

Behavioral Health Recommendations for Managing Long-COVID Symptoms

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With contributions from Long-COVID Patients



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Introduction

The toll of the COVID-19 pandemic on the mental, physical, and emotional well-being of all patients and families is beyond anything most of us have ever experienced before.

Individuals have experienced a wide range of psychological responses to the stress of the pandemic, and this effect is compounded for those who continue to live with COVID long haul symptoms, now commonly referred to as "Post-Acute Sequelae of SARS-CoV-2 infection (PASC)," "Long-COVID," or "Long Haul COVID."

We know that Long Haul COVID brings a host of physical symptoms, including fatigue, brain fog, memory loss, pain and neuropathy, shortness of breath, and changes to sensation, hearing, and smell among many others. All of these symptoms can impact one's ability to work, fulfill their previous roles in family or relationships, or engage in activities they usually enjoy.

Not surprisingly, experiencing this many sudden changes to one's life and functioning can be extremely difficult to cope with. This adjustment gets even harder when we recognize the uncertainty surrounding Long Haul COVID recovery timelines. Many people find themselves feeling anxious, depressed, and traumatized from their experiences.

The hope for this handbook is to review these symptoms and some techniques that can help both people with Long Haul COVID and their families to cope with them, and ultimately to emphasize that you are not alone in what you are feeling.



Emotional Impact

Many people who have been living with "Long Haul COVID" share that they often feel like they are on a "rollercoaster" of physical and emotional symptoms. Some of these symptoms can be difficult to distinguish from those caused by the physical symptoms felt from Long Haul COVID like fatigue and brain fog. Even for those who had a mild case of COVID-19 initially, the intensity and duration of their symptoms can leave them feeling shocked and fearful of what is to come. Others feel traumatized by their experiences, especially if they had moments when they worried they would not survive their illness. A major element of the difficulty of coping with this illness is the uncertainty — uncertainty about who will get sick, what symptoms they will have, and when they will feel better. This can lead to feelings of depression, anxiety, mood changes, and feelings of loss after experiencing so many changes to your life and functioning. These are normal responses to difficult situations, but it's important to seek help if these symptoms persist or stop you from doing the things you like to do.

Before we go further, let's talk about what some of these conditions can feel like in your day-to-day life:

 Anxiety: Cognitive symptoms include feelings of fearfulness, feeling like your thoughts are racing or uncontrollable, struggling to change your thoughts (ie, can't stop thinking "I'll never get better"). Often accompanied by physical symptoms like shaking, sweating, heart pounding, fast breathing, or feeling numb/withdrawn/frozen "I've learned to prioritize what needs to be done in a day, so that when it's a bad day or couple of days, I just do what I can at the top of the list. I remind myself that tomorrow is another day."

- **Trauma:** feeling anxious around reminders of the traumatic event (ie, seeing a hospital or hearing news about COVID infection rates), experiencing sudden mood changes (crying out of the blue, suddenly feeling angry or scared), having flashbacks to or nightmares around the traumatic event, feeling numb or withdrawn
- Feelings of grief/loss: sadness over loss of "how things were" changes to your physical/cognitive/emotional functioning, independence, sense of safety, ability to engage with family/friends or enjoy your usual activities, ability to work, role within your environment (ie going from 'caregiver' to 'needing care')
- Sense of Isolation: long haul COVID is an illness that many still don't fully understand this includes family, friends, and even medical providers. In addition to the physical isolation and/or quarantine that accompany this illness, many experience a sense of emotional isolation due to not feeling understood by those in their life. This can impact overall mood and create anxiety in interpersonal interactions.
- **Depression:** low mood and sadness, sleeping much more than usual, crying easily or often, decreased energy (feeling like everything is an effort), changes to appetite, feelings of hopelessness, thoughts of hurting yourself or not wanting to be alive anymore

If you are concerned for or experiencing any of the above, talk to your doctor and see the resources listed at the end of this handbook.



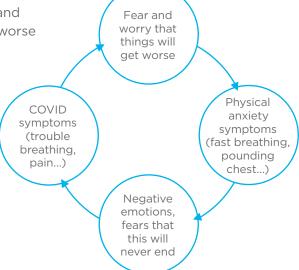


Connection of Emotional & Physical Symptoms

We know that emotional, psychological, and physical symptoms are closely connected. If you've ever been anxious before a test or a big presentation, and then experienced nausea, stomach and head aches, or sweatiness, you can see this is true!

