



## **Supporting someone with Prader-Willi syndrome during COVID-19: *A guide for families and caregivers of people with PWS***

It is widely known that people with Prader-Willi syndrome (PWS) do not cope well with change, especially when the change is sudden, with no time to prepare or when it impacts on enjoyable events or routines. Learning to adapt to multiple changes in a preferred lifestyle is difficult for most people and can create much fear and apprehension. For people with PWS who are naturally anxious, these changes can be very difficult. However, for those who find they no longer have schedules to meet, for example getting ready to leave the house to attend programs or workplaces at particular times, the enforced "home time" may be welcomed.

The changes to lifestyle, brought on by the COVID-19 pandemic, are many. Maintaining positive support for people with PWS, during this time, requires broad thinking and environmental adaptations.

*This article has been written by the Famcare Board of IPWSO and discusses some suggestions for living through the COVID-19 lifestyle changes with your person with PWS.*



### **How do you explain COVID-19 guidelines to your person with PWS?**

As usual, it is always best to be honest and simple in your explanation. Discuss with them the fact that "yes, 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 catching the illness. It is very easy to catch and we must *all* be very careful!"

If your person with PWS is living in a supported residence that is in "lock down", it will be necessary to explain, where applicable, that they will not be seeing family or friends outside their house, for an indefinite period of time. They will not be able to visit family and friends and family members (in many cases) and friends will not be able to visit them. This is to keep them safe from the virus and to keep their family members and friends safe as well. Be very clear in stating that these rules have been made by the government of their country and are now laws that must be kept to avoid fines from the government's law enforcement agencies. "No one knows when these rules will be lifted. This is different and difficult for us all, isn't it? Let's think of things we can do to enjoy ourselves at home."

Most adults with PWS are very happy to abide by general rules, and if these are explained simply, will comply - especially if the rest of the country is doing the same. They will see this as "fair" and they may also like to know that they are helping keep others safe. There may be some adults, however, who feel very anxious about their family and friends, and as much reassurance as possible should be given. Phone calls, letters and cards can be increased and, where appropriate, video calls. This may involve providing the person with PWS with a device which will enable them to do this, as most homes would not allow their own office computer equipment to be used for this purpose. If a special family occasion or birthday is missed, it may be possible to promise a "really special" event once the lockdown is over.



To help prevent catching this illness everyone needs to:

1) **Practise good hygiene**

- cover coughs and sneezes with your elbow or a tissue
- put used tissues straight into the bin
- wash hands often with soap and water, including before and after eating, after going to the toilet, after being outside the home
- use alcohol-based hand sanitisers
- avoid touching eyes, nose and mouth

*Tip: to avoid overuse of soap and/or hand sanitiser or obsessive hand washing, set times and portion out soap/sanitiser by specifying “you need 2 pumps (squirts) of either liquid soap or hand sanitiser each wash”. It is helpful to draw up a chart of when hand washing is needed and how it is performed.*

**How to Handwash?**

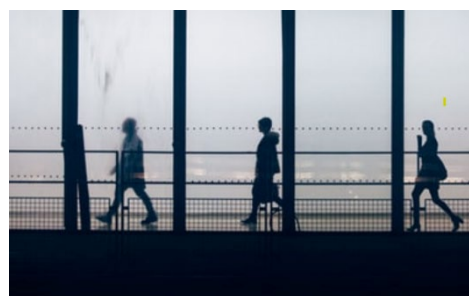
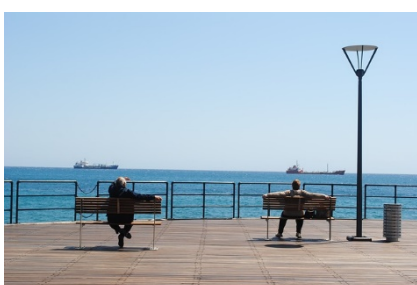


Practice	When	Daily
Washing Hands	Before eating	5 - 6 times
	After eating	5 - 6 times
	After toileting	? -? times
	Arriving home after walking	2 times

