CARING FOR YOURSELF AS YOU CARE FOR A LOVED ONE

- Organizing your caregiver responsibilities
- How transplant affects you, too
- Getting help from others

Justin, transplant recipient, with Kari, his mom and caregiver
Caring for yourself as you care for a loved one

As the caregiver for a loved one who had a transplant, you’re entering a new stage of the caregiving journey. Your loved one is likely home now, and your caregiving role has changed.

While you focus on caring for your loved one, it can be easy to forget about your own needs. But one of the most important things you can do for your loved one is to take care of yourself. The stress of recovery from transplant affects you, too. And if you become physically exhausted or emotionally overwhelmed, you won’t be able to provide the care you want to give your loved one in the months ahead.

This issue provides practical tips to help you:

• Cope with the emotional challenges of caregiving
• Advocate for your loved one
• Get the help you need from others
• Stay connected to your friends and family
• Relax and recharge

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Words cannot begin to explain my gratitude. For those 13 years, I never imagined a life without sickle cell anemia. I never dreamt that life could be so wonderful.” —Kari, Justin’s mother and caregiver (pictured above)
Transplant affects you, too

In many ways, illness and recovery can be as hard on caregivers as it is on patients.

Your experience can be just as intense as your loved one who received the transplant. But what you’re going through is different, and you need your own support and plans for how to cope.

As you go along, you may find your feelings, experiences and needs change. You might not experience the full impact of what you’ve been through until things settle down. But dealing with ongoing stress, anxiety and fatigue can take its toll.

Pay attention to how you’re feeling emotionally, and know when you may need to ask for help.

What you may be feeling

It’s normal to sometimes feel overwhelmed by responsibilities caring for your loved one and other family members. But remember, your needs are important, too.

As caregiver Kay explains, “For you as the primary caregiver to be most effective, you’ll need to indulge yourself once in a while—whether it’s a walk outside, a relaxing massage, an hour with a good book, or simply coffee with a friend. You must take care of yourself.”

It isn’t unusual for caregivers to ignore their own needs. Making your well-being a priority might seem selfish, but it’s important for you to stay healthy so you can help your loved one recover. If you become exhausted and overwhelmed, it can affect your ability to provide good care.

IT MIGHT HELP TO REMEMBER:

• You are doing the best you can
• No one is perfect
• Your feelings are normal
• You may have emotional ups and downs
• Put first things first and let the little things go
• It’s okay to take some time alone
• There are people who can help
• You do many things very well

WHEN YOU FEEL LIKE YOU ARE STRUGGLING WITH YOUR EMOTIONS

Coping is finding ways to deal with and overcome difficulties. Everyone has different coping styles and it may be helpful to think about your style and how it is, or isn’t, helping you. While there are many different ways to cope, some ways of coping are better for some situations than others.

If emotions are so strong that they interfere with your daily life, talk to a counselor or therapist. You can also try these coping strategies to help you through:

**Emotion-focused coping**

Try this when faced with a situation you cannot change. For example, while you cannot change the fact that your loved one is ill, it may be helpful for you to cope by letting out your thoughts and feelings through talking to a friend or writing in a journal.

**Problem-solving coping**

Figure out what’s needed and make a plan. This is best when there is an aspect of a situation that is changeable. For example, if you’re feeling overwhelmed with all you have to do as a caregiver, you may consider making a list, prioritizing tasks and giving some tasks to others.

**Thought-focused coping**

Regain your sense of control by changing your expectations and attitude. Some stress we experience may have more to do with the way we think about an event—and react to it—rather than the event itself.

In some situations, all 3 coping strategies may help you. But other times you may want to use 1 strategy that best fits the situation.
Transplant affects you, too (continued)

I was so busy trying to make it through each day that I never noticed that I had changed. My doctor explained that I was depressed and overwhelmed—and he prescribed anti-depression medicine (which helped). Both my daughters said they were happy to hear me laugh again.”

—Jeanette, caregiver

RECOGNIZE THE SYMPTOMS OF DEPRESSION

If you’ve had any of the following symptoms most days for 2 or more weeks, it can be a sign that you need to ask for help. Tell your doctor about your symptoms and ask about what could help you.