COVID can cause many symptoms, like pain, fatigue, and shortness of breath among others, that can be made worse by intense stress and anxiety, leading to a continuous feedback loop.

It is very important to focus on your mental health in addition to your physical recovery. We know that stress impairs healing in many ways (raising blood pressure, increasing the circulation of stress hormones, impairing sleep, and more), so working to manage your mental health and distress is just as important as focusing on your physical symptoms.





What Can You Do to Feel Better?

Long Haul COVID can be an incredibly difficult and complex process of recovery. Along with the medical specialist care and physical/occupational therapy you may need, there are a number of things you can do to alleviate the mental distress that accompanies this illness.

- **Notice what you are feeling:** when you are feeling upset, take a moment to notice any physical sensations, emotions, and thoughts that might be arising. Naming what you are experiencing can be helpful so you can decide what might most help you in the moment.
- Practice patience & self-compassion: You have been through a lot it may take a
 while to feel like "you" again. Whatever emotions you are feeling are ok. Instead of getting
 frustrated with yourself for these feelings, treat yourself like you would a loved one with
 patience, compassion, and understanding.
- Ask for & accept help: you are not in this alone! Most likely, the people in your life will want to help in some way. For many people with long-COVID, they find themselves shifting from 'caregiver' to 'needing care.' This can be difficult to accept, but it is important to let others help when you need it.
- Make Self-Care a daily practice: when you work out at the gym, your muscles gradually get stronger the same goes for your mental health. The more consistently you practice these techniques for mental wellness, the more natural they will feel, and the greater improvement you will see in your mental health. Incorporating even just ten minutes of self-care, relaxation, or mindfulness techniques every day is a great start!
- Focus on what is within your control: you may not be able to make yourself "better" in this moment, but you can control how you feel & think about your life



If your distress increases to the point where you feel unsafe, please reach out to the crisis lines listed at the end of this guide, or call 911.



Mental Pacing

With the toll that long haul COVID can take on your physical and mental health, you may feel very far off from your "normal" self. It is important to remind yourself that your mental wellness may take some time to improve, and may have ups and downs. Improvements can be hard to see in the day to day; instead, compare your progress not to where you were at your 'pre-COVID' peak, but to where you were at your lowest after you first got sick. It is likely that you have made improvements you may not see until you reflect over several months instead of just days. Some find it helpful to keep a journal of their journey to help recognize how far they have come.



Techniques to Practice Self-Care and Manage Emotional Challenges

There are many helpful techniques for times of intense distress or anxiety. Some examples are listed below (full details are in the <u>exercise guides</u> at the end of this handbook).

Breathing Exercises: we often take breathing for granted until it becomes difficult, whether due to COVID, anxiety, or any other condition. There is a great deal of research that shows that controlling our breathing can lead to improvements in physical and mental pain. Start by taking slow, deep breaths while in a comfortable position. Notice how it feels to fill your lungs if you can. If this is comfortable, try adding a 'hold' between your inhale and exhale — this is called 'triangle breathing': inhale for 3 seconds, hold it for 3 seconds, exhale for 3 seconds. You can increase or decrease the time as needed.

Grounding Techniques: these techniques can help distract from emotional suffering, and calm your body and mind in moments of acute distress. Grounding techniques are broadly broken down into categories of physical, cognitive, and soothing grounding techniques. The important thing is to adapt these to what works for you — everyone is different! These are some examples, and there is a longer list attached to this packet:

- Physical Grounding: cool cloth on your face, hot shower, smelling essential oils, tensing and releasing muscles, taking a walk
- **Cognitive Grounding:** naming favorite foods, listing everything you can see around you, picturing a place from a favorite vacation
- **Soothing Grounding:** picturing loved ones, using safety statements ("I am safe here at home" "I know I can get through this," etc), playing music that makes you calm or happy



Relaxation Techniques: Progressive Muscle Relaxation, Guided Visualization, aromatherapy, listening to favorite music, calling loved ones to connect and chat

Physical Activity: While many long haulers struggle with a range of physical symptoms that can make physical activity challenging, finding a way to maintain some activity is important for your mind and body. Starting slow with small activities depending on your level of comfort is important to work toward building your strength and endurance, and can enhance your mood and coping as well.

