

About Phaeo Para Support UK

Phaeo Para Support UK is a Group managed by the Association for Multiple Endocrine Neoplasia Disorders (AMEND) for the benefit of those affected by pheochromocytoma and paraganglioma syndromes. AMEND is a charity registered in England and Wales (number 1153890). It provides support and information services to families affected by endocrine tumours and syndromes. AMEND encourages research into the conditions by funding annual research awards. It hosts a patient information event every year and runs social media forums connecting patients from around the world. Membership is free.

Please visit our website for more information or to donate:
www.phaeoparasupport.org.uk

Find us on Facebook (www.facebook.com/PhaeoParaSupportUK)

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Membership is FREE



Living with Uncertainty

*Looking after your emotional well-being when
living with an endocrine condition*



written by Kym Winter

Uncertainty often makes us feel uneasy, and too much uncertainty in our lives can leave us feeling more worried or anxious. We all differ in the level of uncertainty that we can cope with. Being diagnosed with a PPGL syndrome can suddenly increase the level we must deal with. These might be wider questions about the impact of the condition on your life overall, or more precise ones such as when or if symptoms may happen, a new appointment be scheduled, or which doctor you will see that day.

If you are struggling with the impact of uncertainty, this leaflet helps provide some practical tips and suggestions to help you cope. PPSUK also have several 'patient experience' videos on our website to help you feel less alone.

1. Accepting uncertainty

This can be one of the most important first steps in managing the emotional impact of uncertainty. Accepting uncertainty allows you to divert your emotional energy from fighting it, into managing it. You are then able to become clearer about what you can influence and control and what you can't. This can sometimes mean acknowledging and grieving losses too, perhaps about what life used to be like, or how you had hoped and imagined your future would be.

2. Managing worry

We often overestimate our worst-case scenarios, and underestimate our own ability to cope at the same time. This is all part of our brain trying to help us prepare for situations that we feel scared about.

Talking through anxieties or worries with people you know, and trust can help you find different ways of looking at them, and of coping. This may help you feel stronger about dealing with the things you are most worried about. Sometimes, talking to a professional might feel easier or more helpful. Depending on what you are worried about, this might be a financial/welfare advisor, a healthcare professional, or a counsellor.

3. Have an Action Plan

If you have physical symptoms that are very active, or if you are feeling very anxious, putting an action plan together in advance may help you manage them when they happen. The action plan could include information on what you need to do practically, such as who to call on for support, and how to arrange time to recover. For example, you might need to arrange for children to be collected from school.

PPSUK has a series of videos on relaxation and managing hormone surges on the website (www.phaeoparasupport.org.uk/new-resources-for-symptom-management/)

Remember! Difficult episodes will pass, so treat yourself gently and kindly until they do.

4. Identify Worry Triggers

Ask yourself if there is any practical action you can take to address your "what if..." worries? If not, think about what might help your worry to pass. This might involve talking with someone about how you are feeling, doing something active, or a 'worry exercise' such as those in Boxes 2, 3 and 4.

If you find that a particular activity triggers your worries (e.g., social media, or being around someone who is anxious themselves), consider taking a break until you feel calmer.

5. Challenge and Manage Negative Thoughts

Both symptoms or difficult situations (such as receiving test results) can lead to negative thoughts and feelings. If this happens, try to remind yourself of positive things that you can do to help the feelings ease or pass, and that you have got through this before.

Try the '5 Point Grounding' technique in **Box 1**.

6. Predictable Routines

When we are coping with a lot of uncertainty, making some things predictable can help us feel more safe and secure. Setting routines and reminding yourself that some things in your life are still predictable can be very helpful. These could include routines for days spent at home working/studying, for bedtime, on waking, mealtimes, or for managing hospital visits.

7. Focus on Controlling What You Can.

When you are living with a rare condition, all the focus can be on trying to manage that better. Sometimes the ordinary self-care that can improve your general health and mood can get lost. Try to eat healthily (in ways that also support your condition), exercise safely where possible, drink enough water, and get enough rest.

Make conscious choices each day. Some days you may only have enough energy to get through the day, so make a choice to 'let go' of some things. For example, cook an easy meal or get a take-away; have a rest rather than tidying up.

If either your condition, or worrying about it is interrupting your sleep, try to make more time to rest in the day when you can, and let your specialist doctor know.

Spoon Theory can be a helpful way of managing energy and fatigue, or just explaining your energy levels to others. You can read more about this at <https://happiful.com/what-is-the-spoon-theory/>

8. Stay in the present

Anxiety often focuses on what the future may hold, and worrying about things that have not yet happened, or might never happen. Even when they do, we often cope better than we first feared.

Learning a technique like Mindfulness may help with living

with both complex health issues, and anxiety. This practical tool works partly by encouraging a focus on the 'here and now', bringing your full energy and attention to dealing only with whatever is happening at that present moment, and then dealing with 'the next thing' in due course.

You can read more about Mindfulness on the NHS website's Every Mind Matters campaign. <https://www.nhs.uk/mental-health/self-help/tips-and-support/mindfulness/>

PPSUK also has more information and a series of short exercises available on the website: www.phaeoparasupport.org.uk/mindfulness/introduction-to-mindfulness/

9. Be kind to yourself

When we are worried or anxious, we can sometimes behave in ways we don't feel good about, such as snapping at a loved one. We may also cope less well with something such as if a hospital appointment is cancelled or is difficult. We may then become very self-critical.

