Mindfulness Techniques for Managing Stress

Information for people with Prader-Willi Syndrome and their families

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MINDFULNESS DURING COVID19

The COVID19 pandemic has changed many of the things that we rely on for a sense of safety and consistency. There is, also, the daily onslaught of pandemic related news, changing restrictions and uncertainty. While we have no choice over the way our lives have changed because of these events, we have a choice about how we respond and how we let these circumstances influence our thoughts and emotions and impact our sense of wellbeing.

Families and caregivers must look after their wellbeing to have the resources to look after those who depend on them. Mindfulness offers a way to navigate theses stresses and challenges and to maintain a sense of calm when interacting with others. Mindfulness is particularly relevant for people with Prader-Willi syndrome (PWS), who are often already under considerable stress.

MINDFULNESS FOR PARENTS

The need for parents to attend to their wellbeing is like the instruction "you must put on your oxygen mask before helping others". The capacity to help others is best protected when one's own ability to function is maintained. The current circumstances add additional demands on carers of those with PWS. Feelings of anxiety, frustration and unease at this time are to be expected, but we do not have to be overwhelmed by them. Mindfulness demonstrates that we have a choice in how we respond to stressful challenges. So, what is mindfulness, how can it help, and how can we achieve it?

What is mindfulness?

Mindfulness involves paying attention in a particular way, intentionally staying in the present moment in a way that is non-judgmental. When we are in the moment, we can disconnect

from the mind chatter, the "what if" or the "I should be" thoughts, and the preoccupation with the changes and threats that appear to dominate daily life. It helps us to focus on the here and now with acceptance. When our minds are in the moment, we feel calm, in contrast to the way we feel angry when our minds are full of frustrating thoughts or feel anxious when our minds are full of worries.

How can it help?

Families often describe their minds filled with worries, anticipations, and frustrations, even when they are not doing something with their child. Worrying does not change what will happen, but it can influence how we feel and behave when faced with the next challenge. Learning to focus attention helps to develop a greater awareness of where we let our thoughts take us, that we have choices in how we think and feel, and ultimately how we choose to act. When carers face constant demands, they can often feel like they are acting on autopilot. A mindful approach can help to break this cycle and enable them to appreciate other options. Neuroplasticity research shows that regular mindfulness practise leads to structural changes in the brain that are associated with lowered anxiety and improvements in learning and memory.

Accessing mindfulness

Letting go of thoughts, being in the moment and getting in touch with the calmness that comes with it, does not come readily - particularly when we are stressed. Our default mode tends to involve multi-tasking, doing one thing and planning several others at the same time. It may seem unachievable. Yet, many people may be unaware that they have already engaged in an activity that involves mindfulness. They can relate to feeling calm and focused when engaged in a task, such as watering the garden, colouring-in, listening to music or building a model.

Afterwards, they may notice that they are better

able to manage demands, think more clearly and more creatively.

While introducing mindful activities to daily life is very useful, the best way to access the benefits of mindfulness is through formal practice such as is meditation. Guided mediation instruction comes in many forms, for example: simply following the breath, progressively focusing attention on different areas of the body, or by using imagery and imagination. For beginners, the best way to try meditation is by listening to guided instructions. There are a vast number of resources available, with different styles to try.

Meditation practice does not have to be complicated, it does not have to take a great deal of time, and it does get easier with practice. With regular practice, the sense of calm that comes from meditation can be accessed anytime and anywhere - even just briefly pausing to take a few measured breaths, accepting and letting go of thoughts and emotions.

Whether you want a brief introduction to mindfulness or to start a longer journey of exploration, there are apps and resources that will help you. Below are a few resources you could try as a starting point.

Mindfulness Resources for parents

Insight timer https://insighttimer.com/

Insight Timer has thousands of free guided mindfulness and meditation sessions and is commonly recommended by experts in the field.

Smiling minds

https://www.smilingmind.com.au/about-us

The below videos are another great source of free guided sessions that are easy to access. We have chosen a few that are similar to the type of mindfulness taught in Session One. However, feel free to explore other videos to find the style that works best for you.

5-minute Mindful Breathing Meditation

https://www.youtube.com/watch?v=nmFUDkj1

Aq0

Counting Breaths Meditation

https://www.youtube.com/watch?v=XUOUidfOp
J0

Guided Meditation (20 minutes)

https://www.youtube.com/watch?v=krKXXmnL
Q80

MINDFULNESS FOR PEOPLE WITH PWS

Meditation on the Soles of the Feet (SoF) is a mindfulness-based intervention designed to help individuals with an intellectual disability regulate their emotions. Scientific trials have shown SoF can reduce rates of physical and verbal aggression in individuals with intellectual disability and individuals with autism. Furthermore, three single-case experimental studies suggest SoF can reduce physical and verbal aggression in adolescents with PWS.

Individuals with PWS have difficulty switching their attention from one thought to another, which can increase the likelihood of an outburst. Some individuals with PWS have reported that they can prevent an outburst from occurring if they have a set activity in place that they can use to switch their attention away from the cause of upset.

SoF teaches the person to recognize the precursors to their anger/frustration/upset, disengage attention from the reason and redirect their attention to the soles of their feet. We are currently conducting a pilot study to evaluate the feasibility and acceptability of the SoF technique for managing temper outbursts in PWS. We are also looking at whether SoF can help improve anxiety-like symptoms.

The study is looking for individuals with PWS aged 13 to 30 years who have either a mild intellectual disability or typical IQ and display at least one outburst a week. This study will be conducted remotely via phone, email and Skye and is open to families both within and outside of Australia.

Eligible participants with PWS and their primary caregiver (parent or resident carer) will be invited to participate in the trial. The primary caregiver will be shown how to teach a mindfulness-based intervention to the person with PWS. The participants will be supported by a clinical psychologist experienced in PWS.

To find out more about the PWS Souls of the Feet Mindfulness study, please contact Lauren Rice fmh.devpsych@sydney.edu.au