Sleep Hygiene & Dietary Habits: Sleep & diet are major contributors to overall wellness. Preparing for sleep (limit screen time before sleep, engaging in calming activities at night) and allowing enough time to rest, as well as focusing on intake of water and nutritious foods have been useful for many Long Haulers.

Meditation & Mindfulness: the goal of these practices is to bring awareness to your physical sensations and emotional state, and then to consciously let them go. For example, many use the practice of visualizing their distressing thoughts, sensations, or emotions, as clouds that they see, and then watch pass by. BIDMC's own <u>Sadhguru Center</u> provides free trainings on meditation and mindfulness exercises. Additionally, many people have found phone apps such as Calm or Headspace helpful tools. You can find a list of mental health focused-apps at the end of this packet.

While these exercises are some introductory ways to help calm yourself and ease emotional pain, it can be helpful to seek professional help in this process as well. Individual and group therapy are great ways to build your coping skills, process your emotions and the experiences you have had, and find support/community.



Impact on Families

What patients often share is that they are worried about the impact their illness has on the people in their lives — whether because they can't do their normal tasks around the house,

"If we can get through COVID, we can get through anything."

can't work and contribute financially, or simply that they're not as "fun" to be around as they used to be. People worry about how their loved ones are managing these stressors and how to talk to them about their concerns. If you have these worries, you are not alone!

What providers often hear is the same feeling of worry from both patients and their loved ones, but each is afraid to talk about their fears and stress because they don't want to "burden" the other. This results in people worrying alone, and often comes out in the relationship in other ways (withdrawal, anger, frustration, etc.).

A more effective way to manage this distress is to be open with your loved ones about what you are experiencing — whether this is frustration, fear, sadness, loss, or other emotions, and think about how these feelings might be impacting both of your actions. Conversations like this can be difficult, but approaching them with patience, understanding, and an assumption that each person has good intentions can make a significant difference. If you feel that additional support would be useful in having these conversations, please see the Section titled "Options for Outpatient Support" at the end of this guide.





How Can You Support a Loved One with Long Haul COVID?

Families, friends, and caregivers of people with chronic illness are often left feeling helpless and unsure of how they can support their loved one. This is no different for families of COVID survivors. General tips for family and friends are:

- Believe your loved one when they say they are feeling unwell. Chronic illness manifests in many different ways, and while a COVID survivor may "look" good or seem "back to normal" from the outside they may still be feeling very poorly.
 Symptoms like brain fog, anxiety, and trauma can be hard to see while still being very present.
- Recognize that the timeline for COVID recovery is uncertain and different for everyone. Even if your loved one has always "bounced back quickly" from illness or stress, that may not be true for the recovery from COVID.

"I try to integrate a backup plan. For instance, if I have a scheduled doctor's appointment and I wake up and it's a bad day for me, having a back-up driver would take a lot of stress out of the equation."

- **Be patient.** Your loved one may be physically or cognitively slower than they were before COVID, or be able to handle a lower amount of tasks or stress. Seemingly 'small' tasks can take a lot of energy for COVID survivors because they can be quick to feel fatigued. They want to feel better faster too, and are working hard to do so, even when it may not be obvious from the outside.
- Try to avoid statements like "you'll feel better soon," or "you're so tough, you can get over this." While statements like these are meant to be encouraging, they can often cause frustration and sadness. COVID survivors already feel frustration, guilt, and worry about the pace and nature of their recovery, and the impact this has on their families and friends. They don't feel tough, or sure that they will get better. Recovery can be very slow, and there is little certainty that it will happen "soon." Instead, try to validate how hard this must be for your loved one, and be ready to hear how they are truly feeling, even if that is "really bad." It can be helpful to say "I'm here for you, in whatever state you may be in."
- You cannot make this 'go away,' but you can be there for support. Talk to your
 loved one about what makes them feel most supported and know that this may change
 throughout their recovery.
- Seek support for yourself! Caring for and living with someone with a chronic illness can be stressful for you too. Reach out to supports like family and friends, your doctors and mental health providers, and take time for self-care. This can be as simple as taking a walk when feeling overwhelmed, calling a friend to vent frustrations, or practicing some breathing exercises. No one is perfect, and both you and your loved one are doing the best you can. The coping exercises above and the therapy resources at the end of this guide are there for you too!



