WELLNESS WHILE WAITING

A Self-Help Guide for Veterans Listed for Transplant

Presented to you by your VA Transplant Team

My **Transplant Coordinator** is: _____

The **phone number** for the program is: _____

ChooseVA

south central mirecc
Mental Illness Research, Education and Clinical Center

Created by:

Shiquina Andrews, PhD | Ali Abbas Asghar-Ali, MD | Jennifer Bryan, PhD

South Central MIRECC | Michael E. DeBakey VA Medical Center

TABLE OF CONTENTS

CORE PACKET

Wellness While Waiting Guide

About This Guide 3
What is Wellness? 4
Emotional Wellness? 5
What's Next during the Wait? 7
Learning & Keeping Good Health Habits? 8
Talking with Your Providers? 9
Being Open and Accepting Help? 10
A Final Word? 11

Visit Agenda Cards 12

Caregiver Wellness Handout 13

ABOUT THIS GUIDE

Congratulations on being listed! This is a major milestone toward your goal of getting a transplant. The staff at the VA Transplant Center where you are listed (now known as your "Transplant Team") look forward to being a part of this journey.

Your Transplant Team is giving you this brief self-help guide, so that you will know what to expect during this next step in your transplant journey... "the wait".

The time between the "work-up" (all the tests that you did before getting on the waiting list) and the transplant surgery itself can be confusing and stressful. The goal of this guide is to let you know what to expect while you wait. We also want to give you more tools to deal with stress, to add to the personal and community resources you may already have to manage stress. Finally, we encourage you to focus on your wellness during this time.

WHAT IS WELLNESS?

As a person who needs a transplant, you're very used to thinking about your physical health. For the people who have serious or long-term health issues (like diabetes, high blood pressure, or organ failure), it's easy to get stuck in thinking only about physical health. It's easy to overlook how else you can feel well.

So, what do we mean when we say that we want you to also think about *total wellness*? When people say "health", they are usually talking about ***not*** having a disease or injury. Because of that, people think of health in an either/or way. For example, "Either I'm healthy ("there's nothing wrong with my body") or I'm not healthy ("I have high blood pressure").

When your Transplant Team says we want you to focus on wellness while waiting for transplant, we mean we want you to pay attention to all the areas of your life that make you feel good, *including* your physical health. Here are some examples of the different types of wellness and things you can do to increase wellness in those areas.

TO BE WELL...	YOU CAN...
PHYSICALLY	• Eat a balanced diet. • Be physically active. • Get enough sleep. • Keep up with your medical appointments. • Take your medicines as directed.
EMOTIONALLY	• Become more aware of your feelings. • Increase positive feelings like joy, hope, and gratitude. • Cope with negative feelings in healthy ways. • Learn and practice stress reduction skills.
SOCIALLY	• Make plans with loved ones. • Make new friends and acquaintances. • Communicate openly with loved ones.
SPIRITUALLY	• Do things that hold deep meaning and purpose for you. • Attend religious services, pray, or engage in other activities that reflect your faith or spirituality. • Do things that feed your personal relationship with your Higher Power.
FINANCIALLY	• Save up over time for emergencies or important events. For example, save for expenses not covered by VA during the time after your transplant. • Make (and stick to) a budget. • Create a management plan. Choose a person to pay the bills and do other financial tasks. Or, decide how you will split those tasks between you and someone else in your home. Check in regularly with each other to see how things are going. • Ask for help before you need it. Talk to your Primary Care or Transplant Team Social Worker for housing or financial resources.

EMOTIONAL WELLNESS

Let's talk more about how transplant can affect people emotionally. It is not unusual for people to feel unsettling emotions throughout this process. Some people feel sadness, fear, distress, or frustration. Even after transplant, people sometimes feel disappointed, guilty, or worried about the future. Again, these are common feelings within the uncommon experience of needing an organ transplant.

