

Living With Uncertainty, Not Under It: Strengthening the Human Side of Cancer Care

This article brings together published research to add to ongoing conversations about improving cancer care.

A person can wake up on an ordinary morning and, by evening, find themselves stepping into something entirely unfamiliar. Cancer often begins quietly. A routine check. A recommended test. A biopsy. And then, suddenly, life feels divided into before and after.

Today may feel unbearably heavy. Tomorrow may bring more questions than answers. And yet, the day after can still hold unexpected beauty. What carries many people through this emotional shift is something deeply human: the ability to hope, to imagine that things can improve, even when the path ahead is not fully visible.

In 2020 alone, nearly 19.3 million people around the world heard the words no one expects to hear: a cancer diagnosis, according to the World Health Organization. Behind each number is not just a statistic, but a person adjusting to a new reality and a family learning to live with uncertainty.

The questions begin almost immediately.

What will treatment involve?

Will it work?

What does remission really mean?

What happens after this phase ends?

Even with excellent medical care, uncertainty quietly shapes thoughts, emotions, and daily decisions.

Uncertainty in cancer is not only about survival statistics. It is about living without clear timelines. It is about waiting for scan results. It is about wondering whether a new ache or a wave of fatigue means something serious or something temporary. For more than three decades, researchers have studied how this uncertainty affects patients and caregivers. Their findings are consistent: uncertainty is not a side issue. It sits at the very center of the cancer experience.

Living With the Unknown

Psycho-oncology research consistently shows that uncertainty increases emotional distress. When cancer interrupts carefully made plans, people often feel as if the ground beneath them has shifted. The future they had imagined suddenly feels less predictable.

Moments that once felt routine begin to carry emotional weight. A scheduled scan. A follow-up appointment. A phone call from the hospital. These are not just calendar entries. They can hold days of anticipation and quiet worry.

Van den Berg and colleagues, in their review of studies involving cancer patients and caregivers in the Netherlands, found a clear pattern. When people felt more uncertain about

their illness, they reported more anxiety, more depressive symptoms, and greater emotional strain. This was true across different cancer types and stages.

What stood out in their findings was something important. Emotional distress was not driven only by how advanced the disease was. It was strongly influenced by how uncertain people felt about what was happening and what might happen next. In other words, it was often the unanswered questions that weighed heaviest.

Patients are not simply reacting to difficult news. They are responding to the ongoing “what if” thoughts that follow. What if the treatment stops working? What if the cancer returns? What if this symptom means something more? Even those who appear steady and composed often carry these quiet questions beneath the surface.

Studies led by *Lebel and colleagues* show a similar pattern. When patients feel unsure about their prognosis or about what certain symptoms mean, their fear of cancer returning or progressing becomes stronger. Many describe scanning their bodies for changes, second-guessing normal sensations, and imagining worst-case scenarios. This constant state of alertness can disrupt sleep, affect concentration, and drain emotional energy over time.

Research on long-term survivorship tells a related story. Work by *Mishel* on uncertainty in chronic illness shows that even after treatment ends and medical tests look stable, many survivors continue to live with the possibility of recurrence at the back of their minds. Years later, a routine scan or a minor symptom can still trigger fear. For some, uncertainty does not disappear. It becomes something they quietly carry alongside their daily lives.

Recognizing this response is not about labeling anyone as fragile. It is about understanding a natural human reaction. When your health and your future feel unpredictable, your mind searches for certainty. The goal is not to eliminate uncertainty. That may not be realistic. The goal is to help people live with it in a way that feels steadier and less overwhelming.

How Support Helps People Cope

If uncertainty is central to the cancer experience, the next question becomes how to ease its emotional weight.

Research points to structured support systems that combine clear information, practical coping tools, and safe spaces for emotional expression.

Van den Berg and colleagues found that programs offering clear explanations, coping guidance, and supportive conversations reduced distress linked to uncertainty. These programs help people distinguish between what is known, what is being monitored, and what remains uncertain. That distinction alone can bring relief.

Rather than being pulled into spirals of worry, patients learn ways to pause, reflect, and respond more calmly.

Cognitive behavioral therapy adapted for cancer care is one example. This approach helps patients notice anxious thoughts about recurrence or symptoms and gently question them. It

teaches them to differentiate between normal bodily changes and signs that require medical attention. Over time, this reduces the exhausting cycle of constant self-monitoring.

Supportive expressive therapy also shows meaningful benefits. In group settings, people often realize that others share the same fears. Hearing someone say, “I feel that too,” can reduce isolation in powerful ways. The sense of not being alone lowers anxiety and builds emotional resilience.

