

SESSION 8: FINAL THOUGHTS AND REVIEW

Review

In the last session, you practiced ways to enhance the support you receive from others and how to communicate assertively.

- Did you identify any ways to enhance the support you receive from others or who you receive it from?
- What assertive statement did you make?
- What went well and what didn't go well?

AGENDA

In today's session, we will:

- 1 Review your practice since our last session
- 2 Discuss conversations with your loved one about making medical decisions and understanding prognosis
- 3 Learn how to find meaning in your current situation
- 4 Review the skills you found most helpful from all sessions and form a plan to continue practicing these skills

In this session, we will explore conversations around **making medical decisions for your loved one** and **managing differences in understanding prognosis**.

This is helpful if you have been avoiding difficult conversations with your loved one or have different opinions about how much information you want to know about your loved one's prognosis. Sometimes, people find ways to **grow from** or **reflect** on their situation. This is helpful if you want to explore ways to find meaning or make sense of what you are going through.

1. Preparing for your role as Health Care Proxy

It is difficult to think about having to make decisions for our loved ones. While we may avoid having conversations on these topics, we know that it is much more stressful to make those decisions if we don't know our loved ones' wishes. Although we hope that your loved one's health will improve, we worry that, if it does not improve, you may not have had these important conversations and feel unsure about your loved one's wishes. How might you be able to have a conversation with your loved one so that you can communicate clearly and be informed, while staying present-focused and not getting stuck in a worry cycle about the future? It may take a few tries or several conversations to reach a decision or understanding. Remember, we are here to support you both in this process. If you are in a position to make decisions on your loved one's behalf, you will not be alone. Your loved one's medical team will support you to make decisions that honor their wishes.

Tips for having a helpful conversation:

- Encourage your loved one to have this conversation with you by using a hope/worry statement:
 - “While we both hope that you pull out of this, I worry that I won't know your wishes if things get worse”
 - “While we both hope that you will get better, I worry that this conversation will be more difficult to have if you don't get better”
- Make a time and safe space to have a conversation where you won't be interrupted.
- Reframe your thoughts about the conversation. Instead of thinking about this as a conversation around dying, think of it as a loving conversation and a loving document that will help you both receive care that matches what you would want until your last moments.
- Include something pleasurable during the conversation such as a cup of coffee or tea, or relaxing music.
- Try talking about the conversation out of the context of your loved one's diagnosis and current treatment. Think in more general terms of what each of you want for your life.

- Use a website such as www.fivewishes.org, www.theconversationproject.org, or www.prepareforyourcare.org to facilitate your conversation and give you a legal document to serve as a template. This takes the guessing out of the conversation and walks you through your options in a sensitive way. Here is another way to start the conversation:
 - If you were to learn that your time is limited, how, where, and with whom would you like to spend your time? Some people value spending more time with family, some want to make sure to avoid bothersome symptoms or pain, and others value independence or being mentally clear.
- Ask to meet with a Palliative Care Physician to help facilitate this conversation. These physicians are trained in having these conversations and are experts in helping patients and caregivers make difficult decisions around their medical care.
- Take turns each expressing your wishes, so that the focus is on both of you, rather than just your loved one.
- If you know someone who died from a serious illness, think back to this time and see if you remember things that went well or things that did not go well. This can help inform your wishes and those of your loved one.
- After you have each expressed your wishes, write it down, put it somewhere safe, and then let it go, choosing to stay focused in the present and move forward with your day.
- Plan to do something enjoyable after such as eating your favorite meal, watching your favorite TV show, or going for a walk.
- Remember that people change their mind over time, so while we have these conversations to guide us, it is a good idea to have a check-in every so often to make sure you and your partner are on the same page.
- As much as we try to anticipate, it is also quite normal for preferences to change once we are actually in the situation. Try to stay open to these changes.

Managing differing desires for information about the future

It is sometimes the case that the person in the role of caregiver desires more information about their loved one's diagnosis, treatment, and prognosis than the patient themselves, or vice versa. Some people want to know the potential length of time, some want to know how the disease changes over time and what to expect in their partner, and others don't want to know any of this information. This can be a source of tension in your relationship and may be difficult to reconcile. It is important for each of you to decide what is most important and helpful and at which points in care you want or need that information. While we may not agree with the other person's wishes, we do have to try to find respect for what they want to know or don't want to know. Here are some helpful tips for coping with these differences:

Tips:

- If you are determined to get more information, is there a way you can do this for yourself without involving your loved one? Think about how you would feel not sharing that information with them.
- If you had more information about your loved one's prognosis, how would that affect how you are living now and the decisions you make? Would you do anything differently?
- Keep in mind that your preference for information may change over time. Although you might think you want to know more about prognosis now, you may find that later on you have less of a desire to know, and more of a desire to stay present-focused.
- There may not be any more information to know or find out about your loved one's prognosis. Sometimes we must accept the uncertainty of not knowing.
- If you and your loved one differ in your desires for information and prognostic understanding, try to communicate openly about that, acknowledge your differences, and accept and respect each other's wishes.

