A GUIDE TO LIFE AFTER TRANSPLANT

- Your 1-year anniversary
- Going back to work or school
- Emotional highs and lows

Dan, transplant recipient, and his wife and caregiver, Deb
Recovery after transplant can be filled with ups and downs. But over time, you may find there is a certain rhythm to your recovery. As you start to feel better, you’ll be able to gradually get back to doing some of your old activities, take on more responsibilities and become more independent. Try not to rush your recovery and don’t ignore your transplant team’s instructions. Remember, eating well, exercising and doing things you enjoy can help you feel better.

This issue includes tips to help you:

- Prepare for your 1-year checkup
- Return to work or school
- Contact your donor
- Renew or buy health insurance
- Manage emotional highs and lows, and more

With low energy levels after transplant, it’s easier to rest and relax than to get back to normal activity. Sometimes just the thought of doing an activity is difficult. Leaving the house was very therapeutic. And exercise, no matter how little, improved my attitude. Trying to do a little more each day really helped.

—Dan, transplant recipient
Your 1-year anniversary

The first anniversary of your transplant is an important milestone in your recovery. It’s a time when you’re likely getting ready for your 1-year checkup with your transplant center. It can also be a time to look back, to reflect on all you’ve been through, and to look ahead and set goals for your future.

Moving around, getting stronger

Getting regular exercise can help you build your strength and endurance, fight fatigue (being tired), reduce pain and improve your quality of life.

If your doctor says it’s okay, you can set exercise goals like:

- Go for a walk every day. Increase your distance or time.
- Exercise with a friend.
- Do a variety of different activities, like riding a bike, lifting weights or doing yoga.

Eating well

Good nutrition is important to help you feel stronger, keep a healthy weight and stay healthy.

For example, getting enough calcium and vitamin D from your food or as a supplement may help protect against thinning bones.

But there are some foods, like grapefruit, that could interact with medicines you’re taking. Ask your transplant team if there are any foods, vitamins or supplements to avoid. And continue to eat a variety of healthy foods every day.

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If you have complications from transplant, such as GVHD, a clinical trial may offer a treatment option for you. The Jason Carter Clinical Trials Program helps patients and families find and join clinical trials.

To learn more visit JCCTP.org or call 1 (888) 814-8610.

Betsy, transplant recipient, with her husband and caregiver, Brian

To learn more visit JCCTP.org or call 1 (888) 814-8610.
Your 1-year anniversary
(continued)

Getting ready for your 1-year checkup

Your 1-year checkup at your transplant center is important for your recovery. Your doctor will check how well you’re doing overall and take care of any problems.

As you plan for your 1-year checkup you may have many different feelings. You might feel hopeful for good test results or worry about test results. Some people feel excited to see their doctors and nurses again. Others feel relieved when the checkup is over. All of these feelings are okay to have.

As you plan for your checkup, write down things that you want to talk to your doctors, nurses or social workers about.

Here are some suggestions to get you started:

- Concerns about side effects from medicines
- Managing graft-versus-host disease (GVHD) or watching for symptoms of GVHD
- Which vaccines you need and when
- Who you’ll see for future checkups
- If you need to make additional appointments with other doctors or specialists
- Concerns about depression, anxiety or PTSD (see story on page 12 for more information)
- Safety of complementary or integrative therapies, like taking a vitamin or getting acupuncture
- Concerns about sexual health
- Which exercises could be helpful

Now is a good time to talk to your transplant center to find out if they’ll be calling you to schedule your checkup, or if you need to make the appointment. If you’ve seen other doctors since your last appointment at your transplant center, ask your transplant center if they have copies of those medical records. Be sure to ask if they are sharing your medical records with your other doctors, too.

It’s also a good idea to have a family member or friend come with you to the appointment to take notes.
Free mobile app helps you manage your care after transplant

Even if you’re feeling well, regular checkups are very important to staying healthy. Our after-transplant care guidelines can help you get ready for your appointments.