Educational sessions add another layer of stability. When healthcare teams clearly explain treatment plans, possible side effects, follow-up schedules, and warning signs, patients feel more grounded. When people understand what doctors are watching for and what steps will follow, fear becomes more manageable.

These approaches do not promise certainty. These programs give people practical tools so they can live alongside uncertainty without letting it consume them.

Clear Conversations Matter

Communication has the power to steady uncertainty when it is clear and compassionate.

Many patients leave appointments remembering only fragments of what was discussed. Strong emotions can make it difficult to absorb complex medical explanations. Even when doctors explain carefully, stress can interfere with attention and memory.

Research by *Roter and Hall* shows that patients and doctors often remember the same conversation differently. This does not reflect poor care. It reflects how anxiety affects how information is processed.

Lebel and colleagues found that when patients felt unclear about follow-up plans or recurrence risks, their anxiety increased. When doctors explained things clearly, patiently, and with compassion, people felt steadier. They understood what was happening, and that understanding reduced fear.

Structured communication methods such as the *SPIKES protocol*, developed by *Baile and colleagues*, guide clinicians in delivering difficult news step by step. These approaches ask doctors to pause and check if the conversation makes sense. They invite questions. They summarize the most important points before the discussion ends. When this happens, people leave feeling clearer and less overwhelmed.

Providing written summaries or offering follow-up discussions gives people time to revisit information at their own pace. In this way, communication becomes an anchor. It does not remove uncertainty, but it makes it easier to stand on steady ground.

When Treatment Ends but Questions Remain

Finishing treatment does not always bring the emotional relief people expect. For many, it introduces a different kind of uncertainty.

Follow-up scans, routine appointments, and lingering physical sensations can stir anxiety. Survivors may feel pressure to return to “normal,” even while they are still adjusting emotionally.

Mishel's research shows that worries about recurrence often persist long after treatment ends. A mild ache or ongoing fatigue can quickly reopen fear.

Survivorship care plans can help bridge this gap. Research by *Grunfeld and colleagues* demonstrates that when survivors receive written follow-up schedules, clear explanations of expected symptoms, and guidance about when to seek medical review, they feel more confident and less anxious.

Uncertainty may still be present. But it no longer dominates every thought. Survivors learn that it can exist without defining their entire lives.

When Families Carry the Weight Too

Cancer affects more than one person. Spouses, children, siblings, and close friends often step into caregiving roles while managing their own fears.

Van den Berg and colleagues found that caregivers experience levels of uncertainty-related distress similar to those of patients. They monitor symptoms, coordinate appointments, and quietly wonder about the future.

Northouse and colleagues showed that when healthcare teams include caregivers in structured family-focused education and support programs, stress decreases and coping improves. When caregivers receive clear information and a safe place to ask questions, they feel more capable and less alone.

One person rarely carries uncertainty alone. Families carry it together, each in their own way.

Barriers to Support and the Need for Equity

Despite strong evidence, access to structured psychological support and detailed survivorship planning is not yet consistent everywhere. Healthcare systems manage high patient volumes and complex treatments, and professionals often work within tight timeframes. Many are doing their best within these realities.

Cultural context also shapes how uncertainty is experienced and discussed. In some communities, families approach conversations about cancer cautiously, often out of care, protection, or cultural values. When communication respects cultural values, language preferences, and literacy levels, patients understand more, and trust grows stronger.

Access varies by geography and resources as well. People in rural areas or those with fewer financial or educational resources may struggle to access comprehensive support services. Mack and colleagues highlight that digital tools, community-based programs, and structured follow-up systems can help close these gaps.

Equitable access to emotional and informational support is not an added extra. It is a necessary part of compassionate, effective cancer care.

Care That Honors the Human Experience

Cancer care exists where medical science meets deeply human experience. Patients deserve honesty delivered with compassion.

Waiting for scan results can make hours feel longer than they are. Noticing a new symptom can send the mind racing. Trying to understand what a test result means can feel overwhelming. These reactions are not signs of weakness. They are part of being human.

When patients and families understand that uncertainty is a shared part of the journey rather than a personal failure, they approach decisions with greater clarity and self-compassion. Policies and practices that prioritize communication, structured emotional support, survivorship planning, and caregiver inclusion reflect this understanding.

Supporting people through uncertainty protects dignity while strengthening resilience.