2. Finding Meaning

Challenging times bring about moments of reflection and self-evaluation. In these reflective moments, we consider our lives and choices more deeply and realize all that we have learned through the experience. While we wish that we never had to go through such experiences, we can also see that we have been changed through it, and in some ways, we may have changed for the better.

Exercise

To explore and appreciate your loved one's legacy, you might try to help them write letters to relatives, children, or friends.

Another way to appreciate legacy is to put together a piece of work that represents your loved one's life and their many gifts, contributions, and talents.

These difficult times can also raise new priorities and goals. Can you think of any ways that you have changed from the experience of caring for your loved one? Is there anything new that you learned or realized from this experience? It is also perfectly fine if you are not able to identify anything positive. Below are some examples:

- Have you done things or activities with your loved one that you otherwise wouldn't have done?
- Is there an appreciation for each other in a way or for life in a way that wasn't there before?
- Do you have more time to talk about your kids or other topics?
- Are you thankful that you have each other?
- Have your priorities or focuses shifted in a way that is beneficial?
- Have you taken on a new goal?
- Are there things that you learned about yourself or your abilities in this caregiving role?
- Is there a legacy in your life or your partner's life that you have come to understand or appreciate?
- Have you explored gratitude or openness?

Use this space to jot down anything that comes to your mind:



CONGRATULATIONS!

Take a moment to congratulate yourself on completing this program. You dedicated meaningful time from your day to learn and practice skills to help you cope with challenges and worries related to your loved one's diagnosis and treatment.

Throughout this program, you learned skills to:

- Manage common concerns and relaxation by breathing from your diaphragm (Session 1)
- Choose helpful strategies to cope with worry (Session 2)
- Identify unhelpful thoughts and patterns of thinking (Session 3)
- Choose more helpful and accurate thoughts (Session 4)
- Improve sleep strategies, self-care, and relax with and relax with Progressive Muscle Relaxation (Session 5)
- Build communication and effectively manage frustration (Session 6)
- Strengthen communication with supports, friends, clinicians, children, and employers (Session 7)
- Learn how to talk with your partner about medical decisions and find meaning in your current situation (Session 8)

The last step is to form a plan to keep using these skills.

What skill was most helpful for you?

How might you make sure that you will continue to use this skill?

Maintenance and Prevention

The next step is maintaining your quality of life and attention to yourself even after these sessions are over. It is easy to slip back into old habits when we do not have daily or weekly reminders in the form of therapy sessions or homework exercises. **We encourage you to continue using techniques and skills that you have learned in the future.** You will find that you can apply these skills to many areas of your life outside of the experience of caring for your loved one.

We want to optimize your chances of maintaining your well-being and the changes that you have made throughout this program. Here are some tips for maintenance:

- 1) Create a calendar** to schedule time for you to engage in pleasurable activities. Make sure to engage in at least one activity (can be as short as a 10-minute walk) per day that brings you joy and is only for *you*.
- 2) Look back on these sessions** to review material and **repeat practice exercises.**

Check-Ins

Plan ahead. When we start to feel better after an infection, we are less likely to finish the cycle of antibiotics (although we always should!). Similarly, when we start to feel better emotionally, we often pay less attention to our use of strategies to manage our mood. While this behavior is normal, it is also a good idea to revisit these strategies on occasion to make sure we have not gotten off track and to prevent becoming overwhelmed in the future. **Pick a day in the future when you will do a check-in.**

During a check-in, ask yourself:

- Have I been scheduling time for myself?
- Have I been using assertive communication to resolve conflict?
- Have I been taking care of my health (exercising, sleeping, and eating well)?

Maintenance Plan

Take a few moments to identify a maintenance plan for yourself and write it below:

When is it time to seek additional support?

If you notice that you are becoming overwhelmed, do not hesitate to reach out for professional help. You have a good foundation from which to build on. To seek professional help, you can ask for a referral or call the MGH Psychiatric Oncology Service (617-726-5130) if you receive care at MGH, or the MSK Caregivers Clinic (646-888-0200) if you receive care at MSK.

Alternatively, reach out to a friend. Sometimes we just need someone else to provide some hope and encouragement even though we think we should be able to get ourselves back on track.

We sincerely appreciate your participation in this study. We hope you have found it helpful as you navigate this time in your life and your role in caring for your loved one.

Now, what is next?