Use our free mobile app to:

- Know what to expect at your checkups
- Help you watch for signs of chronic GVHD with a symptom checker
- Set reminders for appointments, taking medicines and exercising

Available in mobile app, online or print: BeTheMatch.org/careguide.

Free clinical guidelines are available for your doctor, too. Point them to: BeTheMatchClinical.org/guidelines.

RECOGNIZING MILESTONES

As you approach your first anniversary, setting goals, tracking your progress and honoring achievements can be motivating. When you reach a milestone, recognize it with a special activity with family and friends, or simply by reflecting on how far you’ve come and your resiliency.
Going back to work or school can be a big milestone on the road to recovery. You and your doctor or your child’s doctor will work together to decide when it’s okay to make this transition.

When you do head back to work or school, you or your child may feel a lot of emotions. Excitement about seeing friends or co-workers again. Nervousness about how people will react. Concern about “keeping up.”

Read on to learn about steps you can take before you go back to make the transition a little easier, and to make sure your rights are protected, too.

When you’re going back to work

Doctors usually suggest allogeneic transplant recipients wait to go back to work until at least 1 year after transplant. That’s because it can take 9 to 12 months for your immune system to recover. Some people may get their doctor’s okay to go back to work sooner, for others, it takes longer. You might also wait to go back because you don’t feel up to it physically. Or, your job may be physically demanding or put you at a higher risk for infection (like construction work or working with animals).

BEFORE YOU RETURN TO WORK:

- Contact your human resources (HR) department and talk to your supervisor, shop steward or union representative.
- Discuss any special needs and ask for any changes that would make it easier for you to keep your job (e.g., flexible hours, regularly scheduled breaks, working from home, or special equipment).
- Work out clear expectations about your schedule and work load.
- Keep a record of each request and the response.
- Consider asking your employer to tell your co-workers about your situation. Make sure you’re comfortable with the information and how they’ll share it.
- Talk to your HR department about your health insurance benefits. There are laws, including HIPAA and COBRA, which protect your health insurance benefits if you had health insurance before your leave.

When you return to work, you need to take your time. You don’t have to impress anyone. Give yourself permission to take it easy, and one day, you’ll begin to see that you’re accomplishing tasks in a very real and effective way.

-Herschel, transplant recipient

Remember, your health history can’t be used against you when you return to work or look for a new job. And, if you’re looking for a new job, companies can’t ask about your health history and you aren’t required to tell them about it unless you choose to do so.

When it comes to your Social Security benefits:

- Talk to your Social Security plan administrator about how returning to work may affect your benefits.
- Look into the resources through the Social Security Administration (SSA) that could help you get back to work, like a trial work period. A trial work period lets you test your ability to work and still get Social Security benefits for up to 9 months, with more help after the trial period if needed.
- To learn more go to ssa.gov/disability or call (800) 772-1213.
**When your child is going back to school**

There are things you can do both before and after your child returns to school to help make it a smoother transition:

- Ask about resources, accommodations and services available to help your child. By law, your child’s school might be required to provide some of these.
- Form a support team to help your child, including doctors, child life specialists, teachers, guidance counselors and the principal. Meet with them before your child goes back to school.
- Create a list of your child’s medicines and talk to the team about them. If the medicines affect your child’s mood or behavior, work with the team on a plan for dealing with these issues.
- Explain the plans to your child so there are no surprises. If your child is old enough, involve your child in the planning.

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**GETTING YOUR CHILD HELP AT SCHOOL**

As you’re planning for your child’s return to school, you may want to ask about special services such as:

- More time to complete assignments and fewer homework demands
- Help organizing materials
- Being able to use calculators and recorders

For children in kindergarten through grade 12, these special services are typically part of an Individual Education Program (IEP) or 504 Plan. You can learn more about the IEP and 504 Plan process in our special Living Now issue for Parents, available at BeTheMatch.org/patient-after.

