



# Prader Willi Syndrome and strategies for coping with Covid 19



Covid 19 has meant significant changes to our lifestyles and routines. These can be especially tough on our young people with PWS. The paediatric endocrine team recognise that sometimes heroes don't wear capes. We realise that sometimes they are parents of children with special needs, doing their very best, in a historical and difficult period. We commend you for your own heroic efforts.

## Psychological Tips

### 1. Mind yourself first

Make a mindful decision to turn off the news or radio so that you and your family are not bombarded with bad news that can be overwhelming. Download mindfulness apps or engage in stress relieving activities such as a walk on your own and creative fun activities like a water fight with all the kids.

### 2. Stay connected

Physical distancing does not mean emotional distancing. When in touch with family and friends, give yourself permission to talk about the normal run of the mill problems too. (A tantrum can feel every bit as stressful as a global pandemic when you are in the midst of it). Support for those things still matters.

### 3. Be honest

Give clear explanations to questions on Covid 19. Tell them "We are not visiting granny and grandad for a while because there is a virus that can sometimes make old people sick. We are going to talk to them by phone. When the virus goes away we can go see granny and grandad again." Being honest with your child with PWS means that their siblings also benefit from the same narrative and reassurances.

### 4. Exercise

Do lots of short bursts of exercise during the day. Be guided by the physiotherapy programme for your child. Write or have an image of each type of exercise from playing on the trampoline to rolling on a giant ball. Allow your child to choose an exercise activity from a chart of these options. Reinforce the exercise by immediately following it with a favourite activity. Some children with PWS are motivated to do something when an activity is immediately followed by a food reward (so right before snack time for example). For others they are irritable right before snack time and it is best to exercise at other times.

### 5. Timetable

Establish a daily timetable that fits for parents trying to work at home, siblings, and your child with PWS. Where possible include programmes from the therapies they typically access such as SLT. But be kind to yourself and your children- you are not expected to be a parent and a teacher and a therapist. You are expected to be human. Instead, have lots of breaks within the timetable for relatively stress free age appropriate play activities like jigsaws or colouring. Screen time gives everyone time to switch off which is necessary too. Try not to deviate too much from the typical rules around screen time though as it might take a lot of time and work to re-establish those rules for a child with PWS once the crisis is over.

### 6. Medical needs

All of our brains are calmer when we have structure and routine. This is particularly pertinent for children with PWS who will find it difficult to articulate if they are feeling unwell and may not show changes in temperature with a fever. A clear established routine will help you to read changes in their sleep or mood that might indicate illness more readily. Contact your medical team if concerned. They are here to help.

### 7. Food

We are all guilty of emotional eating at times of stress. Try to make healthy food choices and keep within the calorie limits for your child with PWS. Remember let your child have NO DOUBT that they will get their meals and snacks, and NO HOPE of getting anything additional. Certainty relieves anxiety.