"Scan-xiety" - Practical strategies for dealing with cancer-related scans



Anxiety about scans or "scan-xiety" as it's sometimes called, is very normal and causes high levels of worry and distress for those who have been diagnosed with cancer. It is experienced by two thirds of patients, and for one third of patients, it is severe(1) – it's not "silly" or a sign that you're not coping well! It may include intrusive worries, fear, trouble sleeping, irritability, agitation, heart palpitations, low mood, a feeling dread or even being physically sick/vomiting as the check-up looms.

Fears of further disease are often part of the emotional fallout from a loss of confidence and control over your health, and it's natural to worry about test results that may dictate the need for further treatment and what life looks like. If you have always been a "worrier" you may find scans particularly hard with your worry worse around routine scans as well as scans booked to investigate any new health changes you may have noticed, it may peak in the weeks and days before the scan. The first scans after treatment can be especially nerve wracking as you may have received bad news followed by bad news, and it can be hard to believe everything may be OK.

The good news is that evidence-based strategies have been found to help reduce anxiety about cancer coming back as well as reduce 'scan-xiety', so we don't just have to put up with it. (1, 2) You will probably develop more confidence over time as you learn ways of dealing with follow-up checks and feel better physically. It may seem unbelievable in the early days that checkups can become just part of normal life, and it's important to return to other normal life activities and plans to fill up your calendar so it's not just medical appointments!

The following strategies have been shared by medical and radiology professionals as well as patients who have experience with coping with follow-up checks. Please think about whether any of these could be useful for you, and acknowledge your successes as you build your confidence.

Scheduling your care

- Book the appointment at a time that suits you: Early in the morning may work if you are going on to work or have an activity planned afterwards, or later in the day may be better when someone else may be able to come with you. If you are living with pain or fatigue, plan your appointment for when you have most capacity, and consider asking staff for the quietest time of day, or for when appointments tend to run on time.
- Schedule of appointments: Try to book your scan as close to when you will be able to see your specialist to reduce the time you are waiting for your results, or if possible, work out a plan for immediate feedback. Try not to book too many appointments in one day in case they run late and this adds to your stress. If you were diagnosed around a holiday period such as Christmas or a significant anniversary, subsequent scans may fall then so ask about moving them forward so this doesn't happen again. Holiday periods can also be particularly challenging as there is often less support and care staff around.
- The location of appointments: Where you have your scans may be a balance of your medical teams' preferences and a location most convenient/comfortable for you; upsetting news or trauma may be associated with a particular location. It may be that you may wish to ask if you can go to another location, although you may have developed good relationships with staff at a particular setting and there may be advantages to using the same machines or same team for reviewing your scans.
- Anxiety can focus on different aspect of the scans: It may be a fear needles, the ingestion of fluids, an uncomfortable or claustrophobic machine, reminders of a past traumatic experience, or your test results. Please let your team know beforehand so you can problem-solve options to help you you certainly will not be the first persons to have raised the concern!
- General health and wellbeing skills: Work on your general stress management skills in daily life – exercise/physical movement, dietary intake, sleep, pain management etc., to ensure you are entering your medical appointments in the best physical and mental health possible.



Preparation

- Plan your support: If you ask someone to come to your appointment with you think about guiding them in what you find most helpful, such as talking about other topics, breathing exercises, or physical touch. Alternatively, you may find going by yourself reduces the focus on the appointment may fit into your daily routine. If permitted, eat well and have plenty of fluids, and take extra supplies in case there are delays.
- Allow plenty of time to get to your appointment so you don't find yourself rushing, sometimes our body can trick us into thinking we are anxious because we notice a racing heart rate or feel sweaty and hot.
- Educate yourself about anxiety: Anxiety feels pretty unpleasant but it is really our 'early warning alarm system' trying to keep us safe! It's normal and not a sign we are "loosing it"! We need a level of anxiety to keep us alert, but too much isn't helpful and can result in feelings of panic. As we survey our environment for threats of possible danger, 'triggers' tells us to fight (plan and act), flight (get out of there/avoid), or freeze (stay still until the danger has passed). We may notice physical changes (such a rapid breathing, muscle tension, shaking), changes to our thoughts (we may 'blank' or our thoughts seem fast/muddled/intrusive/hyper-focused), changes to our behaviour (such as agitation or showing anger) and strong emotional feelings (such as feeling out of control, fearful, teary or overwhelmed). Our responses dictate the 'actions' we can take to best help ourselves – do we need to calm our body? Try to talk sense to ourselves? Change our behaviour or environment? Or take care of our feelings with compassion, soothing and support?We can learn to refine our skills in all these areas – there are many anxiety and panic management tools we can learn; please see the websites below or talk to a psychologist or counsellor who can help you to manage your anxiety responses.

"When I go near the hospital – I feel all the anxiety again. I've been told it's like going back to a roundabout where a truck shunted my car - it's natural that I'm going to expect the same thing to happen again at the roundabout, and it will take a while for my body and mind to relearn I'm safe, it's OK".



"I do this strange thing with my fingers, but it works – on each hand I tap my first finger to my thumb, then my second finger to my thumb, then third, and fourth, and then start again - it's just enough to keep me focused when my brain starts to spin!"