Lessons from Others with "Long Haul COVID"

As devastating and shocking as long haul COVID can be, many in our Survivor Support Group have shared wisdom around what they have learned to help themselves and their families through this process. We are fortunate to share some of these lessons here.

- "When I have a bad day, I remind myself that it won't last forever."
- "I have to tell myself that even though I'm different now, it's like there's a new me I have to get to know."
- "You don't have to explain yourself to anyone, and sometimes it's easier not to."
- "When people ask if I'm 'better yet,' I like to say that I'm still on my recovery journey."
- "It's ok to cry... even at doctor's appointments! It's hard to talk about what we've been through, and I think it helps to show them how hard this is for us."
- "The hardest part is to be patient with myself. I remind myself of how far I've come and that it's ok to take baby steps."
- One group member shared his "3Ps" patience, perseverance, and persistence. We added a fourth: pacing!
- One group member shared her daily "3A's" Assess where I'm at today, Accept my limitations, and Adjust as needed.



Final Recommendations

YOU ARE NOT ALONE

In the last year and a half, most of our worlds have been turned upside down. For many COVID survivors especially, there is a sense of loss for the way their lives had been "pre-COVID" — how they functioned in their families, relationships, work, and day-to-day activities. Many have lost the sense of safety they once had, a sense of who they are, and the faith that "everything will be ok." Not knowing when or how life will get better is an incredibly difficult place to be, and trying to handle all of the stressors that come along with a chronic illness can be very overwhelming.

All of these things are true. It is also true that there is hope — we have seen patients improve with time, and medical providers learn more about COVID every day that will continue to inform your care.

Most importantly — know that **you are not alone.** Indeed, this handbook was created after seeing a need in so many people, and was guided with lessons learned from patients like yourself. Whatever you are feeling, you can be sure that there are others who feel the same.

With everything you are going through, be patient with yourself in your recovery, and with those in your life who may not fully understand your experience. Rest when you need to, and reach out for support when you need it too. At the end of this guide there is information about various mental health and financial resources which may be useful as you continue to recover.



Resources & Information

Options for Outpatient Support

You may obtain a referral for counseling services through your Primary Care Physician (PCP), or sometimes through your employer if an Employee Assistance Program (EAP) is available.

- Insurance: You can contact your insurance via phone or online to obtain a list of covered mental health providers.
- Therapy Matcher: https://therapymatcher.
 wordpress.com or call 617-720-2828
 Call this agency with your name, insurance, location, and a brief summary of your concerns (anxiety, illness, depression, etc) and they will assist in finding you an appropriate referral.
- Psychology Today: https://www.psychologytoday.com/us/therapists/
 You can filter local counselors by accepted insurance, location, specialty, and more.

Crisis Resources

In some circumstances, people find themselves feeling so acutely distressed and hopeless that they think about hurting themselves or not wanting to be alive anymore. Our hope is that you never feel this way, but if you do, there are many resources to help.

- **911:** If you are feeling suicidal, please call 911 or go to an Emergency Room immediately.
- Crisis Text Line: https://www.crisistextline.org/
 Text HOME to 741741
- National Suicide Prevention Lifeline: https://suicidepreventionlifeline.org or call 988

Caregiver Resources

- There is specific information on long COVID and support groups on these websites: <u>Long COVID</u> <u>Families</u>, <u>Caregiver Wisdom</u>, <u>Solve ME/CFS</u>, and the Center for Chronic Illness.
- <u>Family Caregiver Alliance</u> offers some virtual family groups.
- Partners or caregivers can also apply for <u>Paid</u>
 <u>Family Medical Leave</u>, even on an intermittent
 basis, to get the care and rest they need.