- Constant sad, anxious or “empty” mood
- Sleeping much more or much less
- Changes in appetite and weight, either loss or gain
- Loss of pleasure and interest in activities you used to enjoy
- Restlessness, irritability
- Physical symptoms that do not get better after treatment
- Difficulty concentrating, remembering or making decisions
- Fatigue or loss of energy
- Feeling guilty, hopeless or worthless
- Thoughts of suicide

If you are having thoughts of hurting yourself or others, get help immediately. Call the National Suicide Prevention Lifeline at 1 800 273-TALK (8255) any time—24 hours a day, 7 days a week—to talk with someone who can help.

You can also dial 911 or go to your local emergency room (ER).

If you think you may be depressed, contact your doctor. Tell your doctor about any symptoms of depression you are experiencing and ask about treatment options.
You may experience a range of emotions

Caregiving can bring up a lot of different emotions. That was the case for Allison, who was the caregiver for her husband, Sean.

“You name it, I’ve felt it,” Allison says. “Angry that my husband had this disease. Guilty that I wasn’t being a good enough mom/wife/employee. Panic because there were many ups and downs and many moments that felt very scary. Stretched thin because I felt like I was being pulled in every direction. And, gratitude for all the help that we were given.”

Some emotions, like anger or grief, might seem confusing or wrong. But all of your emotions are normal and okay. Many caregivers feel:

**Sadness.** Feeling sad is normal. But if it lasts for more than 2 weeks, and interferes with your daily life, tell your doctor. It could be depression. The information in the box on page 4 can help you recognize the symptoms of depression.

**Anger.** If you’re angry, try to put your feelings into words. Take time for reflection to figure out why you’re angry. Knowing the cause might help you think of ways to cope.

**Grief.** Almost any kind of change in your life can cause grief because you lose the way things were before. Grief is a process that can take time and attention to work through.

**Guilt.** No matter how dedicated you are, you might feel guilty that you’re not able to do more. You might feel guilty if you focus on your own needs. Be kind to yourself. There are many things you do very well. Caring for yourself is as important as caring for your loved one.

**Loneliness.** You might feel alone because you miss people from the hospital, or friends and family might have stopped visiting. You might feel lonely if you think no one understands what you’re going through. Sharing your feelings with someone you trust may help you feel less lonely.

You have your own path to recovery

You may experience stress and difficult emotions throughout your loved one’s treatment and recovery. But because the focus is on the patient, your stress may be unnoticed and unaddressed.

After transplant, caregivers may have more stress than the transplant recipient. It’s important for you to pay attention to your own health and well-being. Severe or chronic stress can cause depression, problems with memory and concentration, tiredness and other issues if left untreated.

“I wasn’t really interested in any of the things I used to do,” shares Jeanette, caregiver for her husband, Everett. “I was so busy trying to make it through each day that I never noticed that I had changed. My doctor explained that I was depressed and overwhelmed—and he prescribed anti-depression medicine (which helped). Both my daughters said they were happy to hear me laugh again.”

Remember, you’re not alone. Help is available. You can find resources for caregivers throughout this issue. You can also contact Be The Match®. Our Patient Support Center provides support, information and resources for caregivers and families. Call or email us for confidential, one-on-one support from caring experts. We’ll listen and help you find answers. All of our programs and resources are free.

**RESOURCES FOR YOU**

Sometimes it can help to talk with someone who’s been where you are. The Be The Match Peer Connect program connects you with a trained volunteer who is also a transplant caregiver. These volunteers can answer your questions and share their own experiences. Learn more and request a connection at BeTheMatch.org/peerconnect.

The Well Spouse Association provides emotional support for partners of those with a chronic illness and/or disability. They offer support groups and information on issues facing partner caregivers. Learn more at WellSpouse.org.

Stupid Cancer brings together young spouses of adults with cancer to share information, support and experiences. Visit StupidCancer.org/community/categories/caregivers.

The Family Caregiver Alliance offers support to families who are caring for a loved one by providing information and advice, fact sheets and publications, newsletters and support groups. Learn more at Caregiver.org.
You may be so focused on your loved one that you hardly notice how the experience is affecting you. Caring for someone after a transplant requires a lot of energy. You might feel like you have to do everything. Give yourself permission to rest and take care of you, so you'll have more energy in the long run.