Most people experience those emotions because waiting for transplant is often not as straight-forward as people may hope. Some describe the wait as a bit of a roller-coaster. It has unexpected turns and bumps that they didn't imagine before they started. So, just in case, we want to give you some "cushion" for that coaster by building good emotional skills.

It's a good idea to have good emotional skills way before you even get to the point of transplant because your emotions impact your health. Peoples' emotions can impact their health in many ways. Think about it. When we are stressed, it:

- Affects how we sleep or eat.
- Messes with our desire to get things done.
- Keeps us from reaching out for help.
- Can lead to unhealthy coping choices like smoking, drinking, or other things that go against our health goals.

Most people know about those types of connections between health and stress. But, did you also know that too much stress can slow wound healing? Yep, the same body system that's triggered when we're under stress is the same body system that helps the body repair itself. You'll definitely need all the wound healing powers your body can muster after a surgery like transplant. So, by improving your emotional health now, you can not only get more enjoyment out of your current life, but you can also improve your recovery from transplant.

EMOTIONAL WELLNESS

Are you sold yet on the importance of good emotional wellness? Good! **Here's a quick exercise you can engage in to help you de-stress: deep breathing.** Deep breathing triggers your body to feel more relaxed. Follow the steps and give it a try:

GET COMFY	1	**Sit or lie flat in a comfortable, relaxed position.**
PLACE HANDS	2	**Put one hand on your chest and the other on your belly, just below your ribs.**
BREATHE DEEPLY	3	**Take a deep breath in through your nose and let your belly push your hand out. Breathe out through your mouth. Try to keep the hand on your chest still.**
BREATHE SLOWLY	4	**Breathe just like that for a count of 5 each way. Try to do 3 sets of 5. Take slow even breaths each time.**

Now that you've tried it, how to you feel? Hopefully, you feel calmer. If you liked that and want to learn other stress management skills, you can:

- Download the free Breathe2Relax App to learn more relaxation skills;
- Download the Wellness Guide on the VA South Central MIRECC's website at https://www.mirecc.va.gov/visn16/veteran-wellness-guide.asp;
- If you already work with a mental health provider, tell them that you'd like to learn more stress management skills;
- If you're not working with a mental health provider, ask your VA Primary Care Provider or Transplant Coordinator for a referral to Behavioral Health at your home VA.

WHAT'S NEXT DURING THE WAIT?

After you are added to the waiting list, you will continue to get your main care from your home VA. However, your Transplant Team will still track you medically. They will continue to talk with your providers at your home VA about your health. The Transplant Team may ask for repeat labs and tests. They may suggest certain treatments or procedures to help better manage your health. Your Transplant Team will also expect you and your support person to keep the Team informed about important health events like a heart attack, stroke, or hospitalization or The Transplant Team should also be informed about important life changes that may affect how easily the Team can get in contact with you. We need to know right away about a new phone number, a move to another city, or a change in your support person. You should contact your Transplant Coordinator as soon as possible with updates like the ones mentioned.

Remember, some people may spend quite a few years waiting for transplant. **Depending on the length of your wait, the Transplant Team may also invite you and your support person back for an in-person follow-up.** These follow-ups are normal. It's important that we continue to address as many issues as we can before transplant. We want to make sure that you are as healthy as possible going into the surgery. Your work in managing your health will continue while you wait.

LEARNING AND KEEPING GOOD HEALTH HABITS

Speaking of being as healthy as possible, the Transplant Team might have suggested that you make some health changes. Examples could be losing weight, improving your diabetes control, or taking your medications regularly. The point of those recommendations is to get you ready for life-after-transplant. You've heard the phrase "practice makes perfect." Learning good health habits now makes them easier to keep up later.

To make a change or start a new health habit, create a SMART goal versus making a vague wish. For example, a vague wish is "I want to be more active." A SMART goal is "I will walk, either in the park or on the treadmill at the gym, for 30 minutes at least 4 days a week". Here's how to create SMART goals:

S	M	A	R	T
SPECIFIC	**MEASURED**	**ATTAINABLE**	**RELEVANT**	**TIME-BOUND**
Describe your goal as clearly and with as much detail as possible.	Use a number or other way to objectively track your progress.	Make it challenging but realistic, something within reach.	Make sure it's personally important and consistent with other values.	Set a date for when your goal needs to be achieved.