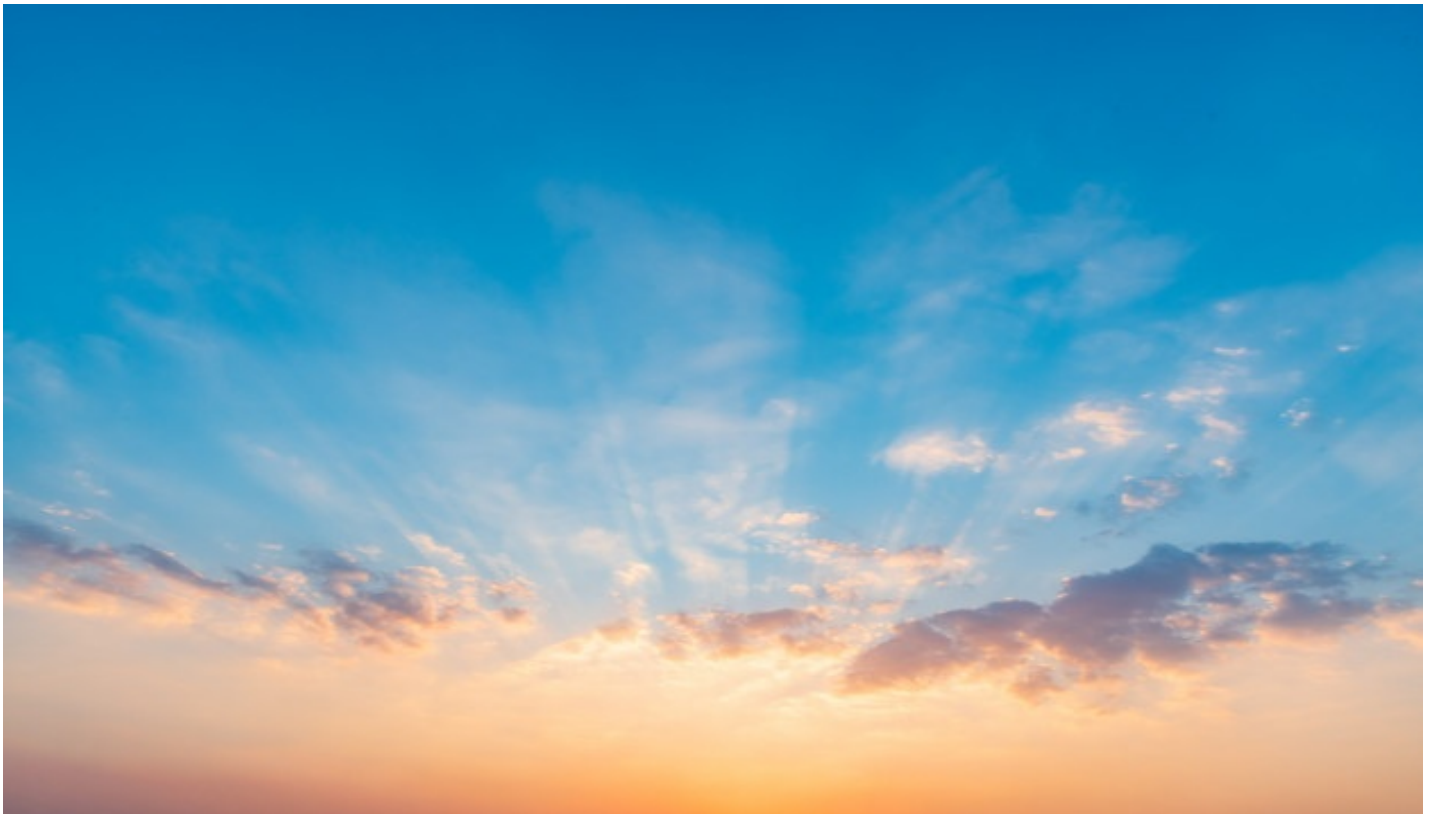
1. We will send you a bonus guided visual imagery exercise.
2. Study staff will ask you to complete a packet of questionnaires after this visit
3. If you would like additional resources, please see page 98.

Bonus Relaxation Exercise: Guided Visual Imagery

Although we won't practice this exercise in our session today, we will send you a bonus relaxation exercise which uses visual imagery to help you relax.

Imagining yourself somewhere else is a good distraction technique to use, in moderation, when you are feeling anxious, worried, or nervous, and there is nothing you can do to solve the problem. It can be an emotion-oriented coping strategy to manage stress and worry.

Try visualizing yourself somewhere else and use the audio recording as a guide.



Additional Resources

Listed below are some resources you may find helpful.

Websites and Programs:

- Cancer Care: www.cancer.org (caregiver groups online and over the phone)
- National Cancer Institute live free information: https://livehelp.cancer.gov/app/chat/chat_launch
- Caregiver Support Video Series: <https://www.cancer.org/treatment/caregivers/caregiver-support-videos.html>
- Cancer Support Community: <https://www.cancersupportcommunity.org/MyLifeLineMemberStories>

Mobile Apps:

- Insight Timer
- Calm
- Headspace
- Stop Breathe and Think

THANK YOU!