Patient Handout: Insights & Tips on Uncertainty

Dear Patient,

During and after cancer treatment, patients go through times of heightened uncertainty. This handout offers insights and tips for responding in ways that strengthen patients’ confidence and hope.

What is uncertainty?
Simply put, uncertainty means that we’re not 100% sure about something. Common scenarios include uncertainty about...
- What’s causing a symptom or abnormal test result.
- What to do about a medical issue.
- What’s going to happen.

What’s causing the uncertainty?
Understanding the cause of uncertainty helps you find healthy responses. In general, uncertainty may be due to...
- Lack of knowledge.
- Unpredictability of future events.

What can you do to manage uncertainty about the cause of symptoms?
When symptoms first develop, we can work together to search for clues—or answers—that tell us which of the many possibilities is causing those symptoms. We take a history, do an examination, and/or order tests. If the results of our evaluation confirm a diagnosis, we know the truth. The uncertainty about the cause of the symptoms resolves.

If uncertainty about the diagnosis persists after an evaluation, what can you do?
You can work with us to make wise decisions about when to proceed with more tests or a consultation with a specialist. Just because we can keep looking for definite answers, doesn’t mean we should.

If your health and safety depend on determining the cause quickly, we will likely proceed with further evaluation. If we have the option of waiting a bit—i.e., there’s no harm in it—or if the risks of further testing outweigh the potential benefits, we may recommend...
- Treating the likely cause based on test results to date.
- Giving your symptoms time to resolve on their own. If the symptoms persist or get worse, we now have an additional piece of information that may prompt us to either proceed with further evaluation or refer you to a specialist.
- Keep in mind that we may never get an answer if modern medicine does not yet have a test that pinpoints your problem.

What if your symptoms resolve and we never know what caused them?
That’s fine. If they resolved without therapy, your body fixed the problem. If you took therapy, the intervention may have helped. Then again, the therapy may have made no difference if the symptoms would have resolved just as quickly on their own. Even though we’re unsure what caused them, we’re encouraged by their resolution. We depend on you to notify us if the symptoms flare again, so we can address them as a second episode, which may need a different approach than our first approach.

What if you feel unsettled by the uncertainty associated with choosing treatment?
Here, the uncertainty arises because we can’t tell you how you will do with each treatment option. The best we can do is make recommendations based on studies that looked at groups of patients like you—and not on clones of “you.” You are unique and may respond better, worse, or the same as most patients.

To calm anxiety, remember this: You are stacking the odds in your favor by making decisions based on research studies and years of experience with other patients. With confidence that your informed decisions put you on the best path, you can move on with hope of the best possible outcome.

Which hopes may help you live with uncertainty?
What you hope for matters. In times of uncertainty, it helps to focus on hopes that help you act when you can do something to improve the outcome and help you wait when there’s nothing more you can do to help. In some situations, not intervening—namely, waiting—is the best course of action to achieve the desired outcome.

It may help to hope for...
- The best possible outcome. Every step of the way, this hope helps motivate patients to take action that increases the chance of improvement: complying with therapies and pursuing health-promoting behaviors (e.g., eating well and sleeping well). Visions born of this hope may stir courage and fortitude today while waiting to see what happens.
- Making the most of today. This hope helps motivate patients to seek life-affirming opportunities within the confines of illness. It helps patients pursue relationships and activities that distract them from the uncertainty while giving life meaning and joy.

What now?
Living well means learning to live with uncertainty. Please let us know if you feel anxious. We may be able to provide additional information that eases the distress. We may recommend therapy (such as antianxiety medications), counseling, or support services to help manage reactions to uncertainty.

Cancer didn’t make life uncertain; cancer merely exposed the uncertainty of life. Control what you can control. Let go of things beyond control. Instead of fighting uncertainty, embrace it as a reason for hope. Each day, find hopes that motivate you to make the most of today and that strengthen your confidence in dealing with whatever tomorrow brings. 01