At Sanjeevani: Walking With Families Through Uncertainty

For years, research has shown something we experience every day: uncertainty doesn't come only from illness. It grows in the quiet spaces where questions remain unanswered or feelings are carried alone. Often, what makes the difference is simply having someone who listens, explains things clearly, and offers support when everything feels overwhelming.

At Sanjeevani... Life Beyond Cancer, we see the impact of that kind of support every day. When people know they are not facing this alone and someone truly understands them, it becomes a little easier to handle what life after cancer brings. Treatment is crucial, and medical teams carry enormous responsibility, but people also need help making sense of what all the information means for their daily lives. They need guidance once active treatment ends, reassurance before a scan, and space to voice fears they rarely speak aloud.

This understanding inspired programs like Satori and Srjan. Satori focuses on holistic healing, helping people reconnect with their bodies, minds, and energy. Through gentle guidance on diet, breathing exercises, and techniques to build mental resilience, participants regain a sense of confidence and control. Research from Monk Prayogshala shows improvements in energy, focus, and emotional balance. More than 300 participants have shared that Satori helped them feel renewed and more ready to embrace life after treatment. The Bloom Journal highlights its meaningful impact, especially for women recovering from breast cancer and their families.

Srjan takes this work further through a structured 21-session online program. Each session lasts between 90 minutes and two hours and is guided by experienced practitioners who thoughtfully weave together traditional wisdom and contemporary science. Participants explore integrative cancer care strategies, ways to manage side effects, nutritional guidance, the science behind yoga and pranayama, breathing practices that support immunity, and the relationship between mental health and the body.

The discussions remain interactive and grounded in everyday life. What foods may support recovery? How can fatigue be managed? What helps when anxiety feels persistent?

Participants complete detailed pre- and post-screenings. In a group of 39 individuals with a mean age of 51, statistical analysis using SPSS showed consistent reductions across multiple concerns. Pain scores reduced from 6.76 to 3.42. Sleep difficulties dropped from 7.11 to 3.5. Worry and anxiety decreased from 7.32 to 3.56. Sadness reduced from 6.54 to 2.78. Participants also reported improvements in fatigue, memory and concentration, eating patterns, fear, loneliness, and anger.

Over time, more than 68,000 people have taken part in Sanjeevani's holistic programs, including Satori, Srjan, and other wellness initiatives. Many of them are still connected. Srjan began in 2023, and some of the earliest participants continue to practice what they learned. They speak about sleeping better, eating more regularly, and feeling less anxious than before. Small shifts that added up over time.

No one describes it as a sudden transformation. It happened gradually. A breathing practice became part of the morning routine. A better understanding of what their body needs. A little more awareness of thoughts and emotions. Some return for sessions. Others simply stay in touch. The learning did not stop when the program ended.

People who attended our other holistic workshops share similar experiences. They talk about feeling more balanced and better able to handle stress. Not perfect. Just steadier.

And sometimes, that steadiness is enough.

Together, these programs show how support beyond treatment can transform life after cancer. People gain resilience, emotional balance, and a sense of belonging. Families feel included and informed, turning uncertainty from something isolating into something shared and manageable.

Recently, Sanjeevani was recognized as the Not-for-Profit of the Year at the SABERA Social and Business Enterprise Responsible Awards in New Delhi. The recognition felt meaningful because it reflects something larger: the courage of survivors moving forward, the quiet commitment of caregivers showing up every day, and volunteers who believe care should remain humane and inclusive.

At its heart, the approach is simple. Stand beside people, offer clarity where you can, acknowledge what remains uncertain, and make sure no one carries it alone. When that happens, uncertainty feels steadier and more manageable, and people face it with strength.

Conclusion

Modern cancer care continues to evolve. Treatments are increasingly targeted. Monitoring methods are more precise. Survival outcomes continue to improve. Yet uncertainty remains woven into the experience.

Research consistently shows that structured emotional support, clear communication, thoughtful survivorship planning, and caregiver involvement ease both emotional and practical burdens. When people feel informed, heard, and supported, uncertainty becomes something they can face rather than something that controls them.

Living with uncertainty does not mean living in constant fear. With guidance, connection, and compassion, many patients and families build meaningful days even while questions remain.

Uncertainty can also sharpen perspective. It can highlight the value of ordinary mornings, quiet conversations, and small acts of courage. Even during difficult seasons, people continue to love, work, and find purpose.

With steady support and humane care, living with cancer does not become a story defined by fear of the unknown. It becomes a story of resilience, dignity, and the strength to move forward one day at a time.

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