To cope with the impact of caregiving on your life, it can help to:

• Write about your experience in a journal
• Talk with others about your experience in a support group for caregivers or with family and friends
• Reflect on your experience through prayer or meditation

It's important to take time for yourself every day, even if it's just a few minutes. Doing things you enjoy helps you recharge.

“My primary ways to relax and recharge were writing and being with my daughters,” explains Brian, caregiver for his wife, Betsy. “One allowed me to relax and process. The other made me smile, made me laugh and reminded me that, despite the circumstances, I was lucky after all.”

The following list of activities can help you take short breaks, emotionally or physically:

• Exercise (go for a walk or run, or take a yoga class)
• Read a book
• Express your creativity through writing, drawing, painting, sculpting or singing
• Listen to music
• Cook or bake
• Go out to dinner
• Watch a funny movie
Regardless of the day I was having, I made time to take a walk. I also tried to sleep or take naps anytime I had the chance.”

—Clark, caregiver

“I tried to head to bed early every night to be by myself and read, which was especially helpful because we had other family caregivers living with us for 6 months,” shares Allison, caregiver for her husband, Sean. “That was my time alone, and I felt no guilt about it.”

Maybe you and the person you’re caring for can benefit from the same activities. Or, you each may have your own needs. Seeing visitors might make one of you feel better, the other might want quiet time alone. It’s important to value your differences and find activities that are right for each of you.

Making healthy food choices, even when time is short

Stress can affect how you eat. Sometimes you may eat too much or too little, or choose something quick or comforting, but not nutritious. The choices you make may end up causing you to have less energy or get sick more easily.

Here are 3 small things you can do each day to eat healthier:

1. Keep healthy snacks on hand like yogurt, string cheese and crackers, bananas, grapes and nuts.
2. Keep a bottle of water with you so you drink water throughout the day; consider having water instead of caffeinated soda or coffee.
3. Have a baked potato and side salad at a fast-food restaurant instead of a burger and fries.

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10 WAYS TO RELAX AND RECHARGE

These ideas can be easily added to your daily routine to help you relax and recharge.

1. Take 5–10 minutes every day to be quiet and breathe. You could stretch, gaze out the window, do a 5-minute meditation and listen to the sounds of nature.

2. While you are stopped at a stop light take your hands off the wheel for one moment and put them in your lap. Take 1 deep breath in and out and then be on your way.

3. Take breaks to truly stop and relax, rather than only “pausing.” Take a short walk or sit outside quietly.

4. Change your environment.
   Get up and go outside.

5. Take time to appreciate the warmth and water as you shower.

6. Hold and pet your cat for a few minutes or play outside with your dog.

7. Spend a few moments playing with your child or grandchild, or read them a book.

8. Watch a few funny online videos to get your funny bone working again. If you have more time, have a movie night with your loved one.

9. Escape into a chapter of a good book or a magazine (even if just for 15 minutes).

10. Turn up your favorite song and sing loudly in the car on the way to the grocery store.

At the end of the day, retrace the day and recognize your accomplishments. If you need to, make a list for tomorrow. You’ve done enough for today.
Getting enough sleep and exercise

Sleep and exercise might be things you’re not getting enough of right now. But they can have a big impact on how you’re feeling physically and emotionally.

If you aren’t sleeping well, you will have far less energy to do what you need to do each day, and you may have a harder time coping with your situation.

Here are 5 tips to help you sleep easier:

1. **Go to bed and wake up** at about the same time every day.
2. **Use the bedroom only to sleep.** Don’t eat or watch TV in bed.
3. **Make sure your room is comfortable,** like dark until the sun rises, a comfortable temperature and free from distracting noises. Try using a fan for background “white noise” or soft earplugs.
4. **Use relaxation techniques** like deep breathing or meditation to help you relax at bedtime.
5. **Don’t have caffeine, nicotine or alcohol** 4 to 6 hours before bedtime. That means limiting coffee, tea, soft drinks, beer and wine.