If you're having some trouble sticking to your SMART goal, here's how you can get some help:

- *Want tips and things try on your own?* Download the free MOVE! Coach app for a self-guided weight loss program.
- *Need help with knowing what or how much to eat and finding physical activities to do?* Ask to talk to the Transplant Dietitian if your Transplant Team has one. If not, ask to talk with your PACT dietician, if the team has one, at your home VA.
- *Need help with motivation?* Ask your Primary Care Provider for a referral to Behavioral Health or Primary Care Mental Health at your home VA.

By the way, you can use SMART goals for other wellness goals. For example, a social wellness SMART goal could be, "I will go to the movies or out to dinner with my friends at least once a month". Also, remember that making any behavior change is about progress, not perfection. There may be a few times when you don't meet your SMART goal, and that's okay. Being consistent more often than not is what matters.

TALKING WITH YOUR PROVIDERS

It is important that you and your Transplant Team continue to talk with your providers at your home VA about your health. Patients who talk with their providers have better medical results and are happier with their care.

Your providers want to make sure you understand your health condition and treatment recommendations so that you can be fully involved in your health care. So, get comfortable with talking! Here are some tips to help you talk with your providers:

- If your provider uses a medical term that you don't understand, ask them to explain it to you.
- Ask how you can improve a symptom. No question is silly.
- To make sure you and your providers are on the same page, share your understanding of the information with your provider. That will help you work through any kinks in communication.
- Share your concerns about treatment or risks. This will help you choose the best options and the right treatment path for you together.

We understand that sometimes medical visits may be shorter than some Veterans like. It can be helpful to prepare before the appointment to make the most of your time together. In this package, we've included Visit Agenda sheets that you can use to prepare for your appointments.

BEING OPEN AND ACCEPTING HELP

Earlier, we talked about how normal it was for waiting for a transplant to feel like a roller-coaster. Instead of sharing their feelings with others, some people close themselves off and bottle up everything. People may do this for a few reasons.

First, they may believe that not thinking or talking about their fears or struggles is a good way to cope. They think they are giving themselves "a break" from what's going on with their health. It's true that it isn't healthy to worry too much over your health or the future. Yet, it is also not helpful to "bury your head in the sand" and avoid facing issues. Avoidance can lead to more anxiety because the underlying issue is never addressed. So, don't be shy about opening up.

Second, some people worry about burdening others with their problems. Being considerate about overwhelming other people can be helpful. But, those who care want to know what's going on with the people in their lives. Also, some people are used to helping others and have a hard time receiving help from others. They may think of accepting help as a sign of weakness or neediness. Or, they simply haven't had the experience of having someone to lean on in the past. Because of those things, accepting help can be downright uncomfortable for some people.

But please... **let someone join you on the ride.** That "someone" can be your support person, a friend, or another loved one. It can be someone on your Transplant Team or another health care provider. It can even be someone else who is also waiting for transplant. People who have good support tend to have better quality of life and health outcomes after transplant. Don't be shy about accepting others' help.

In case you want to talk with others who are also waiting for transplant (or maybe, someone who has already received transplant), ask your local Transplant Coordinator if there is a transplant support group near you. There may be one at your VA or one in your local community. There is a list of transplant support groups by state at https://transplantliving.org/community/support-groups/. You may also want to join an online support group on a social media platform like Facebook.

