

LIVING BEYOND DLBCL

Understanding and Managing Fear of Relapse

Developed following a discussion with people living with DLBCL and representatives from Patient Organisations as part of a patient council from Sobi.

The insights below reflect real experiences shared by patients about fear of relapse, its triggers, and what helps them regain a sense of control.



88% of patients with lymphoma experience fear of relapse

Fear of relapse is one of the most common and least visible emotional challenges after treatment. Many people appear well on the outside while carrying significant worries beneath the surface.

Source: Latella LE et al. *J Psychosoc Oncol* 2020; 16 (38): 251–271.



KEY MESSAGES

- Fear of relapse is common
- Fear of relapse is normal
- But fear does not have to control life

With support, connection, knowledge and the right coping tools, fear can become something that is managed — not something that controls life.

Find more information here:

<https://www.youtube.com/@Sobi-Pharma> See playlist DLBCL.



WHAT PATIENTS FEAR MOST Fear of relapse is often not only about cancer returning

Patients described fears related to:



Being a burden for others



Not recognising symptoms quickly enough



Uncertainty about the future



Losing future opportunities and life milestones



Having to go through cancer treatment again



Fear about mortality

The specific fears often depend on personality, life stages and personal priorities.

PATIENT VOICE

"Whenever I start to feel safe, it's almost like the back of my brain says: don't get too comfortable."

WHAT TRIGGERS FEAR OF RELAPSE?



PHYSICAL TRIGGERS

Patients repeatedly described physical symptoms as the strongest trigger.

- Persistent cough
 - Tickle in the throat
 - Night sweats
 - Itching
 - Unexplained pain
 - Swollen lymph nodes
 - Aching legs
 - Symptoms resembling those experienced before diagnosis
- Many patients become hyper-aware of bodily sensations after treatment.

PATIENT VOICE

"The slightest little symptom, your mind does tend to go there."



EMOTIONAL & SITUATIONAL TRIGGERS

- Follow-up appointments
- Scans and medical reviews
- Waiting for test results
- Diagnosis anniversaries
- Birthdays and milestones
- Starting a business or major life plans
- Hearing about another patient's relapse

Scans and follow-up appointments are typical triggers also called "scanxiety".

PATIENT VOICE

"The closer the day of the scan, the stronger the fear."

HOW DOES FEAR SHOW UP?



PHYSICALLY

- Poor sleep
 - Exhaustion from worrying
 - Fatigue
 - Experiencing symptoms more intensely before appointments
 - Increased heart rate
 - Sweating
- A vicious cycle can develop: symptoms attract more attention, which can make them feel worse. The more we focus on them, the more distressing they can become.

PATIENT VOICE

"A few days before the check-up, I got all the symptoms."



EMOTIONALLY

- Anxiety and worry
 - Feeling constantly on edge
 - Hyper-awareness of bodily changes
 - Difficulty relaxing
 - Fear returning during positive life moments
 - Feeling unable to fully enjoy milestones
 - Depression
- For a lot of patients the fear always remains in the background. Some describe it as a "stalker".

PATIENT VOICE

"I don't think there's a day that goes by without me thinking there's something happening in my body."

DOES FEAR CHANGE OVER TIME?



Immediately after treatment
Fear is often strongest



Before follow-up appointments
Fear frequently increases



Over time
Many patients gradually gain confidence

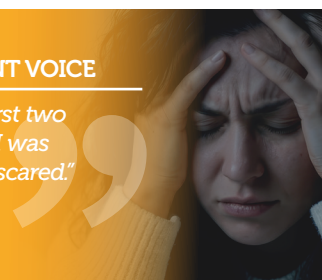


Long-term
Fear may never disappear completely, but often becomes easier to manage

Several patients reported that the first 1–2 years after treatment were the most difficult.

PATIENT VOICE

"The first two years I was really scared."



FROM FEAR TO CONTROL

DIFFERENT STRATEGIES HELP DIFFERENT PEOPLE



HEALTHY ROUTINES

- Physical activity
- Sleep hygiene
- Working in a job you like
- Relaxation techniques
- Journaling

WHY IT HELPS

Consistency often helps reduce anxiety.



KNOW YOUR OPTIONS

- Discuss future scenarios with your healthcare team
- Understand what therapy options may exist if relapse occurs
- Ask questions and seek reliable information that is understandable for you

WHY IT HELPS

Patients described fear as being closely linked to uncertainty. Understanding available options can help restore a sense of preparedness and control.



SHARE YOUR FEARS

- Talk openly with family and friends
- Connect with peers
- Speak honestly with healthcare professionals
- Look for psychological help
- Identify a trusted person who can support you

WHY IT HELPS

Many patients have said that this fear often remains hidden – they say 'I feel fine' when they are really struggling internally.



KEEP MOVING FORWARD

- Continue making plans
- Focus on future goals
- Celebrate milestones
- Pursue meaningful projects
- Do things you love

WHY IT HELPS

Creating future plans helps you move towards purpose and control.

Developed and funded by



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Always consult a qualified healthcare professional if you have any questions about your medical condition or treatment.



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