

Active Surveillance: Living with Uncertainty & Tools for Anxiety Management

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If you live with chronic skin cancers or have a history of one or more advanced or high-risk skin cancers, you may be a patient on what clinicians call “active surveillance.” Active surveillance means you are being closely monitored by your skin cancer team for the development of new skin cancers, or the recurrence of previously treated ones. For many patients, active surveillance involves frequent medical appointments, biopsies and imaging studies, some more nerve-wracking than others. You may recognize a familiar cycle of anxiety in the days or weeks leading up to an appointment, stress during the visit itself, and lingering worry afterward while waiting for biopsy or imaging results.

Living with active surveillance is one of the most challenging and least discussed aspects of skin cancer survivorship. Beyond the physical fatigue of numerous procedures and scans, many patients describe living in a state of “fight or flight” - feeling as though their treatment is never truly finished and always worrying that a new cancer will appear or a previous cancer will return. Living in this in-between state can weigh heavily on patients.

In recent years, healthcare has begun to more openly acknowledge and study this type of cancer-related anxiety.(1) Terms like “scanxiety”, used to describe the anxiety surrounding imaging and imaging results, have recently emerged to give language to an experience that many patients know all too well.(2) While the hope is that cancer centers will continue to hear their patient’s concerns, and expand survivorship resources, many individuals still find themselves navigating these fears largely on their own.

Below is a survivor’s toolkit with strategies to help manage fears and anxiety before, during and after dermatology appointments:

Before Your Appointment

Anxiety often peaks days or weeks before your appointment. Here are a few strategies to help reduce anticipatory anxiety:

- Schedule appointments early in the day, when possible, to shorten the buildup of worry.
- Write a “worry list” of spots or questions to bring with you to your appointment. Writing may help conceptualize your concerns, and having a physical list ensures you won’t forget important questions.
- Limit lesion-checking to a set number of times per day. If helpful, keep a brief “thought record” of when you feel the urge to check and log how this behavior impacts your mood and day. (3)
- Take pictures of your spot(s) of concern in the weeks/months leading up to your appointment. Pictures can help your dermatologist assess the progression of your lesion.
- Practice simple self-talk, such as: “I have felt this fear before, and I survived the outcome.”
- Keep a journal. Studies show that expressive writing, especially positive writing, can help reduce symptoms of depression, anxiety and stress. (4,5)

During Your Appointment

- Bring a trusted person to your appointment or ask if you can use FaceTime or video call during the appointment.
- Bring a notebook or writing pad so you or your companion can take notes, reducing the pressure to remember everything that was discussed.
- Ask your clinician to repeat the reason for your current treatment plan. Understanding why a strategy was chosen can reinforce trust and reassurance in your care team.
- Tell your doctor or provider how you are feeling in the moment. Anxiety is relevant medical information your doctors will want to know.
- Focus on slow, steady breathing (especially during biopsies!). (6)

After Your Appointment

- Many survivors say the hardest part isn't the biopsy, it's the waiting for the results. Check results on a fixed schedule, such as once a day at lunch. Refreshing the patient portal rarely eases anxiety and often makes it worse. (3)
- Find distractions in your favorite hobbies such as listening to audiobooks, podcasts or music, which have been proven to help reduce anxiety. (7)
- Reframe surveillance as protection, not as a threat, when and if that feels possible. It is okay if this mindset takes time. Instead of seeing appointments solely as feared days, some patients find it helpful to view them as opportunities to protect their health. The very point of surveillance is to catch disease early, before it becomes a larger problem
- Redefine success. For many survivors, success may not mean zero biopsies, but as maintaining function, quality of life, and emotional resilience.

If your worry becomes overwhelming, cancer-specific support groups and counseling can be valuable tools. Survivorship is not just about diagnosis and treatment; it is about utilizing tools and routines, prioritizing mental health, and perhaps most importantly, learning how to live in uncertainty.

References

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