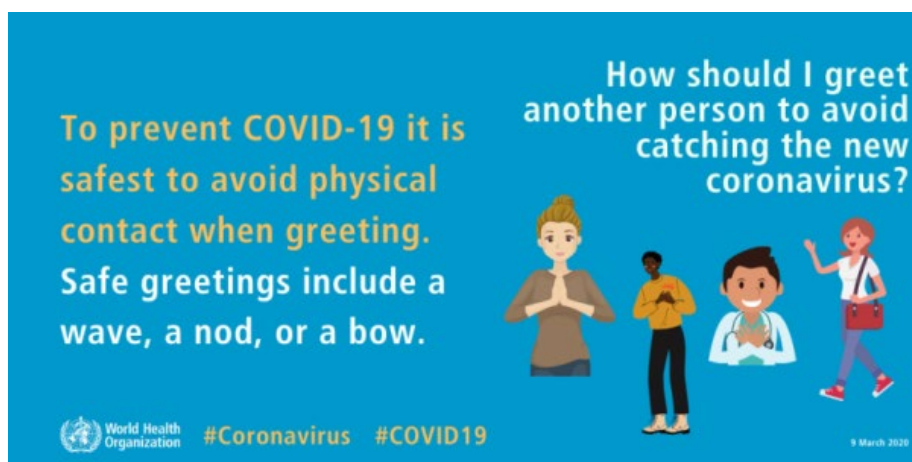
*Keep hands busy!* Now is the perfect time to bring out the jigsaw puzzles or find-a-word puzzles. Encourage drawing, teach your person with PWS to knit or crochet or make beaded jewellery, greeting cards or other hand crafts, that will occupy their hands for prolonged periods of time. Use IT screens appropriately, but not for prolonged periods without a break.

2) **Practise social distancing**

- stay at home and only go out if it is absolutely necessary
- keep the recommended distance (for your country) away from others
- avoid physical greetings such as high-fives, handshaking, hugs and kisses
- avoid public gatherings and at people who are at risk, like older or sick people



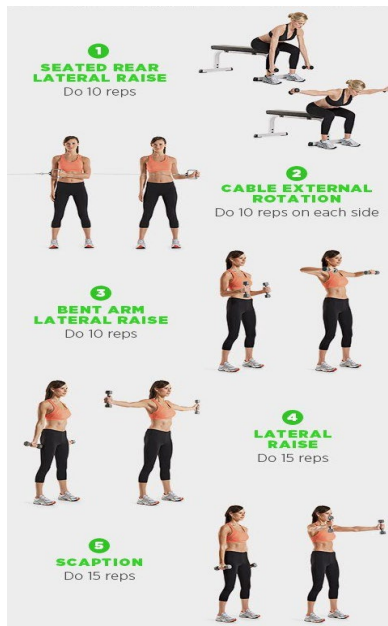
Explain that although your person with PWS has not been diagnosed with the virus, they do not want to catch it or pass it on unknowingly, to their older family members or friends. The more you emphasise the fact that these “rules” are for everyone and that “you must also be very responsible, as I know you can be”, the easier it will be for your person with PWS to accept.



- 3) **Exercise regularly** – it is most important to maintain or increase physical activity as your person with PWS will be relaxing at home more than usual.
- If you have exercise equipment at home, such as an exercise bike, treadmill, X-trainer or rowing machine, then the aim is to continue the usual exercise program or increase the number of days it is done.
  - It's great to get into the fresh air and go for walks with family members or a carer.
  - Try some home-based exercises such as: i) bouncing a basketball against a wall or the ground or tossing to and catching it from another person, ii) skipping with a rope, iii) walking up and down stairs at home (or nearby) for 10 minutes, iv) encourage all family members compete in a homemade obstacle course. Remember how competitive people with PWS can be. They usually like a challenge and they always like to win! Follow a simple strength exercise routine every day using plastic bottles of water for hand weights



## ARMS



## LEGS



### 4) **Maintain a healthy daily meal plan**

- Being at home for longer periods during the day can be a risk for all people as they look for snacks to consume when they are bored, not fully occupied, out of routine, or have fewer things on which to focus.
- If your adult child with PWS has moved back into your home from their supported residential service, you will need to ensure your home is PWS-safe again. This can be challenging, but is really necessary to maintain the good health strategies that they have been living with in their supported residence.