Many schools do a good job meeting students’ needs and making accommodations to help them succeed. But if you think your child isn’t getting support, there are several things you can do:

- Bring your concerns from the teacher to the principal or the superintendent, if needed.
- Request other resources—such as tutors—to help your child.
- Learn more about your child’s educational rights. Consult with an attorney who specializes in education.
- Change schools or home school your child.

To learn more about special educations services, including IEPs, go to ed.gov/parents.

**RESOURCES FOR YOU**

Cancer And Careers provides tips and resources for people going back to work (and looking for work) after cancer treatment. Learn more at CancerAndCareers.org.

The American Childhood Cancer Organization offers a booklet for parents and teachers called *Educating the Child with Cancer: A Guide for Parents and Teachers*. Find it at acco.org.

LD Online offers resources for parents wanting to learn more about the IEP process. Learn more at LDonline.org/indepth/iep.
Going back to work or school (continued)

Stay involved even when your child is back in school. Your child might not want special accommodations for fear of not fitting in. But it can be just as frustrating if your child feels overwhelmed.

If you think there are issues at school, talk to the teachers and principal right away. Remember, you are your child’s advocate. Insist on what’s right for your child.

—I was getting really tired at school so we switched to a half load. I went to the first 2 classes of the day and then went home. I usually took a nap, ate something and would do the homework for those 2 classes. Then I had a tutor who would come around 3 o’clock to get me caught up.

—Joe, transplant recipient

When you’re going back to college

If you’re going back to college, you may or may not be ready to take on a full class load when you go back, and that’s okay. You need to ease back into things just like people who are going back to work.

Before you start your next college semester:

• Meet with the school’s disabilities office or academic support center to learn about the resources available to help you.

• If you’ve already decided on your major, meet with a senior academic advisor in that area and ask for their support. They may be able to give you advice, and be your advocate if needed.

• Talk with each of your professors before classes start for the semester or soon after. Work with them to set reasonable accommodations for completing your work.

Be The Match can help you find resources to help with the transition back to work or school. Contact our BMT patient navigators at patientinfo@nmdp.org or 1 (888) 999-6743.

Get more tips for helping your child return to school. Go to the Transplant for Children and Teens section of BeTheMatch.org/patient. Then, go to Going back to school.
Many patients wonder about their donor and want to connect after having an allogeneic unrelated donor transplant. And many donors like to hear how you’re doing after transplant. This is a very personal choice for both you and your donor.

If you do want to connect, start by talking to your transplant center coordinator. Contact between you and your donor will depend on Be The Match confidentiality policies. If your donor lives outside the U.S., contact will also depend on the donor’s registry and its policies. Your transplant center coordinator can let you know the specific policies that apply to you and your donor.

Here is some general information to keep in mind:

• In most cases, during the first year after transplant you and your donor can have anonymous communication, such as letters, cards and an inexpensive gift.

• If both you and your donor agree, registries in some countries allow direct contact between recipient and donor after a certain amount of time has passed. The waiting period for direct contact is different by registry, which follows the laws of their country. It will be at least 1 year, but may be 2 years or more. However, some do not allow any direct contact between recipients and donors.

• Cord blood donations will always remain anonymous. That means if you had a cord blood transplant, you won’t be able to have any contact with your donor.

Having a transplant and being a volunteer donor are personal and often emotional experiences. For many reasons, you or your donor may choose to not have contact with each other. That’s okay. You and your donor have the same rights to privacy.

Whether or not you are able to connect, rest assured that your donor knows his or her donation is valued and appreciated.

Thank you for giving us back the future we have hoped and dreamed and planned for! I hope one day we can meet, but for now, sweet angel, I hope you are happy and proud, and peaceful and loved.

—Part of the anonymous letter written by Janet and Ron, 4 months after their daughter Ava’s transplant

Ava, transplant recipient, and her donor, Michelle

Talk to your transplant center team to learn more about contacting your donor.