When it comes to exercise, even a little each day can help you:

- Relax your tense and aching muscles
- Prevent illness
- Give you more energy
- Improve your concentration
- Boost your mood

Not sure when you can find time to exercise? Here are some ideas you can try:

- Ask someone to fill in for you at home, and pick a regular time to go for a walk with a neighbor or friend
- Walk the dog an extra 5 or 10 minutes
- Instead of meeting a friend for coffee, suggest a walk
- Walk around your house during TV commercials
- If it’s okay with the doctor, take short walks outside with your loved one

You might be surprised how good it feels to get moving. Think of it as an opportunity instead of an inconvenience.
Everyone needs support when they are going through a difficult time. It’s okay to accept or ask for help. Remember, you would want to help your family and friends if they were in your situation.

Reach out to family and friends

Don’t hold back on letting family and friends know that you still need their help once you’ve returned home. If asking for help is hard for you, try to keep in mind that many people really want to help. Because they may be unsure on how to help, you could provide them with ideas on meaningful ways to get involved.

Keep a list of specific tasks you need help with, like:

• Meals
• Childcare
• Transportation
• Yard work
• Housework
• Grocery shopping

Post the list in your home where people can see it, and share it with friends, family, coworkers, your faith community or any other potential source of support.

I was so amazed at the network of friends willing to make dinner or give a ride to the doctor.”

—Jody, caregiver for her husband, Steve

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Getting help from others (continued)

Stay connected

With all you are trying to do, it can be easy to lose touch with family and friends when you need that support and connection the most. Maintaining your relationships with those who are important to you can help you feel less lonely and isolated.

Here are 5 simple ways to do just that:

1. **Walk it out.** Arrange a time with a friend to walk the neighborhood.
2. **Talk it out.** Invite a friend over after dinner for a chat.
3. **Schedule a phone date.** Arrange a regular time to connect. You’ll get through the day better when you know that you will connect with a friend later.
4. **Share the things that are bothering you.** Telling your concerns to someone can be the first step in identifying solutions.
5. **Declare a medical-free zone.** Agree not to talk about medical things. Give yourself a break!

Remember, it’s okay to be brief. Even if you only have 15 minutes to talk, still reach out. These activities can help you to relax, de-stress and recharge.

Even family and friends who don’t live nearby can offer support over the phone. And they can help you in other ways, too. For example, they might be able to raise money for your family to help cover costs not covered by insurance, like lost wages, travel and co-payments. They can find information on the rules for raising money at BeTheMatch.org/patient. In the search box, type “Fundraising”.

Get together with other caregivers

It can be helpful to get together with other caregivers. Caregivers can share what they’ve learned, suggest creative solutions to common problems and provide emotional support. A caregiver support group can also be a safe place to share fears and frustrations without feeling judged or misunderstood. Caregivers can understand what you’re experiencing in ways that other people might not.

Ask your transplant center if there’s a caregiver support group near you, or if they can refer you to another caregiver you could talk to one-on-one. You can also request a connection with another caregiver at BeTheMatch.org/peerconnect.

Find a respite caregiver program

Your county or other public agencies may have a respite caregiver program of trained volunteers who could stay with your loved one while you take some time for yourself. Ask your transplant center for information about respite caregiver programs in your county.

RESOURCES FOR YOU

Some caregivers find it helpful to organize a caregiving team. ShareTheCare.org offers one way to do so. You can also check out an online calendar tool for helpers at LotsaHelpingHands.com.
HELP OTHERS HELP YOU

When you ask your family or friends to do tasks for you, be ready and be specific. Here are some tips:

Don’t say

“Do you mind picking up a few groceries for me sometime?”

“Maybe you could watch the kids sometime.”

Do say

“Could you go the grocery store for me before this Friday? I can email you my list right now.”

“Next week we have several doctors’ appointments. Could you watch the kids next Friday afternoon from 2-4?”

Although it’s best to be specific, it’s also important to be flexible. So whenever possible, give people several choices on ways they can help.
Organizing your caregiver responsibilities

There can be so many things to do when you’re a transplant caregiver, you may not know where to begin. The following information can help you organize your responsibilities, which include:

- Being an advocate for your loved one
- Organizing health information
- Communicating with family and friends
- Following doctor’s instructions

Be an advocate for your loved one

Even if your loved one is a good advocate for themselves, they may need your help and support at times. The keys to being a good advocate are:

- Asking questions
- Talking to the transplant team
- Gathering information

Collect and organize health information

Doctor visits

- Write down and prioritize questions before visits
- Go to doctor visits with your loved one and take notes
- Ask if you can record the conversation so you can listen to it later
- Ask the doctors and nurses to explain test results and the purpose of medicines and other treatments

Medical information

- Keep a list of your loved one’s doctors. Share this list with all of their doctors.
- Ask for copies of medical reports, test results, etc.
- Use a calendar to write down appointments.
- Make a chart to help track medicines and doses. See the stories in Living Now Issue 1 on medicines to help you get started or talk to your pharmacist about ways to organize medicines.

