



Prader-Willi Syndrome (PWS) COVID-19 information

Preparing for a challenging flu & COVID-19 season

Information for those who are supporting someone with PWS

Australia is expecting a challenging flu season combined with an increase in COVID-19 infections. You can put things in place to help ensure you are ready to best support those who have Prader-Willi Syndrome (PWS) throughout the coming months.

It is very important to be fully prepared and armed with the best knowledge possible of how to manage COVID for someone who has PWS. This is especially significant in the home environment (whether the family home or supported living) as those are the supporters who can make the most comprehensive observations.



Vaccinate, Vaccinate, Vaccinate!

Make sure vaccinations are up to date* for both COVID-19 and the Flu.

For more information see: www.coronavirus.vic.gov.au www.dss.gov.au

Mask up and avoid crowds and remember good COVID-19 hygiene

- Avoid crowds, but if crowded areas unavoidable, wear an N95 mask, especially indoors
- Do not forget good COVID-19 hygiene – hand sanitize and keep 1.5 metres apart.

Know what's normal

A person with PWS is keen to please and get on with life. As such, they may 'soldier on', even when unwell. Therefore, it's good to have an understanding of what that person's baseline vital signs are. For example, get measurements of oxygen saturation, heart rate and breathing rates (indication of pain) when the person is well. That way, any measurements that vary from the baseline norm can alert the medical practitioner-led monitoring program.

Be alert for COVID-19 symptoms and complete a RAT immediately

Remember people who have PWS are unable to accurately monitor or report on their own health and wellbeing. They rely on those who support them to monitor and identify any changes to their health and wellbeing.

If new respiratory symptoms are noted, urgently do a Rapid Antigen Test (RAT), and consider repeating the RAT, or if symptoms worsen getting a PCR test, even if there is an initial negative RAT reading. A quick identification of COVID-19 increases the treatment options available (see overleaf).

The Victorian Government Health Department website has information about managing COVID-19 at home that may help: www.coronavirus.vic.gov.au

Have the discussion with your respiratory specialist, GP, or Hospital staff about the use of antiviral medications.

EARLY DIAGNOSIS OF COVID-19 IS VERY IMPORTANT BECAUSE ANTIVIRALS NEED TO BE USED WITHIN 5 DAYS OF THE FIRST SYMPTOMS

Ideally have this discussion with your GP before any illness, so the doctor can assess a person's suitability for these drugs in advance.

If suitable, the doctor will then assess the patient's other health conditions such as diabetes, obesity, and the other medications the person with PWS is already taking. The doctor can then decide which oral antiviral would be most appropriate if COVID-19 were to occur.

Recommendations could potentially be noted in a letter and/or in the medical record at the GP.

If at some point the person tests positive and the drugs were needed, the patient could more easily get the prescription sent by the GP. The local GP would be best placed to know which local pharmacy is likely to have stock of the medication.

Once COVID-19 is diagnosed monitor carefully for any changes of symptoms

Oximeters are useful monitoring devices but should be part of a health practitioner-led monitoring program. They are not expensive and can be purchased from pharmacies. If the person with PWS also has sleep apnoea or other respiratory illnesses, you should establish their base-line measurements prior to any COVID-19 infection. Measurements should be taken at rest and with light exercise. Monitor for any fluid retention which could indicate other emerging medical issues.

Post COVID-19 care should involve careful assessment and follow up

The person with PWS may appear to recover and assure everyone that they are ok. But be mindful that the person with PWS is not an accurate monitor of their own health and may not recognise or report their own discomfort. Careful observations from those who support them is essential.

PWSA Vic would like to thank Professor Lou Irving and Professor Kirsty Buising from the Royal Melbourne Hospital for the information contained in this PWS COVID-19 information bulletin.

** This guide is intended to provide information only - not to diagnose or advocate particular treatment options. The diagnosis and treatment of COVID-19 or flu should be made through a qualified medical professional. Patients should not change treatment without first consulting their doctor.*

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