




Managing Fear of Recurrence

Samantha A. Burns, PhD
Department of Rehabilitation Medicine, UW
Attending Psychologist, Cancer Rehabilitation Medicine,
Fred Hutchinson Cancer Center
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- 1** Fear of recurrence in cancer survivorship
 - 2** Cognitive and behavioral coping strategies
 - 3** Working with thoughts
 - 4** Brief relaxation exercises
 - 5** Mindfulness-based coping strategies



Fear of cancer recurrence

“fear, worry, or concern relating to the possibility that cancer will come back or progress”

- Fear of recurrence is one of the most common psychological concerns among cancer survivors
- Across cancer types and geographic regions
 - around **58–59%** of survivors experience **at least moderate** fear of recurrence
 - approximately **19%** report **severe** fear of recurrence
- Other studies report prevalence ranges from **47.7% to 63.4%**

REVIEW WILEY

What is the prevalence of fear of cancer recurrence in cancer survivors and patients? A systematic review and individual participant data meta-analysis

Yvonne L. Luigjes-Huizer^{1,2} | Nina M. Tauber³ | Gerry Humphris⁴ | Nadine A. Kasparian⁵ | Wendy W. T. Lam⁶ | Sophie Lebel⁷ | Sébastien Simard⁸ | Allan Ben Smith⁹ | Robert Zachariae³ | Yati Afyanti¹⁰ | Katy J. L. Bell¹¹ | José A. E. Custers¹² | Niek J. de Wit² | Peter L. Fisher¹³ | Jacqueline Galica¹⁴ | Sheila N. Garland¹⁵ | Charles W. Helsper² | Mette M. Jeppesen¹⁶ | Jianlin Liu¹⁷ | Roxana Mititelu¹⁸ | Evelyn M. Monninkhof² | Lahiru Russell^{19,20} | Josée Savard²¹ | Anne E. M. Speckens²² | Sanne J. van Helmond^{1,2,3} | Sina Vatandoust²⁴ | Nicholas Zdenkowski²⁵ | Marije L. van der Lee^{1,2,3}

Risk factors and impact on survivors

- **Risk Factors**

- **Age:** Younger survivors tend to report higher fear of recurrence
 - **Gender:** Women generally report more fear of recurrence than men
 - **Cancer type:** observed across all cancer types, though some studies note higher prevalence in breast, lung, and melanoma survivors
 - **Time since diagnosis:** persists across all time periods post-diagnosis and does not significantly decrease over time if unaddressed
- Low levels of fear of recurrence can be helpful:
 - Promote treatment adherence
 - Motivate healthy behaviors such as exercise and eating healthfully
 - Moderate or high levels of fear of recurrence can significantly affect **quality of life**, leading to:
 - Increased anxiety and depression
 - Impaired daily functioning and social engagement
 - Heightened vigilance and frequent medical consultations
 - Chronic stress and reduced emotional well-being



Common psychological concerns in survivorship

- Adjustment reaction
 - Can have depressed or anxious features
 - Sometimes described as grief reaction, or as “situational” or “reactive” depression
- Anxiety disorders
 - Anxiety is a common response to threats of **uncertainty**, suffering, and mortality
 - Generalized anxiety disorder, panic disorder, specific phobias, social anxiety, OCD, PTSD
 - Prevalence estimates of clinically significant anxiety symptoms in cancer patients range from 10-34%
- Depressive symptoms
 - Depression is the most common psychological symptom in patients with cancer

All of these conditions can be treated! Please talk to your medical team if you would like help or referrals.

Coping with uncertainty in survivorship

- There is uncertainty in many medical situations, including cancer survivorship
- Any novel and/or threatening situation can cause distress – this is a NORMAL reaction
- If we can't know the future or immediately solve the problem, what can we do?
 - We could pretend it isn't happening
 - We could panic
- Or, we could try to find the middle ground –
 - Tolerate the distress, while
 - Finding ways you can feel better
- We will discuss ways to do this!