Resources

- Ask your loved one’s doctors and nurses for more information—printed materials, DVDs, credible websites, etc.
- Join a caregivers’ support group online
- Contact organizations that help patients with the same disease to see what support and resources they could offer you and your loved one
Communicate with family and friends
If your loved one isn’t feeling well, you may need to talk with family and friends. Let them know what your loved one wants and needs.

Does your loved one:
• Want to see visitors or prefer time alone?
• Want to talk about what they have been through or prefer to talk about other things?
• Want to hear about other people’s daily activities or personal thoughts and feelings?

You can also explain to visitors how to help lower the risk of infection by making sure:
• People who are sick do not visit
• All visitors wash their hands when they enter your home

You may also want to update your family and friends about how you and your loved one are doing.

Updating family and friends shouldn’t be an overwhelming responsibility. You can send out group emails or use resources such as CaringBridge.org to let others know what is going on and what they can do to help. Using resources like CaringBridge® may also help you express your feelings, like a form of journaling.

Follow the doctor’s instructions
After transplant, it’s important that your loved one continues to work with the doctor to watch for complications and get treatment. This means following instructions the doctor gives, such as taking medicines as directed.

As a caregiver, make sure you understand what needs to be done. For example, some medicines need to be taken at exact times or they will not work as well. You can help keep track of medicines and be sure instructions are followed.

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CAREGIVER BILL OF RIGHTS

As a caregiver, I have the right to

- Take care of myself, to rest when I am tired, to eat well and to take breaks from caregiving when I need them.
- Recognize the limits of my own endurance and strength.
- Seek help from family, friends and the community at large.
- Socialize, to maintain my interests and to do the things I enjoy.
- Acknowledge my feelings, whether positive or negative, including frustration, anger and depression, and to express them constructively.
- Take pride in the valuable work that I do, and to applaud the courage and inventiveness it takes to meet the needs of my loved one.

Adapted from Ilardo & Rothman, I’ll Take Care of You: A Practical Guide for Family Caregivers
One phone call was all it took for Robin’s world to be turned upside down. Her mother, Gail, had just spent 2 weeks with Robin, helping the new mom and her husband, Kevin, take care of their newborn baby, Charlie. Then a few weeks later, they got the call that Gail was diagnosed with acute myeloid leukemia (AML).

After her first round of chemotherapy, Gail’s AML came back, and doctors said an allogeneic transplant would be her best treatment option. As Gail’s caregiver, Robin and her family faced many challenges, but also found positives along the way.

As told by Robin, caregiver for her mother, Gail

When my mom was diagnosed with AML, Charlie was just 7 weeks old. We went from the high of having a new baby and my mom being a nana for the first time to what we call ‘THE PHONE CALL.’

There was never any question that I would be my mom’s caregiver. I knew I would be there for her just as she’d been there for me. My mom moved in with us, and it wasn’t always easy. One of the biggest challenges was the shift in roles within our relationship.

We very much had the traditional parent/child relationship, and that changed overnight. It was really hard for both of us. It wasn’t easy for me to tell my mom, ‘No, you can’t do that.’ It was just as hard for her to ask me for help.

It was also hard for me to push her to do things sometimes. For example, my mom didn’t want to meet with a registered dietitian because it was ‘just one more appointment to go to.’ Nutrition after transplant is so important, and I struggled with all of the precautions you need to take, not to mention her changing tastes. When we finally met with the dietitian, I thought, ‘That would have been so helpful 6 months ago!’ I didn’t want to make my mom feel like a child by insisting we make the appointment, but it would have saved me so much time and frustration.