More information about Be The Match confidentiality policies is also available at BeTheMatch.org/patient in the section on Life after transplant.
When you’re renewing or buying health insurance, there are new things to consider now that you’re on the road to recovery. And, sometimes it can be hard to know where to start. The information in the box to the left can help you get started.

Remember, your insurance coverage can change from year to year—especially your provider network and prescription drug formulary. So be sure you review this information every year before you enroll again.

To help you plan financially, be sure to learn about and understand your:

- **Monthly premium**: This is the amount you pay each month to your insurance company for your health insurance policy.

- **Deductible**: This is the amount you pay for health care services (such as treatments or office visits) before your health insurance begins to pay.

  — For example, if you have a $5,000 deductible, you must pay $5,000 for covered health care services before your health insurance company starts paying for any of your covered care.

  — The deductible re-sets every year. So if you reach your deductible in October, your health insurance company will help cover costs through December. Then, in January, you have to reach your deductible again before your health insurance company will share costs again.

- **Co-insurance**: This is the percent of health care costs that you pay after your deductible is met, such as 20% of the charge for an office visit.

- **Co-payments (co-pay)**: This is a fixed amount you pay after your deductible is met, such as $20 for an office visit.

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**A GOOD FIRST STEP IS TO LOOK AT THE HEALTH INSURANCE POLICY AND CHECK THE:**

- **Summary of benefits**, which gives an overview of your coverage
- **Certificate of coverage**, which has more details about your plan
- **Prescription drug formulary**, which tells you which medicines are covered, how much your insurance company will pay and how much you will pay

Find out if your insurance plan will cover your:

- Appointments with your transplant doctor, hematologist/oncologist, primary care doctor and other specialists you see
- Hospital stays at your local hospital or your transplant center
- Blood tests, imaging tests (like PET or CT scans), and emergency room visits
- Prescription medicines at your local, specialty or mail-order pharmacy

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Gloria, transplant recipient, and her caregiver, Jeff
If you buy your own health insurance, review your options carefully. Alicia Silver, MPP, a Health Economics and Policy Supervisor at Be The Match, cautions, “Be sure to look at all of the costs you’ll have to pay.” There are plans that have low monthly premiums, but they often come with a high deductible and pay less for your care after you meet your deductible. This means that an insurance plan with a lower monthly payment could cost you more each year.

“When choosing your deductible level, make sure that you have enough money to pay that cost,” Alicia adds. “All of your medical costs will be your responsibility to pay until you’ve met that deductible. So, look at your financial situation before choosing a plan.”

Be The Match BMT patient navigators can talk with you about your situation and help you find the resources that best fit your needs. Talk with a BMT patient navigator by calling 1 (888) 999-6743 or email patientinfo@nmdp.org.

RESOURCES FOR YOU

If you’re buying your own health insurance, the best place to start is healthcare.gov. You can see all of your options and compare plans side-by-side to decide which plan is the best option for you.

CancerInsuranceChecklist.org has useful tools that can help you organize treatments, costs and other pieces of your care that you need to think about when buying or renewing insurance.

CMS.gov offers a glossary of commonly used health insurance terms. Enter the search term “uniform glossary.”

Survivorship Webcasts

View educational presentations on survivorship topics like GVHD, after-transplant care guidelines and healthy living.

BeTheMatch.org/patient-after

FINANCIAL SUPPORT FOR PATIENTS AFTER TRANSPLANT

Even when you have health insurance, the ongoing medical costs after transplant can add up. Be The Match offers grants that can help cover the costs of:

- Medicines
- Co-pays
- Groceries
- Other ongoing transplant-related costs

Your transplant center social worker can help you find and apply for these and other grants you may be eligible for.

Along with your transplant center social worker, BeTheMatch.org/PartnerResources is a resource to connect you and your family with financial support and information from organizations you can trust.

Remember, the medicines you take after transplant and your follow-up appointments are very important to your health and recovery. If you ever have trouble paying for any of them, let your doctor or social worker know right away. There is help available.

