LIVING BEYOND BREAST CANCER®

Helping breast cancer patients navigate fear of recurrence after treatment

Recognizing fear of recurrence

Advisory support provided by Pamela Ginsberg, PhD, psychologist and member of LBBC's Medical Advisory Board

Your patients' clinical visits at the end of active treatment are key moments. While they may feel relief that treatment is over, the prospect of less frequent appointments and uncertainty about what comes next can leave them feeling emotionally vulnerable. **One of the most common emotional experiences for these patients is fear of recurrence.**

Fear of recurrence is a normal response to a life-threatening illness and does not necessarily indicate a mental health disorder. Psychologist Pamela Ginsberg, PhD, notes that fear is already present throughout the entire breast cancer continuum. But, it may reemerge during moments of uncertainty or transition.

Patients may experience fear:

- After surgery, radiation, or chemotherapy
- During follow-up appointments and scans
- When noticing new or unexplained symptoms
- As they transition out of active treatment
- Around anniversaries, milestones, or reminders associated with diagnosis or treatment

Fear may increase when patients experience new physical symptoms, even when those symptoms are unrelated to recurrence. Scan appointments, changes in the body, or uncertainty about the future can trigger periods of heightened anxiety and hypervigilance.

Providers should recognize that these emotional responses are common and understandable. Normalizing fear without minimizing it can help patients feel heard, validated, and more comfortable discussing their concerns openly.

Recognize when fear affects quality of life

Fear of recurrence may present differently from patient to patient. Some individuals openly discuss anxiety and uncertainty, while others may avoid conversations about fear entirely.

Signs of fear of recurrence you may notice include:

- Difficulty making decisions
- Avoidance of appointments or follow-up care
- Excessive reassurance-seeking
- Trouble sleeping
- Hypervigilance about physical symptoms
- Difficulty concentrating
- Distress that interferes with work, caregiving, or relationships

One of the most important questions you can ask is: *"How much is this interfering with the person's life?"*

Fear becomes more concerning when it disrupts daily functioning, relationships, sleep, or the ability to engage in care. In some cases, fear may contribute to avoidance behaviors, including delaying appointments, avoiding symptom reporting, or withdrawing from support systems.

At the same time, don't assume that fear and related behaviors indicate pathology. Fear and anxiety may be present without reaching the threshold of an anxiety disorder or psychiatric crisis. Providers can play an important role by assessing how emotional distress affects a patient's ability to cope and function.

Four helpful communication approaches

These best practices can support your patients in critical moments:

1. Normalize fear without dismissing it.

Avoid: *"That's normal, don't worry."*

Try: *"Many people experience fear of recurrence after treatment."*

"It makes sense to feel uncertain after what you've been through."

"You're not alone in feeling this way."

Validation can help patients feel understood without minimizing their emotional experience.

2. Use direct language.

Patients may feel more comfortable discussing fear when providers are direct. Try:

- Naming "fear of recurrence" directly
- Encouraging open discussion
- Avoiding euphemisms or dismissive language

Use clear language to reduce shame and help patients recognize that fear is a common and expected response.

3. Ask open-ended questions.

Examples include:

"How has this fear been affecting your day-to-day life?"

"Are there areas where you feel you need more support?"

"What feels most difficult right now?"

"How are you coping between appointments or scans?"

Open-ended questions may help providers better understand how fear is affecting quality of life and identify unmet support needs.

4. Prepare patients for emotional patterns.

Use messaging like:

"It's common for anxiety to increase around scans or follow-up appointments."

"Many people notice fear increases after treatment ends."

Prepare patients for these emotional patterns to help reduce distress and uncertainty while reinforcing that fluctuating fear responses are common.

Support coping and quality of life

Dr. Ginsberg suggests laying out for patients a plan to reregulate their daily life through **supportive coping strategies like:**

- Sleep and hydration
- Nutrition and movement
- Social connection
- Mindfulness or calming practices
- Reengaging in meaningful routines and hobbies

Encourage patients to reconnect with activities, relationships, and routines that support emotional well-being and help restore a sense of stability after treatment.

Psychosocial support recommendations may include:

- Support groups
- Peer support
- Psycho-oncology services
- Individual therapy
- Advocacy and community organizations

"Warm handoffs" to social workers, navigators, or mental health professionals may help reduce barriers to support.

✓ Keep a list:

Provide patients with specific names, contact information, or referrals to make support services feel more accessible and less overwhelming.

This project is supported by Grant/Cooperative Agreement Number NU58DP007913 from the Centers for Disease Control and Prevention. Its contents are solely the responsibility of the authors and do not necessarily represent the official views of the Centers for Disease Control and Prevention.