- Monitor your breathing and signs of stress from the moment you leave home if notice if your breathing becomes shorter or shallower, please pause, breathe out and gently slow your breath to a comfortable calm rhythm: you may wish to breathe in to the count of "1-2-3" and breathe out as you think "1-2-3 relax", keep checking your breath and helping your body stay calm. There are many options for practicing relaxation and meditation skills in day-to-day life so you can draw on these skills at these difficult times, please don't get focused on what is the best strategy it's more about what you find easy to use in the moment and works for you.
- Distractions: Finding things to redirect your attention can help with passing time, and of course won't work all the time, but even if it gets you through another few minutes think of it as a 'win' and move to another strategy. Take things to do or listen to while waiting, and call ahead if you think appointments are likely to run late. Mobile phones can be good source of distraction, but if you enter areas where they are not permitted, think about what you can take to do with your hands, such as a craft, a word puzzle, a child's fidget type toy, or even a ball of Blu-tac or plasticine to keep them occupied. You can also think about activities to keep your mind occupied if you are required to be still – think about your favourite holiday, list all of your teachers through school or players in your favourite AFL team, count ceiling tiles, count backwards from 100 in 3's, or use self-guided breathing and relaxation skills.

If your level of anxiety or distress means you delay or avoid check-ups, please talk to your care team about what they can suggest or short-term help from medications to ensure you get the care you need.

Simple 4-step calm breathing...

1. Bring your attention from the room around you, to your body and to the rise and fall of your breath. Fix your gaze on a point in the room or close your eyes...

2. Let your breathing become smooth and calm as you breath out through your mouth and in through your nose. Count in, two, three, hold..., then breath out, two, three, relax, ...letting your shoulders drop, and your body become a little more heavy with each breath. Repeat the count again and again...

3. Let yourself sit in peace, breathing slowly and calmly counting, noticing thoughts come and thoughts go; if you notice outside sounds just redirecting your attention back to your breath,...this is all you need to do in this moment...

4. When you are ready to come back to the moment, move your attention from your breath, back to the room around you, and back to this current moment, pause, and find yourself ready to move on with the rest of your day. Know you can use this simple exercise whenever you need to simply pause and calm yourself.

The more often you practice these four steps the easier it will become to settle yourself when you notice any sign of stress. Try to build moments or minutes of practice into your day, when you are standing in the shower, waiting in a queue, or enjoying sitting in nature - it is your exercise to use whenever you need.

In the appointment

- Make friends with the staff! Good clinical care involves caring for your wellbeing and staff are there to help you so need to know how to be most helpful: some people may prefer small talk to distract them, others like to know exactly what is going on step by step, while others prefer quiet to focus on their breathing skills.
- If you don't find interacting with others helpful, think about what you can do to deter or minimise unwanted conversations: Consider wearing a mask, avoid eye contact, use visible headphones, a hat, or take a book.
- Remind ourselves that anxiety is to be expected as it is our body's way of "trying to look out for us"; anxiety often follows a wave-like pattern and when it builds we feel it's going to keep building, so try to catch it early, slow our breath to settle ourselves, and 'ride the wave', noticing it settle and pass. Remind ourselves that: "...anxiety is to be expected, this will pass... I have got through this before".
- Be our own coach. It often seems we have an unhelpful voice in our head, warning us about everything that can go wrong and all the worse-case scenarios "the what if's", or "there may be nothing that can be done" thoughts. Catch these thoughts and ask yourself: "is this a fear or a fact?", pause, come back to the moment, our breath, and remind ourselves about the facts and any helpful things our doctors may have said. A process to 'talk back to the thoughts' and keep our perspective is explained in the following handout: Tip-Sheet-Managing-Unhelpful-Thoughts.pdf (headwayhealth.com.au), and could also be discussed with a counsellor or psychologist.
- Learn and practice assertiveness so your care team can understand how best to help you; see HWH-Communicating-Effectively-.pdf (headwayhealth.com.au).

References

Bui KT, Liang R, Kiely BE, et al. Scanxiety: a scoping review about scan associated anxiety. BMJ Open 2021;11:e043215. doi:10.1136/ bmjopen-2020-04321.

Butow , Turner, Gilchrist et al., 2017. Randomized Trial of ConquerFear: A Novel, Theoretically Based Psychosocial Intervention for Fear of Cancer Recurrence 2017. Journal of Clinical Oncology 35, no. 36 (December 20, 2017) 4066-4077.

A very special thank you for the expert input of patients of The Patricia Ritchie Centre for Cancer Care and Research, The Mater Hospital, North Sydney, NSW and our colleaugue.

If your matter is urgent and involves the safety of yourself or someone else, please consider the following numbers: Ambulance and Police: 000; Lifeline: 13 11 14; BeyondBlue: 1300 224 636, and the 24 hour Mental Health Telephone Access line: 1800 011 511 or your local emergency services. "I used to just dread the scans but now I try to think they can give me reassurance, and I won't have to worry until the next one! It does get easier with practice although I wouldn't have believed that in the early days".

Resources

Expert Podcast: Coping with "Scanxiety" Cancer.Net

"Finding calm during cancer" Podcast with Dr L Lane, Cancer Council NSW. For information and free relaxation and mindfulness exercise on mindfulness of breath, imagery, abdominal breathing and body scan see: www.cancercouncil.com.au/cancer-information/livingwell/complementary-therapies/podcast-meditation-andrelaxation/.

Relaxation, mindfulness, guided imagery and progressive muscle relation exercises, thanks to J Medd and S Bulter. See bottom left of webpage: Resources - HeadWayHealth

Tip-Sheet-Managing-Unhelpful-Thoughts.pdf (headwayhealth.com.au) A simple process to help us learn to 'talk back to the thoughts' and keep our perspective.

Relaxation-techniquesfact-sheet.pdf (blackdoginstitute.org.au)

Websites

www.headwayhealth.com.au www.blackdoginstitute.org.au www.beyondblue.org.au www.cancer.org.au

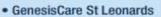


Headway Headway TeleHealth

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- SAH Wahroonga
- Centre for Welbeing Mater North Sydney



- Northern Beaches
 Breast Clinic
- TeleHealth