Throughout the transplant journey, Kevin kept reminding me to take care of myself so I could be the best mom for Charlie and the best caregiver for my mom. It was easier said than done. For a long time, taking care of myself was vegging out at the end of the day and watching a really bad reality show on TV! It took me a long time to be okay with that. Sometimes I felt like I’d failed because I wasn’t ‘making time for myself.’

Then, I realized that while I might not have been taking a yoga class, I was doing things for me. Spending an hour hanging out on the couch with my mom or lying on the floor with my son doing tummy time … that was awesome. Now I’m to the point where I can set aside time to go out with friends or exercise, but at the time I just couldn’t do it.

While the transplant journey hasn’t been easy, there have been many positives along the way. My husband and my mom have gotten very close, and it’s been fun to watch. I didn’t think it was possible, but my own relationship with my mom has gotten closer. Seeing what my mom has gone through has made me appreciate everyday things so much more.

As a caregiver, the journey ahead of you won’t be easy, and sometimes it may seem like there is nothing to be happy about. But, there is always hope. There is good that will come out of this. You might not see it today, but it will come.”

There is always hope
Your sense of self

As you care for your loved one throughout recovery, the following questions can help you be mindful of your thoughts, feelings and actions:

• How has my life changed—for better or for worse?
• What parts of my life have been on hold?
• What have I gained?
• What new goals would I like to set for myself?
• What steps can I take to begin working toward my goals?
• What can I do each day to take care of me?
• How can I balance my role as a caregiver with other parts of my life?

THE LIVING NOW SERIES

Each issue in the Living Now series addresses different aspects of life after transplant—from 3 months after transplant to 2 years and beyond. Each person’s experience is different. The articles in the magazine are not a timeline to measure your loved one against. They are a collection of observations, tips and resources designed to help make the most of life after transplant.

This newsletter is produced by Be The Match® Patient Support Center. The information is based on input from blood and marrow transplant experts and represents general principles and recommendations. It is not intended to replace, and should not replace, a doctor’s medical judgment or advice. Always consult with your loved one’s medical team regarding your specific situation.

Be The Match offers many free programs and resources to support patients, caregivers and family members before, during and after transplant. Connect with us in the way that works best for you.

ONLINE: BeTheMatch.org/caregiver
REQUEST INFORMATION: BeTheMatch.org/request
EMAIL: patientinfo@nmdp.org
SUBSCRIBE TO ENEWS: BeTheMatch.org/patient-enews
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Support for caregivers at every step

Our Peer Connect program can connect you with a trained volunteer who’s been there. No matter where you are in the transplant process, caregivers like you are available to talk by phone or email, sharing their experience and tips.
To request a connection, visit: BeTheMatch.org/peerconnect

The Be The Match® Patient Support Center provides support, information and resources for caregivers and families. We are here to help you get reliable, easy-to-understand information from diagnosis through recovery. Call or email us for confidential, one-on-one support from caring experts. We’ll listen and help you find answers. All of our programs and resources are free.

Our services include:
- Telephone counseling and one-on-one support
- Financial grants for patients
- Support groups and telephone workshops
- Caregiver support
- Tips for talking with your health care team
- Educational books, DVDs, newsletters and fact sheets
- Information and support in many languages

CONTACT THE PATIENT SUPPORT CENTER

CALL: 1 (888) 999-6743
Monday through Friday, 8 a.m. – 5 p.m. Central Time

EMAIL: patientinfo@nmdp.org

LEARN MORE: BeTheMatch.org/patient

ORDER RESOURCE MATERIALS: BeTheMatch.org/request

Every individual’s medical situation, transplant experience, and recovery is unique. You should always consult with your own transplant team or family doctor regarding your situation. This information is not intended to replace, and should not replace, a doctor’s medical judgment or advice.

About Be The Match®

For people with life-threatening blood disorders—like leukemia and lymphoma—or other diseases, a cure exists. Be The Match connects patients with their donor match for a life-saving blood or marrow transplant. People can be someone’s cure as a member of the Be The Match Registry, financial contributor or volunteer. Be The Match provides patients and their families one-on-one support, education, and guidance before, during and after transplant.

Be The Match is operated by the National Marrow Donor Program® (NMDP), a nonprofit organization that matches patients with donors, educates health care professionals and conducts research so more lives can be saved.

Learn more at BeTheMatch.org/patient or call 1 (888) 999-6743.