

# Mindfulness



## And its Meaning in Palliative Care

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# Mindfulness and its Meaning in Palliative Care

by Lauren Kriegel, MSW, LSW, Rutgers Cancer Institute of New Jersey

## Introduction

“That’s life: starting over, one breath at a time.”

– Sharon Salzberg, best-selling author and meditation teacher

In the cacophony of 21st century living, there’s a growing buzz about mindfulness and its effectiveness in easing anxiety, reducing stress and healing the body and mind. In palliative care – where the focus is managing symptoms, improving quality of life and empowering patients to live fully – the benefits of practicing mindfulness are unmistakable.

Healthcare professionals, especially social workers, nurses or counselors, should have mindfulness as an integral tool in their patient play book.



In this eBook, you’ll learn:

- The **benefits of mindfulness** for palliative care patients and others suffering from stress or anxiety
- How to teach patients to practice **mindfulness**
- How to help patients manage **unwanted emotions**
- How to improve communication and **interpersonal effectiveness**
- How to boost patients’ ability to **tolerate distress**
- How to lead patients toward **radical acceptance** – enjoying a life that isn’t the one they wanted

Enjoy this practical guide to mindfulness and how it can benefit your most vulnerable patients.

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## Why mindfulness?

You see it all the time: A client or patient struggling against a tidal wave of fear, pain and stress that comes with a chronic illness or life-changing diagnosis.



Palliative care is about easing symptoms, restoring hope and helping patients find joy. Its effectiveness can hinge on simple strategies that give patients a greater sense of peace and control.

Over the past several years, mindfulness has emerged as a transformative tool that can be applied widely in modern-day life to reduce anxiety and stress. In palliative care, the benefits of mindfulness are even more crucial. Health professionals are key to helping patients understand mindfulness, access it and implement it.

Mindfulness is a **learned skill – an intentional state of being** that allows people to focus on a specific experience or feeling, to observe the thoughts, emotions and sensations that accompany it, and to make choices on how or whether to respond.

Scientist, writer, and meditation expert Dr. Jon Kabat-Zinn says mindfulness is “paying attention in a particular way: on purpose, in the present moment, and non-judgmentally.”

The roots of mindfulness are in Buddhism, but its application in palliative care is informed by **Dialectical Behavior Therapy (DBT)**, a treatment model developed by Marsha Linehan for working with patients who have borderline personality disorder.

DBT is comprised of four skill sets – **mindfulness, emotion regulation, interpersonal effectiveness and distress tolerance**. Mindfulness is typically viewed as the foundation of this therapeutic approach.

Though traditional DBT has a very regimented and specific mode of delivery, its underlying principles can be applied across a variety of settings.

Mindfulness and other DBT-informed practices can be life-changing for patients with a chronic disease or diagnosis that undermines not just their physical health, but their emotional and mental well-being.

Take cancer patients: It’s not surprising that a cancer diagnosis can have a devastating effect on a person’s sense of hope and contentment. A 2013 study by A. Mitchell confirmed that assertion, showing higher rates of anxiety and depression in cancer patients compared to a healthy control group. Left untreated, those mental-health disorders

can lead to a reduced quality of life, poor self-care and impaired functioning.

What’s surprising, Mitchell’s study found, is that while depression typically wanes after treatment is over, anxiety persists – often for years. In fact, it actually increases.

*“Our results suggest that after diagnosis of cancer, increase rates of anxiety tend to persist compared with healthy controls, whereas increase rates of depression are less long lasting. In the period immediately after diagnosis, depression is roughly twice as common as in healthy controls, but this increased risk only lasts for roughly two years. An increased risk of anxiety disorders seems to persist for up to 10 years or more. (Mitchell 2013)*

So why the increase in anxiety over time? Fear of recurrence plays a major role. A 2013 study by J. Addington-Hall found that not only do cancer survivors experience a reduced quality of life, but almost half (47%) who are at least 5 years out from treatment report fear of recurrence.

How can practicing mindfulness help? Research shows it can have a profound effect, both in improving quality of life and in managing the symptoms of disease or post-cancer treatment.

Mindfulness can:

- Reduce pain, tension, and stress
- Increase joy and happiness
- Improve physical health and relationships

A 2013 study by R.C. Anderson focused on DBT and the psychosocial stress experienced by newly diagnosed breast cancer patients. In the study, patients were given tools to measure stress before and after receiving training in mindfulness and other DBT skills. Stress levels were reduced in all categories after the training.

