Managing anxiety before a scan or diagnosis

Waiting for the results of a scan, or an appointment to discuss a diagnosis, will inevitably for most people be an unsettling or scary time. Self-care at this time is crucial, and it's helpful to use a variety of strategies to look after yourself and avoid your thoughts becoming unhelpful or catastrophic.

We wanted to share some strategies that the people we support have shared with us, which help them manage to stay calm and grounded whilst they have had to sit with uncertainty.

Tolerating Uncertainty

When we are anxious, we tend to over-estimate the danger, and the odds, of bad things happening, and under-estimate our ability to cope if or when those bad things happen. Even if the odds of a bad thing happening are really small, that tiny chance is enough to really upset us.

We call it "intolerance of uncertainty". We might think things like "I just can't cope with not knowing", "I have to be 100% certain", "uncertain events are almost always bad", so "I must prepare for each uncertain event".

The thoughts make us feel anxious, so we try to reduce the uncertainty by planning and preparing as much as possible for the hypothetical future event. Sometimes we even think it would be better if the bad thing happened right now, because that would be better than living with the uncertainty.



However, worrying doesn't affect the future outcome, we cannot prevent all bad things from happening and life remains uncertain. It only makes us feel worse and makes us less able to cope with real life.

Reduce your need for certainty using the acronym: APPLE



<u>Acknowledge</u> - Notice and acknowledge the uncertainty as it comes to mind.

Pause - Don't react as you normally do. Don't react at all. Just pause, and breathe.

<u>Pull Back</u> - Tell yourself this is just the worry talking, and that the need for certainty you are craving, though understandable, is not helpful and not needed.

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Let Go - Let go of the thought or feeling about needing certainty.

Tell yourself it is only a thought or feeling. Don't believe everything you think! Thoughts are not statements of fact. They will pass. You don't have to respond to them. You might imagine them floating away in a bubble or cloud.

Explore - Explore the present moment, because right now, in this moment, we are ok. Notice your breathing, and the sensations of breathing. Notice the ground beneath you, look around you and notice what you see, what you hear, what you can touch, what you can smell. Then shift your focus of attention to something else - on what you need to do, on what you were doing before you noticed the worrying thought, or do something else - mindfully, with your full attention.

Useful Links:

Based on an article by http://www.getselfhelp.co.uk/

Other ways to manage "scanxiety"

Being mindful

Mindfulness is a term that is used a lot these days, and essentially means trying to stay in the present moment – especially important when our anxiety levels are heightened but there is nothing we can physically do but wait – in order to not let anxious or unhelpful thoughts take hold.



Mindfulness encourages you to notice when anxious/ catastrophic/unhelpful thoughts pop in, which they often do, and, instead of engaging with them, with purpose pull your attention back to the present, and engage in an activity that will absorb you for a while. This can be anything from peeling potatoes, to making the bed, to something more enjoyable such as gardening or watching a favourite TV programme. By doing this you are breaking a cycle of negative thinking that could start to build.

Distraction

Distraction can be helpful when you are going through a period where your thoughts understandably will drift to unhelpful places. Keeping yourself occupied during this tricky time with various activities (ideally pleasurable) will help stop the anxious thoughts from taking hold. Some examples include: watching TV, crafting, meeting up with friends, going out to the cinema or a museum, and gardening.

One young person we support said that they paint pottery. Each time they have an upcoming scan appointment they go out beforehand and buy some form of pottery and then paint it. They explained that this works in a few ways - firstly it's obviously a good distraction but also it's something they look forward to doing, and they now associate their upcoming



scans with something positive, and the scan provides them with the reason to do this thing that they enjoy. In addition, they now they have this collection of pottery that they have painted and they can keep. They've dated each item underneath, so it's also a visual representation of each stage and what they have managed to achieve and overcome.

Belly breathing

When we are feeling stressed, we often don't breathe deeply enough, and tend to breathe from the chest, and not the belly. When you breathe in this shallow manner, you get all the air you need to live, but you can also get other symptoms which add to panic, such as chest pain or heaviness, because you've tightened the muscles of your chest to an uncomfortable degree.

You might feel lightheaded or dizzy, because shallow breathing can produce the same sensations as hyperventilation. You can also get a more rapid heartbeat, and maybe numbness or tingling in the extremities.

People often don't realise these unpleasant physical sensations can come from feeling anxious, and not knowing the cause of the sensations you're experiencing can lead to increased anxiety, and off we go... into that anxiety spiral.



brain tumour charity!

To practice belly breathing...

