular treating clinical teams in their treatment and care plan. Additionally, health professionals must have access to both expert knowledge and robust clinical guidelines to inform their practice. Health

¹ Commonwealth of Australia (Department of Health). Coronavirus (COVID-19) health alert. Accessed from <https://www.health.gov.au/news/health-alerts/novel-coronavirus-2019-ncov-health-alert/advice-for-people-at-risk-of-coronavirus-covid-19> on 8 April 2020.

² Elliott EJ, Zurynski YA 2015. Rare diseases are a 'common' problem for clinicians. *Australian Family Physician* Vol. 44 No. 9 pp.630-633. Accessed from <https://www.racgp.org.au/afp/2015/september/rarediseases-are-a-%E2%80%98common%E2%80%99-problem-forclinicians/#1> on 8 April 2020.

³ © Commonwealth of Australia (Department of Health) 2020. National Strategic Action Plan for Rare Diseases 2020. Accessed from <https://www.rarevoices.org.au/page/171/covid-info> on 7 April 2020.

professionals are not typically taught sufficiently about rare diseases as part of their standard training⁴. With thousands of different rare diseases, it is impossible for any individual (including health professionals) to be aware of them all⁵. It can be difficult for health professionals to gain deep, specialised knowledge and experience when seeing low patient numbers in comparison to more common diseases⁶.

In line with the guiding principles of the Action Plan, including equitable access to healthcare and health technologies for all Australians, RVA proposes the following measures to State and Federal health authorities and policy makers, medical and hospital bodies, and healthcare workers managing COVID-19:

- Ongoing review of triaging of resources, critical care and other relevant clinical guidelines to ensure all guidelines respond to the clinical care needs of Australians living with a rare disease. Where gaps are identified in existing clinical care guidelines, solutions should be developed through appropriate collaboration with specialist clinical experts, colleges, organisations and other key groups.
- Continue efforts to ensure sufficient PPE, ICU beds and respiratory equipment are available to all Australians requiring such support, throughout all stages of the pandemic.
- Increase efforts to ensure Australians living with a rare disease, their families and carers, are aware of their vulnerability to COVID-19. Some individuals who are compromised could be at significant risk. Include rare disease patients and their carers as a priority group in recommendations for stricter self-isolation protocols and enhanced access to testing. RVA has already called for all Australian states and territories to adjust their protocols to allow for priority testing and quick testing turnaround times for people living with a rare disease who are displaying COVID-19 like symptoms.
- When a person living with a rare disease presents with COVID-19 symptoms, healthcare workers, in particular ICU doctors, should familiarise themselves with the facts relevant to the particular rare disease through consultation with rare disease experts and relevant organisations (including through online resources/guidelines specifically developed in response to the COVID-19 crisis). The patient's regular treating clinical team should be contacted and involved in the development of an appropriate treatment and care plan.
- Increase the utilisation of digital health, including virtual clinics and telehealth (telemedicine) services. Leverage existing infrastructure to support care and improve integration⁷.
- Recognising the prominent role that families and carers play in the daily management of rare disease patients, and their knowledge of the disease, carers should be involved as a support for hospital and ICU staff in the treatment and care of rare disease patients.

About Rare Voices Australia

Rare Voices Australia (RVA) is the national peak body advocating for people living with a rare disease. The most widely accepted definition is that a rare disease is one that affects less than five in 10,000 people^{8 9}. Contact RVA's CEO, Nicole Millis, via phone (0459 021 204) or email (nicole.millis@rarevoices.com.au) for further discussion.

⁴ Vandeborne L, van Overbeeke E, Dooms M, De Beleyr B, Huys I 2019. Information needs of physicians regarding the diagnosis of rare diseases: a questionnaire-based study in Belgium. *Orphanet Journal of Rare Diseases*. Vol.14 No.99. Accessed from <https://ojrd.biomedcentral.com/articles/10.1186/s13023-019-1075-8> on 7 April 2020.

⁵ © Commonwealth of Australia (Department of Health) 2020. National Strategic Action Plan for Rare Diseases 2020. Accessed from <https://www.rarevoices.org.au/page/171/covid-info> 7 April 2020.

⁶ © Commonwealth of Australia (Department of Health) 2020. National Strategic Action Plan for Rare Diseases 2020. Accessed from <https://www.rarevoices.org.au/page/171/covid-info> on 7 April 2020.

⁷ © Commonwealth of Australia (Department of Health) 2020. National Strategic Action Plan for Rare Diseases 2020. Accessed from <https://www.rarevoices.org.au/page/171/covid-info> on 7 April 2020.

⁸ European Commission n.d. Rare Diseases. Accessed from https://ec.europa.eu/health/non_communicable_diseases/rare_diseases_en on 7 April 2020.

⁹ Orphanet 2012. About Rare Diseases. Accessed from https://www.orpha.net/consor/cgi-bin/Education_AboutRareDiseases.php?lng=EN on 8 April 2020.