Anxiety is rooted primarily in past experiences and in how we envision our future. We get upset about things that have happened and worry about things that might happen. That’s often reflected in spiraling thoughts.

A negative spiral might look like this:

- What if my cancer comes back?
- What if the treatments don’t work?
- What if I die?

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As humans, we're much less likely to engage in positive spiraling:

- What if my treatments are successful?
- What if my cancer doesn't come back?
- What if I live to be a wrinkled old man or woman?

Mindfulness can help stop a negative spiral because it's designed to reduce mindlessness. Practicing mindfulness allows patients to exert greater control over their minds by increasing their ability to focus attention; improving their ability to detach from unwanted thoughts, images and sensations; and decreasing their reactivity to mental events – helping them observe what's going on without reacting or trying to change it.

## PRACTICING MINDFULNESS



There are a variety of ways to practice mindfulness:

- Have a sensory experience:
  1. Wash a clean dish
  2. Take a shower
  3. Take a walk
- Take a moment to pause
  1. Stop and check in on your feelings
  2. Repeat that process two or three times a day
- Change the Channel
  1. Get a clear mental image of something relaxing. Practice this when not stressed.
  2. When your thoughts start to race – change the channel.

One of the best things about mindfulness is that it can be done anywhere and at any time. When a patient says "I

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don't have even 5 extra minutes in my day," a doctor, nurse or social worker can say "Are you going to take a shower today? Because you can take a shower mindfully. Pay attention to what the water feels like as it hits your body, get a really good smelling soap and pay attention to how it smells as you use it."

*Changing the channel* is another tool that takes a lot of practice. Patients must repeatedly work on conjuring up a clear, detailed image that brings them a sense of happiness and relief. Creating that image and practicing how to recall it should take place when the patient isn't stressed, but is feeling relaxed. Once they've mastered focusing on their "happy place" image when calm, it will be much easier to do so when stressed.

## REGULATING EMOTION

Emotion regulation is the ability of patients to control or influence which emotions they have, when they have them and how they experience and express them.

This is not as robotic as it sounds. Emotion regulation isn't about turning off feelings, but about learning skills that help manage them.

There are several goals to emotion regulation:

- Naming and understanding one's own emotions
- Decreasing the frequency of unwanted emotions
- Decreasing emotional vulnerability
- Decreasing emotional suffering

It should be noted that emotion regulation should only be used when emotions are ineffective. Emotions are key to a rich and healthy life and it's often important to experience them, even when painful.

Emotions are effective when:

- Acting on the emotion is in the patient's self-interest
- Expressing the emotion will get the patient closer to his/her goals.
- Expressing the emotion will influence others in ways that are helpful to the patient
- The emotion is sending the patient a message that needs attention



Emotions have an impact on three states of mind that DBT identifies as helping to shape our thoughts and actions:

**Reasonable mind** – Cool, task-focused and ruled by logic and facts. Without reasonable mind we would never be able to plan an event.

**Emotion mind** – Hot, mood dependent and ruled by

feelings and urges. Most people think acting out of emotion is bad, but that's not true. Without "emotion mind" we couldn't fall in love, or a parent wouldn't run into a burning building to save a child. Reasonable mind would say "that building is on fire!" But emotion mind takes over in that moment.

**Wise mind** – The wisdom within, the middle path, the quiet place where reason and emotion interact.

Patients dealing with chronic illness are experiencing extraordinary levels of stress, making it difficult to operate out of "wise mind." Sometimes the first step in quieting anxiety is helping them recognize which state of mind they are operating from.

### Dealing with unwanted emotions

When patients are overwhelmed with unwanted emotions, the first strategy should be checking the facts. What is the evidence that supports their thoughts? What is the evidence against?

For instance, if a patient's fear is "My cancer will come back and I will die soon," help them examine the evidence for and against that thought. The evidence against their worse-case scenario could be recent blood work that looks good, or scans that are clear. In that case, the evidence does not support the thought.

If the emotional reaction fits the facts, however – the test results don't look good, the prognosis is poor – help the patient practice radical acceptance (more on that later) and work on changing unwanted emotions.

### Changing unwanted emotions



The first strategy for changing unwanted emotions is simple problem solving: Identify a goal, brainstorm possible

solutions, choose a solution that fits the goal and is likely to work, and put the solution into action!

DBT advances the idea that every emotion has an "action urge." For instance, fear = run away; anger = attack; sadness = withdraw; shame = hide.