- 1. Place one hand just above your belt line, and the other on your chest, right over the breastbone. Your hands will tell you what part of your body, and what muscles, you are using to breathe.
- 2. Open your mouth and gently sigh, as if someone had just told you something really annoying. Let your shoulders and the muscles of your upper body relax down with the exhale. The point of the sigh is not to completely empty your lungs. It's just to relax the muscles of your upper body.
- 3. Close your mouth and pause for a few seconds.
- 4. Keeping your mouth closed, inhale slowly through your nose by pushing your stomach out. The movement of your stomach precedes the inhalation by a fraction of a second, because it's this motion which is pulling the air in. When you've inhaled as much air as you can comfortably (without throwing your upper body into it), stop.
- 5. Pause. How long? You decide, because everybody counts at a different rate, and everybody has different sized lungs. Pause briefly for whatever time feels comfortable. Be aware that when you breathe this way, you are taking larger breaths than you're used to. For this reason, it's necessary to breathe more slowly than you're used to. If you breathe at the same rate you use with your small, shallow breaths, you will probably feel a little lightheaded from over-breathing, and it might make you yawn. Neither is harmful, they're just signals to slow down.
- 6. Open your mouth. Exhale through your mouth by pulling your belly in.
- 7. Pause.
- 8. Continue with Steps 4-7.

Ideally, get into the habit of belly breathing throughout the day every day to keep general levels of anxiety down, and to get you into to the habit for when you need it more, during those anxious times of waiting.



Music

Playing music on your way to a scan or medical appointment helps some people keep calm, and together with focussing on your breathing, can be really effective. You can also ask for music to be played during a scan, and might be able to take your own music in.

Eye masks

Some people find it helpful not to be able to see the inside of the scanner, particularly if you know you can feel claustrophobic. The hospital can supply them, but you may have to ask.

Meditation

Meditation isn't for everyone, but for those that benefit from it, it is a great tool to calm the mind and body down. If you haven't mediated before, we would recommend starting with a guided meditation to get you used to it. There are many apps you can subscribe to, as well as guided meditations on the internet, and different ones will suit different people. If you are looking at apps, we would recommend 'Calm' and 'Headspace'. You have to pay a monthly subscription, but they let you try out many of their resources for free first.

In addition, we have some free guided meditations on our website; click here to view them.

Reward yourself afterwards

Try and plan something pleasant for after the scan or appointment – even if it just to have a rest! Having something positive to look forward to after the scan will help to reduce the impact of the anxiety, and that sense of being 'rewarded' after such a trying day is important psychologically, for self-care.

Allow emotions to be there

Although it is of course helpful to soothe and calm yourself, it's important to remember that experiencing a range of emotions is normal and to be expected.



One patient told us "the best thing my counsellor ever told me was it's perfectly normal to feel bad, sad, worried, anxious, angry, etc, nobody can ever be happy all the time. Having that permission actually has the effect of not feeling as bad, because it alleviated the guilt of having the "wrong" feelings."



Finally, some wise words from a brain tumour patient supported by the charity:

"I've learned, because of fatigue, to treat my energy as a precious commodity. Everything I do, including thinking, is using energy, so I've learnt not to waste it on things which are out of my control or aren't as important in the grand scheme of things.

"Any thoughts which start with 'If only', 'what if' or 'maybe' are all hypothetical, so I don't entertain them as it's wasting energy on something which might not even happen. I'll deal with it if and when it does.

"I've also learned to question whether something is within my control eg the results of a scan, as it's a waste of energy to worry about something which I can't control. I can only react at the time of getting the results. At the moment, it can take a few months to get results back; that's a long time to be in an anxious state. It will only cause stress, bad physical days, sleeplessness, low moods and overall bring me down, which is not helpful.

"I know on the day of the scan I will and do get upset. It's very overwhelming, it brings it all back to the fundamental issue, a brain tumour. I try to be extra kind to myself on this day and say it's ok to get upset, it's a massive thing to have to deal with. I know that the following day I'll be ok again and what will be will be.

"In the past if I've felt anxious I've asked myself 'have your symptoms got worse?' The answer has always been no, so then I ask myself 'what makes you think that there's been any change in the tumour?' There's nothing to support my reason for anxiety! It's always worked for me to ground my emotions."

Further support

We are here to support you in any way we can, at all the difficult stages you might find yourself going through.

Please do not hesitate to contact us if we can help by emailing info@yorksbtc.org.uk, calling 0113 340 0111 or visiting yorksbtc.org.uk/support