There are some general caregiver tips at https://www.cdc.gov/coronavirus/2019-ncov/long-term-effects/care-post-covid.html

Community & Financial Resources

Many people have lost their jobs due to their Long-Haul symptoms. If you are struggling financially, here are some resources and general information that may help:

- Local Community Action Programs (CAP):
 https://www.masscap.org/agencies/

 Every town in MA is covered by a local CAP.
 The services vary from town to town but these agencies can generally help with food scarcity, benefit applications like Emergency Assistance, SNAP, and SSDI, rental assistance, and job training programs among others. You can find your local agency at the link above.
- FMLA & PFML: https://www.mass.gov/guides/family-and-medical-leave-options-fmla-and-pfml-for-commonwealth-employees
 Learn more about your eligibility for these programs at this link. Both patients and their caregivers can be eligible for these benefits.
- Employer Benefits: Ask your employer or HR
 department if you have access to Short or Long
 Term Disability Benefits. Typically, you pay into
 these programs along with your other benefits.
- Social Security Disability Income (SSDI): https://www.ssa.gov/disability/disability.html
 If your symptoms have lasted or are projected to last more than 6 months and prevent you from returning to work you could be eligible, but would still need to apply and get approval. Please be aware that the process takes several months, and that many people get denied on their first application and need to appeal the decision, so it is not an immediate source of financial relief.
- Unemployment Benefits: https://www.mass.gov/how-to/apply-for-unemployment-benefits
 Find information on eligibility and how to apply at the link above.



WHAT IS GROUNDING?

Grounding is a set of simple strategies to **detach** from emotional pain (for example, drug cravings, self-harm impulses, anger, sadness). Distraction works by focusing outward on the external world—rather than inward toward the self. You can also think of it as "distraction", centering," "a safe place," looking "outward," or "healthy detachment."

WHY DO GROUNDING?

When you are overwhelmed with emotional pain, you need a way to detach so that you can gain control over your feelings and stay safe. As long as you are grounding, you cannot possibly use substances or hurt yourself. Grounding 'anchors' you to the present and to reality.

Many people with PTSD and substance abuse struggle with either feeling too much (overwhelming emotions and memories) or too little (numbing and dissociation). In grounding, you attain balance between the two — conscious of reality and able to tolerate it.

GUIDELINES

- Grounding can be done any time, any place, anywhere and no one has to know.
- Use grounding when you are: faced with a trigger, having a flashback, dissociating, having a substance craving, or when your emotional pain goes above 6 (on a 0-10 scale). Grounding puts healthy distance between you and these negative feelings.
- Keep your eyes open, scan the room, and turn the light on to stay in touch with the present.
- Rate your mood before and after to test whether it worked. Before grounding, rate your level of emotional pain (0-10, where 10 means "extreme pain"). Then re-rate it afterwards. Has it gone down?
- No talking about negative feelings or journal writing. You want to distract away from negative feelings, not get in touch with them.

Stay neutral—no judgments of "good" and "bad'.
For example, "The walls are blue; I dislike blue
because it reminds me of depression." Simply say
"The walls are blue" and move on.

- ☐ Focus on the present, not the past or future.
- Note that grounding is not the same as relaxation training. Grounding is much more active, focuses on distraction strategies, and is intended to help extreme negative feelings. It to believed to be more effective for PTSD than relaxation training.

WAYS TO GROUND—Mental Grounding

- Describe your environment in detail using all your senses. For example, "The walls are white; there are five pink chairs, there is a wooden bookshelf against the walt..." Describe objects, sounds, textures, colors, smells, shapes, numbers and temperature. You can do this anywhere. For example, on the subway: "I'm on the subway. I'll see the river soon. Those are the windows. This is the bench. The metal bar is silver. The subway map has four colors..."
- ☐ Play a "categories" game with yourself. Try to think of "types of dogs", "jazz musicians", "states that begin with "A", "cars", "TV shows", "writers", "sports", "songs", "European cities."
- Describe an everyday activity in great detail. For example, describe a meal that you cook (e.g., First I peel the potatoes and cut them into quarters, then I boil the water, I make an herb marinade of oregano, basil, garlic, and olive oil...").
- Imagine. Use an image: Glide along on skates away from your pain; change the TV channel to a better show think of a wall as a buffer between you and your pain.
- Read something, saying each word to yourself.
 Or read each letter backwards so that you focus or the letters and not on the meaning of words.

