



INTERNATIONAL
PRADER-WILLI SYNDROME
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**Discussing COVID-19 Illness and Medical Care
for someone with Prader-Willi Syndrome
A guide for families and caregivers of people with PWS**

Are people with PWS at a higher risk of developing COVID-19?

Not necessarily, but anyone who has compromised respiratory health may be at risk of a more severe COVID-19 illness. This is one reason it is important for people with PWS to maintain good health, stable weight (or lose weight) and regular physical activity. Discuss with them the fact that there is a viral infection that is affecting people all over the world and because of it we must *all* make changes to help reduce the spread and avoid contracting the virus. But what happens if your person with PWS does develop COVID-19?

This article has been written by the Famcare Board of IPWSO and discusses the general health care stages of COVID-19.



When someone with PWS contracts COVID-19 (also known by the viral name SARS-CoV-2)

This virus affects people in different ways. Not all people who contract the virus will become severely ill. Some people may have it without even knowing, as the symptoms may be so mild they are not obvious or detected.

Most importantly speak calmly, reassuringly and in a “matter of fact” manner, when explaining COVID-19 to a person who is well or has only a very mild illness. Your person with PWS will immediately pick up on your anxiety and fear.

Watch for any deterioration in their health. This can be demonstrated by increased sleepiness or slowness in movement, increased rate of breathing, lack of interest in eating or drinking, the development of a dry cough and a change in temperature, if you had been monitoring their temperature while they were well. They may also say they have a “scratchy (or sore) throat”, but this may be better indicated by eating slowly or a reluctance to eat. If you are concerned seek medical advice or an assessment and ask for a COVID-19 test for your person with PWS, if it is available.

What does a COVID-19 test involve?

A nose or throat swab is taken to test for this virus. The swab tests are a little uncomfortable, so prepare your person with PWS, by explaining that a long cotton-tipped swab, similar to a “cotton bud” will be moved around the inside of one of their nostrils or the inside of their mouth (or sometimes, both) for about 10-15 seconds. It is not painful, just uncomfortable and they will need to keep their head very still. It might be helpful for them to count or sing a song, in their heads, while it is being done. They will need to stay away from other people until the result is determined.



If their test is found to be positive, they will need to stay indoors and away from contact with other people, even other family members and/or carers for 2 weeks. They may need to wear a surgical face mask at all times, except when eating or



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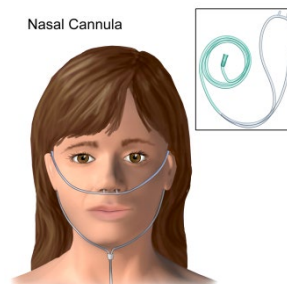
drinking. They will need to be closely watched for signs of deterioration, especially 1 week after illness onset.

If their breathing becomes laboured or difficult they will need urgent hospitalisation. There are no medications recommended to treat the virus. Assure your person with PWS that going to hospital is necessary to receive assistance with breathing. They will need to wear a surgical face mask to and while in the hospital.

At the hospital they may be started on intravenous therapy, which will require the insertion of a needle (also called a cannula) onto which a drip will be attached.

Oxygen therapy will be started. This will involve nasal prongs or small tubes that will go into their nose, under the surgical face mask, to deliver oxygen and help with breathing.

When a person is obese with hypoventilation, or has chronic obstructive lung disease they may be treated with CPAP (constant positive airway pressure) or another form of NIV (non-invasive ventilation). However, should they normally use a CPAP machine to treat their sleep apnoea, they will most likely *not* be allowed to use their own machine while they are in hospital.



If your person with PWS does not respond well to the oxygen therapy or the CPAP/NIV therapy and remain short of breath and weak or they present to the hospital with severe pneumonia, the doctor may transfer them to the intensive care ward for further treatment. This treatment will involve the use of an assisted breathing machine, known as a respirator or ventilator. They will be put to sleep (anaesthetised) to relax and allow for the insertion of a tube into their throat to which the machine is attached. A respirator or ventilator is required so their lungs are better ventilated. While they are on the ventilator they will most likely remain asleep (anaesthetised) so the ventilator can work without them becoming agitated or trying to breath against the machine. This will also prevent them from feeling any discomfort and from attempting to remove the tubing. While on a ventilator they may be positioned lying on their backs or their fronts, whichever position is deemed better for ventilation and lung improvement. This positioning may be altered during the course of their stay in the intensive care unit.



The time they spend on the ventilator will vary. So far, there have been reports of people with PWS recovering well from this virus after the need for hospitalisation and ventilation.

Ideally, by practicing regular, good hand hygiene and appropriate social distancing, your person with PWS will avoid the COVID19 disease or Sars-CoV-2 virus altogether. Keeping active and maintaining a healthy weight or losing weight, if currently obese, will improve overall health.

Remember, if they do become unwell and require medical treatment, please provide all healthcare staff with a copy of the Medical Alerts that can be downloaded in many languages, from the IPWSO website at www.ipwso.org, to ensure they have the opportunity to know important facts about PWS.

Thank you to Patricia Douglas, physiotherapist in Sydney Australia, for her assistance with this information.