To change unwanted emotions, a patient can practice "opposite action" – like when a shopper reacts to a rude salesperson by killing them with kindness. In moments of fear, take a Superman stance; when sad, engage instead of withdraw. Changing body posture and actions has a clear effect on emotions.

Another DBT approach uses the acronym ABC PLEASE:

- A**ccumulate positive emotions
- B**uild Mastery
- C**ope ahead of time
- Treat **P**hysical illness
- Balance **E**ating
- Avoid mood **A**ltering substances,
- Balance **S**leep
- Get **E**xercise

**Accumulating positive emotions** is doing simple self-care. It doesn't have to be big – a bubble bath or listening to a favorite song will do the trick.

**Build mastery** means practice. All DBT strategies, including mindfulness, are most effective when they're used consistently, several times a day.

**Cope ahead of time** involves rehearsing an experience the patient dreads so they're better prepared to deal with negative emotions. For example, if a patient is anxious about getting an IV placed, they should practice the scenario – extend an arm, think about the cool sensation when skin is wiped with alcohol. What would help calm their nerves? Having a stress ball to squeeze? Listening to music on headphones? Having a plan to cope will reduce anxiety.

The principles of **PLEASE** are basic reminders that good health practices have a positive effect on patient's physical and mental well-being.

### INTERPERSONAL EFFECTIVENESS

Communication is a foundation of human interaction, but it can be especially challenging in the heightened emotional environment surrounding chronic illness and life-and-death decisions.

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**Interpersonal effectiveness** is a tenet of DBT that can be extremely useful for patients who want to communicate more clearly with their loved ones, and need help speaking up for their needs.

In teaching interpersonal effectiveness, you can encourage and empower patients to be clear about what they want.

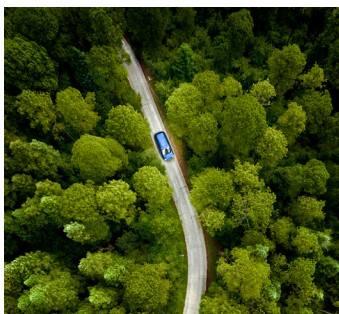
If a patient uses direct language like “I don’t need you to do *that* for me, but it would be great if you could do *this*” it can be meaningful for loved ones, who are often looking for an opportunity to feel helpful and involved.

At the same time, illness often shifts the balance of a power in a relationship, which can lead to anxiety and conflict.

Helping a patient exercise interpersonal effectiveness can help strengthen their current relationships, and balance acceptance with the changing dynamic.

Clear communication means:

- Being mindful of others
- Walking the Middle Path



The “Middle Path” is one of **harmony** that **accepts reality as it is**. It **doesn’t** mean 50% of one point of view and 50% of another.

Some examples of walking the Middle Path are:

- Accepting reality and working to change it
- Working and resting
- Independence and dependence
- Openness and privacy
- Accepting yourself as you are and working on self-improvement

## DISTRESS TOLERANCE

Palliative-care patients are in very tough circumstances. Hearing others acknowledge that can be very validating.

Distress tolerance is aimed at helping patients survive crisis situations without making them worse. That means accepting reality and the possibility of moving forward, and becoming free from the relentless demands of their own desires, urges and intense emotions.

How can you help patients better tolerate distress? The first thing is teaching them to **STOP**:

**S**top – Don’t react. Emotions try to make us respond without thinking. Stay in control.

**T**ake a break – Take a step back. Let go. Take a breath. Don’t let feelings lead to impulsive action.

**O**bserve – Notice what is going on inside and outside.

What is the situation? What are your thoughts and feelings?

**P**roceed mindfully – Act with awareness. Think about goals. Which actions will make it better or worse?

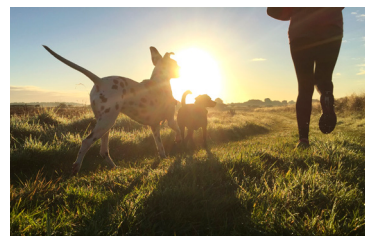
Another strategy patients can use in building distress tolerance involves changing body chemistry to interrupt negative emotions.

In DBT, this is called TIP:

- **T**ipping the Temperature
- **I**ntense Exercise
- **P**aced Breathing

Tipping the temperature could involve a patient holding a Ziploc bag of cold water over their eyes and briefly holding their breath, which triggers a “dive response” in the body that demands attention. Another technique could be asking a patient to melt an ice cube in the palm of their hand. It isn’t cold enough to hurt, but is cold enough that it forces them to focus on that experience. Patients should think about what the ice feels like on their skin, how it drips as it melts, and how the shape changes as it melts.