Cognitive and behavioral strategies

Notice your thoughts

- What are you saying to yourself? What are you thinking?
- How you think is important – it determines your emotional state, what you do (your behavior), and how you feel physically

Event	Automatic thoughts	Emotions	Actions	Physical reactions
New pain in your back				



Common unhelpful thought patterns

- Catastrophizing
- All or nothing thinking (black and white thinking)
- Overgeneralization
- Disqualifying the positive
- Jumping to conclusions (fortune telling)
- Magnification or minimization
- “Should” statements



Notice your “self-talk” or automatic thoughts

- Overly negative:
 - “My back hurts. My cancer is back! There will be nothing my doctors can do.”
- Overly positive:
 - “My back hurts. If I ignore it, it will go away.”
- Balanced:
 - “My back hurts. I may have pulled a muscle. I should make an appointment and have my doctor check it out.”





Reframing unhelpful or overly negative thinking

- Challenge the overly negative thoughts
 - How accurate is this belief?
 - What would you say to a friend going through this same situation?
 - What is the evidence for or against this thought?
 - What is the worst thing that could happen? What is the best?
 - What are some things you can think about or say to yourself to make yourself calmer?
- Aim for **balanced, rational** thinking



The power of alternative thoughts

- Try to keep your thoughts in a place that is more accurate, realistic, helpful

Event	Alternative thoughts	Emotions	Actions	Physical reactions
New pain in your back				

Coping and Control

- Ask yourself what elements of the situation are in your control **right now**

Controllable	Uncontrollable
Xxxx Yyyy	Aaaaa Bbbbb

Problem-focused coping

Information seeking
Goal setting
Conflict resolution
Asking for help

Emotion-focused coping

Reappraisal of the situation
Reframing thoughts
Exercise
Hobbies
Relaxation exercises
Social support



Diaphragmatic Breathing

- Sit in a comfortable position.
- Place one hand on your chest and the other on your stomach, in order to monitor your diaphragmatic breathing (only your stomach should move).
 - Inhale deeply and slowly (approximately 4 seconds) through your nose.
 - Exhale deeply and slowly (again approximately 4 seconds) through your mouth, allowing the air to fully escape.
- Continue this deep breathing for at least 60 seconds.
- Practice this **at least once a day**, but especially at times when you feel yourself becoming stressed.



Progressive Muscle Relaxation

- Tense a specific muscle group to about 1/3-2/3 maximum tension for 4-5 seconds, followed by a complete release of tension for 45-60 seconds.
- Repeat before moving on to the next muscle group.
 - **Both legs:** Lift both legs off the ground, straighten your knees and point your toes toward your head.
 - **Chest:** Take a very deep breath (through the upper chest, not the diaphragm) and hold it.
 - **Both arms:** Turn your palms up, then make a fist. Bring your fists up to your shoulders while tensing the biceps.
 - **Abdomen:** Tighten these muscles as if you were about to be hit in the stomach.
 - **Shoulders:** Lift both shoulders up toward your ears.
 - **Back of Neck:** Tuck in and lower your chin toward your chest.
 - **Forehead:** Raise your eyebrows.
 - **Eyes:** Squint.



Mindfulness-based strategies

What is mindfulness?

- A state of intentional, nonjudgmental focus on the present moment.
- Mindfulness techniques are often incorporated into other practices, such as yoga or meditation. It is often thought to include the following elements:
 - **Awareness** – Being tuned in to what is happening in the present moment, including sights, sounds, smells, or physical sensations you might usually ignore.
 - **Focus** – Paying attention to the present moment, without thinking about past or future events.
 - **Acceptance** – Accepting whatever you might be feeling or thinking, without judging it or trying to change it or your reactions.
 - **Observation** – Recognizing unpleasant sensations, thoughts, and feelings as temporary and fleeting, observing them objectively without reaction or judgment.