A FINAL WORD

Finally, your Transplant Team wants to encourage you to **LIVE WHILE WAITING ON THIS LIST.** What do we mean by that? We want you to keep doing the things that make you happy, bring you joy, give you purpose, and make you feel fulfilled, *even if the way you do those things now is different than how you did them before.* Here are some examples of how you can stay engaged in life while waiting on transplant:

- If you can't work, you could be a volunteer or do something that reminds you of your old career. This may give you the same good feeling of purpose that your work gave you. It may also give you chance to give back to your community. Also, you could make your own schedule, to work around your medical appointments.
- If you love to travel with family, plan ahead for things like transient dialysis and still take that trip. This way, you won't miss out on important quality time with the ones you love. Continuing to make memories is important.
- If you have trouble getting out of the house, learn a fun new hobby or get back into an old one. Try things like arts, crafts, learning a new instrument, or fixing things around the house. Engage your creative side.

Whatever the meaningful activity is, or was, you don't have to give it up completely because of your health. Whatever you value, be deliberate about living out those values on a daily basis, so you can be well during the wait. ***We thank you for your service and look forward to taking this journey with you!***

MY VISIT AGENDA

Get the most out of your medical visit by having a plan. A plan can help you remember questions or changes in your health that come up between visits. **Use the space below to write down things you want to talk about during your next visit.** Examples of what to write down include: things you don't understand, things with which you need some help (like eating better, feeling more motivated, sleeping more), or changes you've noticed in your health (like new pain or symptoms, side effects from medications). If you run out of room below, just write on the back!

Adapted from: Agency for Healthcare Research and Quality, AHRQ Pub. No. 10(11)-0094-1

MY VISIT AGENDA

Get the most out of your medical visit by having a plan. A plan can help you remember questions or changes in your health that come up between visits. **Use the space below to write down things you want to talk about during your next visit.** Examples of what to write down include: things you don't understand, things with which you need some help (like eating better, feeling more motivated, sleeping more), or changes you've noticed in your health (like new pain or symptoms, side effects from medications). If you run out of room below, just write on the back!

Adapted from: Agency for Healthcare Research and Quality, AHRQ Pub. No. 10(11)-0094-1

CAREGIVER WELLNESS

As a Transplant Support Person, you are an important part of your loved one's care team. You help make sure the Veteran has the care they need to get the best health outcomes. You spend a lot of time thinking about, and providing for, your loved one's needs. But, when is the last time you stopped to take care of yourself? **Prioritizing your needs is a crucial part of caring for your loved one.**

Your loved one is not the only one who may be experiencing a range of emotions that may come along with the transplant process. **As a Support Person (or caregiver), you too probably feel the worry, sadness, or frustration that comes along with waiting for a transplant.** You also may feel the pressure of being a caregiver. Caregivers can feel like they are being pulled in many directions at once. Trying to balance caring for yourself and others can be tough. Sometimes caregivers can feel overwhelmed or discouraged, and that it is okay. Caregiving can be stressful, and it is normal to feel stressed from time to time.

The Transplant Team wants you to know that your well-being is important. The Team wants you, as a caregiver, to take good care of yourself during this process. You can do this in many ways:

- Take regular breaks.
- Get sleep.
- Eat healthy.
- Do fun things just for you.
- Exercise.
- Make sure you are going to your medical appointments.
- Ask others for help in doing things for the Veteran, so you don't feel that everything is "all on you."

Want more support? The VA has resources for caregivers.

- The VA Caregiver Support Line (1-855-260-3274) can connect you with local services or offer a listening ear.
- The REACH VA program helps caregivers learn how to manage stress and other helpful skills that are useful for caregivers. You can enroll by contacting your local Caregiver Support Coordinator. Find them here: https://www.caregiver.va.gov/support/New_CSC_Page.asp

You can also **look for support groups near you or try online support groups for caregivers of transplant patients,** like Partners for Life (https://www.facebook.com/groups/PartnersForLife/) or Caregiver Lifeline (https://www.facebook.com/groups/caregiverlifeline/). Finally, if you'd like, you can also look into behavioral and mental health services for yourself. Those services can be a great way to get regular support. Counsellors in the community often accept insurance or may be willing to reduce fees.

The Transplant Team truly appreciates all that you do.

We encourage you to take good care of yourself.

From: Wellness While Waiting, created by Shiquina Andrews, PhD, 2019