Intense Exercise is just like it sounds – a brief burst of jumping or running. It’s hard to dwell on negative thoughts when the body is using its energy



Paced breathing and paired muscle relaxation involves breathing deeply into your belly (belly breathing). In this exercise, patients breathe out longer than they breathe in. While breathing in, they tense one muscle group, and while breathing out, they think about the word “relax.” As they let go of the tension, they should note the difference in how their body feels.

Continuing its obsession with acronyms, DBT also advocates helping patients “**IMPROVE** the moment,” reinforcing earlier strategies:

**I** – Imagery (i.e. “Changing the Channel.)

**M** – Meaning – Thinking about the bigger picture. Why do these treatments? What does the patient want from life?

**P** – Prayer – Can be through formal religion or just a sense of purpose

**R** – Relaxation

**O** – One thing at a time – Reinforcing mindfulness. Focusing on one thing is calming to the brain.

**V** – Vacation – An actual trip or just a break from routine. Ideas include ordering take out from a favorite restaurant or creating a spa like experience at home.

**E** – Encouragement – Teaching patients to be their own best cheerleader. Positive self-talk is important. (Example: “So far I have survived 100% of my worst days. I am doing great.”)

## RADICAL ACCEPTANCE – When the life you’re living isn’t the one you wanted

One of the most important tools a palliative care patient might need is learning how to practice “radical acceptance.” What is radical? It means all the way, complete and total. It’s accepting in one’s mind, heart and body the truth of their current situation. It’s when patients learn to stop fighting reality, stop throwing tantrums because reality is not the way they want it, and let go of bitterness. Radical acceptance is not approval, compassion, love – it’s simply acknowledging what’s real.

Start the conversation with patients about radical acceptance by challenging them to redefine acceptance. Acceptance has a bad connotation that if you accept something it means you’re OK with it. You can hate something with every fiber of your being and still accept it as true.

What has to be accepted?

- Reality as it is, even if unpleasant
- There are limitations on the future for everyone
- Life can be worth living, even with painful events



### Why accept reality?

- Rejecting it doesn’t change it
- Pain can’t be avoided; pain is for the living
- Refusing to accept can leave you stuck in unhappiness
- Acceptance may lead to sadness, but deep calmness usually follows
- The path out of hell is through misery. By refusing to accept the misery that is part of the climbing out of hell, you fall back into it.

Radical acceptance involves turning the mind to embrace an uncomfortable reality. It’s not a one-step process, but an effort that must be practiced over and over.

Patients can practice turning the mind by:

- Observing when they aren’t accepting. (Often marked by thoughts such as: Why is this happening to me? Why Me? It shouldn’t be this way.)
- Making an inner commitment to accept reality as it is
- Repeating the process; continuing to turn the mind toward acceptance
- Developing a plan for turning back when you drift out of acceptance



Turning the mind also requires an attitude of willingness, rather than willfulness.

Willingness involves doing what is needed, listening to and acting from the Wise Mind, and acting with awareness that you are connected to the universe.

***Willfulness means refusing to tolerate the moment or make changes, giving up, and insisting on being in control.***

Patients can practice willingness by:

- Observing any willfulness, labeling it and experience it
- Radically accepting that they feel willful
- Turning their mind back toward acceptance and willingness

A lot of radical acceptance comes from mastering one’s mind, but there are ways patients can practice radical acceptance using body language. A half smile and willing posture are two strategies that have shown success.

Encourage patients to try these exercises. A half-smile is a relaxed face, neck and shoulders, with lips just slightly turned up at the corners. A willing posture is hands unclenched, palms up and fingers relaxed. A willing posture is part of the opposite action for anger.

## CLOSING

As you train your palliative-care patients in mindfulness and other DBT-informed practices, you'll be handing them the power to reduce anxiety, better manage their symptoms and embrace life in all its imperfections. If they're willing to practice these strategies, the benefits are immeasurable.



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### About the Author:

*Lauren Kriegel, MSW, LSW, is an oncology social worker who received her master's degree in social work from Columbia University School of Social Work. Lauren works full time at the Rutgers Cancer Institute of New Jersey in hematology/oncology, working exclusively with bone marrow transplant patients. In this role, Lauren provides psychosocial support for patients and families from diagnosis through transplant and into survivorship.*

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