Benefits of mindfulness

- Improves mood
- Reduces stress and its consequences
- Improves coping with pain
- Improves brain functions (attention, focus)
- Helps with weight management



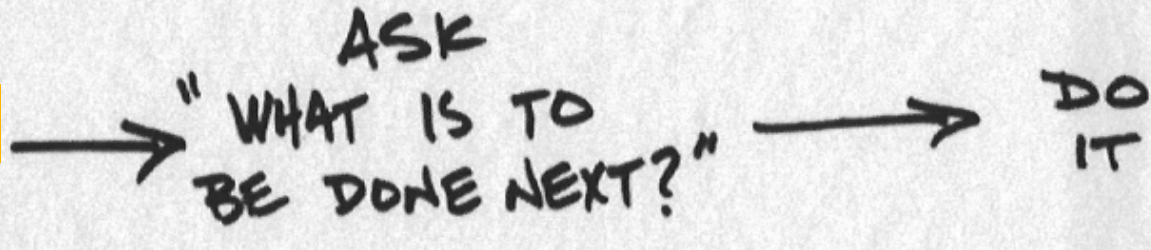
Acknowledge distress – it's OK to be having a hard time

- Remember, uncertainty is difficult for us
- Many emotions are possible:
 - Anxiety
 - Fear
 - Worry
 - Sadness
 - Anger
 - Irritability
 - Impatience
 - Restlessness



ACKNOWLEDGE

UNCERTAINTY



DO IT

REPEAT





“Drop Anchor”

- In difficult times, we’re all going to experience ‘emotional storms’: unhelpful thoughts spinning inside our head, and painful feelings whirling around our body. If we’re swept away by that storm inside us, there’s nothing effective we can do.
- The first practical step is to ‘drop anchor’, using the simple ACE formula:
- A = Acknowledge your thoughts and feelings
- C = Come back into your body
- E = Engage in what you’re doing

- Ideally, run through the ACE cycle slowly 3 or 4 times, to turn it into a 2- 3 minute exercise.





Other mindfulness techniques and resources

- Mindful breathing
- Body scan
- Mindful eating
- Loving kindness meditation
- Mindful movement

Mindfulness/relaxation resources

- Apps
 - Calm
 - Headspace
 - Insight Timer
 - Mindfulness Coach (VA app)
- UCLA Mindfulness Center <https://www.uclahealth.org/uclamindful>
- YouTube, Spotify, etc.



Additional support for managing fear of recurrence

- Talk to your medical providers (oncology, survivorship, primary care)
- Local organizations:
 - Cancer Lifeline
 - Cancer Pathways
- Support from a psychologist, social worker, or counselor with knowledge of cancer, treatment, and survivorship
 - Psychology Today – therapist search
 - For stem cell transplant survivors - BMT InfoNet mental health provider directory

The image shows two screenshots. The top one is a 'Psychology Today' therapist search page with a 'Filters' sidebar. The 'Cancer' filter is selected. The bottom screenshot is the BMT InfoNet website, featuring a 'Directory of Mental Health Providers' section with a photo of a smiling woman.

Psychology Today Therapists

Filters

- Bipolar Disorder
- Blended Family
- Body Image
- Borderline Personality (BPD)
- Bulimia
- Burnout
- Cancer
- Career Counseling
- Child Anxiety
- Chronic Illness
- Chronic Pain
- Hoarding
- Infertility
- Infidelity
- Intellectual Disability
- Internet Addiction
- Life Coaching
- Life Transitions
- Marriage Counseling
- Medical Detox
- Medical Trauma
- Medication Management

BMT INFONET

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Directory of Mental Health Providers

Find a mental health provider—a psychologist, social worker, or other counselor—who has experience working with transplant and CAR T-cell therapy recipients and people living with graft-versus-host disease (GVHD). Providers who offer telehealth can assist clients in several states.

In addition to those listed in the directory, your transplant or CAR T-cell center may be able to recommend a mental health provider or organization who can assist you.

Your search results will display each mental health professional

Session summary

- Fear of recurrence is common in cancer survivors
 - Can be severe, and can affect quality of life
- Uncertainty about the future can also be distressing
- Several coping strategies can be useful for managing fear of recurrence
 - Working with thoughts that might be overly negative or unhelpful
 - Considering what is (and is not) in your control right now
 - Use behavioral coping strategies as needed (exercise, relaxation practice)
 - Mindfulness-based strategies can be particularly useful for working with distress and uncertainty
 - Grounding
 - Present-moment focus
- Seek additional help if needed





Thank you