Use humor. Think of something funny to jolt	through a hard time. You'll get through this.			
yourself out of your mood.	☐ Think of favorites. Think of your favorite color,			
☐ Count to 10 or say the alphabet very slowly.	animal, season, food, time of day, TV show.			
☐ Repeat a favorite saying to yourself over and over (e.g., the Serenity Prayer).	☐ Picture people you care about (e.g., your children; and look at photographs of them).			
Physical Grounding	Remember the words to an inspiring song,			
☐ Run cool or warm water over your hands.	quotation or poem that makes you feel better (e.g. the Serenity Prayer).			
Grab tightly onto your chair as hard as you can.	Remember a safe place. Describe a place that			
■ Touch various objects around you: a pen, keys, your clothing, the table, the walls. Notice textures, colors, materials, weight, temperature. Compare objects you touch: Is one colder? Lighter?	you find very soothing (perhaps the beach or mountains, or a favorite room); focus on everything about that place—the sounds, colors, shapes, objects, textures.			
■ Dip your heels into the floor— literally "grounding" them! Notice the tension centered in your heels as you do this. Remind yourself that you are connected to the ground.	☐ Say a coping statement. "I can handle this", "This feeling will pass."			
	☐ Plan out a safe treat for yourself, such as a piece of candy, a nice dinner, or a warm bath.			
□ Carry a ground object in your pocket—a small object (a small rock, clay, ring, piece of cloth or yarn) that you can touch whenever you feel triggered.	☐ Think of things you are looking forward to in the next week. Perhaps time with a friend or going to a movie.			
	WHAT IF GROUNDING DOESN'T WORK?			
☐ Jump up and down.	Practice as often as possible. Even when you			
■ Notice your body: The weight of your body in the chair; wiggling your toes in your socks; the feel of your back against the chair. You are connected to the world.	don't "need" it, so that you'll know it by heart.			
	Practice faster. Speeding up the pace gets you focused on the outside world quickly.			
■ Stretch. Extend your fingers, arms or legs as far as you can; roll your head around.	Try grounding for a looooooonnnng time (20-30 minutes). And, repeat, repeat, repeat.			
■ Walk slowly, noticing each footstep, saying "left," "right" with each step.	Try to notice whether you do better with "physical" or "mental" grounding.			
■ Eat something. Describe the flavors in detail to yourself.	☐ Create your own methods of grounding. Any method you make up may be worth much more			
Focus on your breathing. Noticing each inhale and exhale. Repeat a pleasant word to yourself on each inhale (for example, a favorite, color or a soothing word such as "safe" or "easy").	than those you read here because it is yours.			
	Start grounding early in a negative mood cycle. Start when the substance craving just starts or when you have just started having a flashback.			
Soothing Grounding				
☐ Say kind statements, as if you were talking to a small child. E.g"You are a good person going				

Mental Health Focused Apps

You can explore all these apps and more in a wide database of available apps where you can search by features, pricing, platform, and more: https://apps.digitalpsych.org/.

All of these apps are free to download, so you can explore what they offer and see what might be a good fit. All have both a free and paid version so you can choose which makes the most sense for you.



Calm: https://www.calm.com/

This app allows you to enter in goals that you want to achieve (ie improve sleep quality, reduce stress, improve focus). From there, the app offers a wide variety of options including Sleep Stories, nature scenes and sounds, video lessons on mindful movement, and guided meditations.



Insight Timer: https://insighttimer.com/

This app has free and paid versions, and focuses on interventions for sleep, anxiety, and stress. To do this, the app offers live events around wellness. mindfulness, and yoga; a variety of courses you can take, music and sounds for relaxation, as well as a wide variety of guided meditations and bells for unguided meditation. They have users around the globe and can allow you to connect with others, as well as to search by teachers that you like or have found useful. They also offer specific options for parents and children around managing stress, sleep aid, and a variety of other topics.



Breathwrk: https://www.breathwrk.com/

Breathwrk describes its services as "a simple yet powerful way to alleviate stress and anxiety, fall asleep faster, energize yourself, or improve endurance. Learn and feel the power of breathing with guided exercises that are backed by science and research. We teach the same techniques used by Olympic Athletes, Psychologists, Yoga Experts, Navy SEALs, and Zen Masters." Their goal is to use breathing and guided work to assist with a variety of concerns like sleep apnea, pain management, ADHD, low energy, stress, anxiety, and more.



Headspace: https://www.headspace.com/

Created by a Buddhist monk, this app aims to teach mindfulness and meditation in an attempt to improve general health and happiness. Their exercises can aid in healing stress, anxiety, and sleep concerns via guided meditations, education, and helpful discussions.

Beth Israel Lahey Health Beth Israel Deaconess Medical Center