Does your home provide a food secure environment for your person with PWS? Is food only available when someone is supporting them? Remember, the portion sizes for someone with PWS are smaller than yours. Provide hand size protein servings according to this basic key. This model suits all members of the home and is helps to describe why we all have different sized protein serves.



**Red meat**

**Chicken**

**Fish**

- Fill half their lunch and dinner plates with vegetables that are not dense with carbohydrates
- Enjoy only 2 serves of fruit per day and avoid fruit juice

As some countries move into the warmer months extra low energy snacks maybe included – such as ice-blocks/popsicles made from sugar-free cordial or water with lemon juice and mint leaves. Moulds make them even more attractive.



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Registered as a charity in England & Wales, charity no. 1182873

### **Are people with PWS at a higher risk of contracting COVID-19?**

Not necessarily, but anyone who has compromised respiratory health may be at risk of a more severe illness in response to COVID-19. This is one reason it is important for people with PWS to maintain regular exercise. Exercise improves lung fitness by stimulating deep breathing. People with PWS do not naturally breathe deeply due to the reduced muscle strength of their chest muscles.

### **Signs to watch for in people with PWS**

As we know pain and illness are not readily expressed by people with PWS.

Due to their high pain tolerance, poor body awareness and thermodyregulation, poor health is not easily diagnosed. Due to thermodyregulation the taking of a person's temperature may not be the best warning sign of contraction of COVID-19. If you want to watch for changes in temperature you will need to be aware of their usual temperature range, before a rise or fall in temperature can be diagnosed. To find out the usual range of temperature for your person with PWS take their temperature for 5 consecutive days, at the same time of the day, preferably before they eat or drink. Remember, people with PWS can have fevers with no rise in temperature and can also present with a raised temperature and no obvious fever.

Injury, pain, discomfort or illness are more readily picked up by a change in appetite, mood, movement and how they respond to things they normally enjoy. Be aware of any change in the rate or depth of their breathing, when they are at rest or on exertion. Note if they develop a dry cough. Increased daytime sleepiness is often a sign that they are not well. Watch for signs of a fever such as sweating or a flushed face. Prepare a list of their medications (and doses) and any other known conditions such as diabetes, asthma, sleep apnoea, to have on hand if needed.

If your person with PWS does become unwell and requires hospitalisation, be sure to take a copy of the Medical Alerts Booklet found on the [www.ipwso.org](http://www.ipwso.org) website with you as well as the above mentioned list, for the medical staff assessing her or him.

### **Normality in Life**

If your person with PWS has scheduled medical appointments due, check with their medical or dental practitioner about the importance of the consult, before cancelling or missing the appointment "due to COVID-19". If a prescription is required, ring the doctor to see if it can be emailed to their pharmacy to avoid an unnecessary trip.

Remaining calm for your person with PWS, when you are feeling anxious during this difficult time, is good but remember, it's ok to express your concerns for the impact of COVID-19 on your family and friends. Global stress is not as readily understood by people with PWS due to their reduced abstract comprehension. They may under or over dramatise the situation to themselves and others. Encourage them to focus on the health and needs of their family and friends, rather than those of the world. This will help reduce their self-focus and limit "uncontrollable" grandiose focusing. This change in lifestyle will (hopefully!) not be forever, so spend time discussing the enjoyable things in their life that they will be able to resume when COVID-19 strategies are removed. It's not possible to determine when this will be, so make sure you don't set dates!

Lastly, *but importantly*, take care of yourself as the caregiver - especially if your son or daughter has returned from their residential environment temporarily during this COVID-19 period. Share responsibilities, if possible, so that you can take a walk by yourself or have a period of downtime; sleep in, read a book without interruption. It is absolutely understandable if you become stressed! However, your son or daughter will be quick to pick up on this and tempers may flare. It happens!

On a positive note, a 19-year-old man from America has survived a severe case of COVID-19 and is now home with his family. We all look forward to the post COVID-19 times!