If you find yourself being self-critical, it is important to remind yourself that it is ok to find something upsetting or difficult to deal with. Sometimes, being kind to yourself simply means acknowledging all that you have had to manage, and that you have kept going despite everything.

10. Talk to someone you trust

It is said that 'a problem shared is a problem halved'. Difficult situations often feel 'lighter' and easier to manage when we feel listened to and understood.

Talking with friends, family members, a religious community leader or your PPGL peer support network may be all the help you need. If you are still struggling, or it would help to talk to someone in confidence outside your current network, let your health/social care professional know or contact one of PPSUK's professional support services.

Did you know...?

PPSUK run a peer support Facebook Group and meetings, an Annual Patient Information Day, and a specialist Counselling Service.

More information on our website at www.phaeoparasupport.org.uk

11. Relationships

Living with a lifelong health condition like a PPGL syndrome may be very stressful at times. There may be times when your relationship with a partner or someone in your household may feel under strain due to its impact. There may be difficult decisions to make around lifestyle, finances, or future choices. Genetic conditions can sometimes bring families closer together, but equally may cause tensions too due to the strong feelings involved.

The 'ups and downs' in your family life or partnership may resolve naturally as part of adapting to life with your new condition. When you are struggling with the impact of your condition on your relationship or family life, it can also help to talk things through someone else that you trust. This might be a professional counsellor, a member of your religious/cultural community, or your health/social care professional. It can sometimes take time to find the 'right' person who feels helpful, so don't give up.

Remember! Whatever you are dealing with, you are not on your own. PPSUK is your patient community.

Box 1: 5 Point Grounding

Try to take a couple of long slow breaths in and out to the count of 5. Then focus on:

- 5 things you can see (e.g., table, chair, dog)
- 4 things you can touch (e.g., ground under foot, phone, my knee)
- 3 things you can hear (e.g., clock, voices, birdsong, traffic)
- 2 things you can smell (e.g., perfume, furniture, clothing)
- 1 thing you can taste/ imagine tasting something you like (e.g., coffee, chocolate, chips)

Repeat as necessary, or alternate with 'Box Breathing' (Box 4)

Box 2: The Worry Jar

This is a helpful technique (for either adults or children) to help set worries aside for a while, whilst also knowing they are kept 'safe.' It is particularly useful for worries which are about imagined situations, or that have no simple solutions.

1. Find a nice bottle, container, or jam-jar
2. Decorate it, and label it 'Worry Jar'
3. Whenever you have a 'worry thought', write it on a small piece of paper
4. Fold the paper up, and pop it in the jar
5. Once a month/week, go through the jar and read out your worry notes aloud.
6. Throw away any worries that are no longer bothering you, or where what you worried about happening didn't happen
7. Put back into the jar any 'worry notes' still on your mind to keep them safe for later.

Box 3: Worry Time

1. Choose a day, time, and place for 'worrying'. Try not to use your bed, or favourite chair.
2. Choose a blank notebook as a 'Worry Book'
3. When a worry surfaces in the day, write it down. Tell yourself you do not have time to 'worry properly' right now and will do so later when you can give it your full attention.
4. Close the book.
5. Return your focus to the task that was interrupted by the worry.
6. At an allocated time in the day (at least an hour before bedtime) look at your worries one at a time for at least 30 minutes. If you no longer feel worried, you don't need to do this step!
7. At the end of the overall allotted time, stop. Cross off any worries you no longer feel so concerned about, or that you feel able to let go. Leave others on as necessary.
8. Close the Worry Book, and make sure you have a transition activity to look forward to such as a cup of tea, a walk, crafting, watch TV, listen to music, etc.

Repeat as needed.

Box 4: Box Breathing

This is a good exercise you can do anywhere to help stay calm. First, imagine a square (close your eyes if you can/want to) and gently breathe out. Then:

1. Breathe in for a count of 4 (going up the right-hand side of the square)
2. Pause your breath for a count of 4 (going along the top of the square)
3. Breathe out to a count of four (coming down the left-hand side of the square)
4. Pause your breath for a count of 4 (along the bottom of the square)

Repeat as often as needed.

Useful Resources

PPSUK Counselling Service provides a limited number of free confidential counselling to registered members with a specialist rare disease counsellor familiar with PPGL syndromes. Join PPSUK for free via the website to access the service. www.phaeoparasupport.org.uk/patients/join/

Every Mind Matters is the NHS website for mental health support and has lots of useful resources: www.nhs.uk/every-mind-matters/

Anxiety UK has a range of online resources, and a helpline on 03444 775 774: www.anxietyuk.org.uk

MIND have lots of useful leaflets on everything from sleep problems to money worries, to mental health: www.mind.org.uk

Carers UK has lots of useful advice for carers: www.carersuk.org/help-and-advice

Relate is an organisation that offers support, advice, and counselling for relationships: www.relate.org.uk/relationship-help

BACP is a website listing professionally registered counsellors and psychotherapists by local area: www.bacp.co.uk

Mindfulness Resources

Oxford Mindfulness Centre offer several free, short introductory mindfulness exercises and podcasts, as well as longer courses: www.oxfordmindfulness.org

PPSUK has a series of 10-minute Mindfulness videos/podcasts: www.phaeoparasupport.org.uk/mindfulness/

Crisis support

If you are **struggling, or in a mental health crisis** contact your **GP** or **NHS 111**. If you feel imminently at risk, you can also go straight to your local **hospital A&E Department** or call **999**.

The Samaritans provide an excellent 24 hour listening/crisis support on 116 123 or jo@samaritans.org

Text **SHOUT** to **85258**

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