To learn more about Be The Match financial grants for patients after transplant, visit: BeTheMatch.org/financial-grants.
Whether you or your loved one had a transplant, you’ve been through a lot. Even if you were very upbeat throughout treatment and recovery, it’s normal to sometimes feel down or worried after transplant. At the same time, you may also find meaning and personal growth from your experience.

Emotional highs and lows after transplant happen. But when feelings of anxiety, worry or feeling down won’t go away or get in the way of activities of everyday life, it’s time to ask for help. You can’t just “shake off” depression or anxiety. But both are very treatable.

Recognizing anxiety and depression

Symptoms of anxiety include feeling worried, fear or dread. Some of the symptoms of depression include:

- Feeling sad, irritable or an “empty” mood that won’t go away
- Sleeping more or less than usual or not being able to sleep
- Not being interested or finding pleasure in activities you used to enjoy, including sex
- Having trouble concentrating, remembering or making decisions
- Feeling guilty, hopeless, helpless or worthless
- Thoughts of hurting or killing yourself

If you’ve had any of these 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. Your doctor might suggest a prescription medicine, talking to a therapist or both. Ask to see a therapist or counselor who has experience helping people who are recovering from a life-threatening illness or caregivers.

If you are having thoughts of hurting yourself or others, get help immediately. Call the National Suicide Prevention Lifeline at (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 hospital emergency department (ER).
Recognizing PTSD

Sometimes the anxiety is so intense after going through a very difficult experience that post-traumatic stress disorder, or PTSD, develops. If untreated, PTSD may affect your relationships and your ability to function at home, school or work.

Some of the symptoms of PTSD include:

- Bad dreams
- Scary thoughts
- Reliving your experience over and over
- Feeling emotionally numb, guilty, depressed or worried
- Feeling easily startled, tense or “on edge”

These symptoms may come early in your recovery or later on. If any of these symptoms last more than a few weeks, they might be PTSD. Tell your doctor about your symptoms.

Many people with PTSD get better with medicines, counseling and/or group therapy.

Finding meaning

Even if you’re overcoming depression or anxiety, you may experience personal growth from all you’ve been through. Growth and meaning after transplant can come in many different ways.

Brian, a caregiver, dealt with feelings of uncertainty and helplessness as he helped his wife through the difficult times after transplant. But, their family found positives along the way. “We had a lot to celebrate, and made a point of acknowledging every milestone we could,” he says.

Reflecting on your transplant journey and how it has affected you can help you grow from the experience and find meaning.

STARTING THE CONVERSATION ABOUT ANXIETY OR DEPRESSION

If you think you’re depressed or have anxiety, or you’re concerned about a loved one, it can sometimes be hard to talk about it. Try these tips to get the conversation started.

With your doctor:

- “I haven’t been feeling like myself lately. I’m concerned that I’m depressed or overly anxious.”
- “What do you recommend so I don’t feel like this all of the time?”
- “My friend told me she’s worried about me. She wondered if I was depressed.”

With a loved one:

- “You don’t seem like yourself. How are you feeling?”
- “I’m worried I might have depression or anxiety. Do you think talking to a doctor could help?”
- “It’s okay to ask for help. Your doctor would want to know about these feelings you are having so she can help you.”
- “I’d like to help you get treatment. Would you like me to be with you when you make an appointment with your doctor?”
There is life after transplant!

From a sailboat in Puget Sound to a hospital bed; from stomping through the jungles of Cambodia to receiving chemotherapy. Kristina defined herself by her zest for adventure and travel. Then she was diagnosed with myelodysplastic syndrome (MDS), a rare disease that was discovered by chance, with no symptoms. Her disease quickly turned into acute myeloid leukemia (AML) and doctors told her she needed a transplant as soon as possible.

Luckily, Kristina found a matching donor and had a transplant soon after diagnosis. But as she would find, this was just the beginning of recovering her fiercely independent sense of self and an active lifestyle.

As told by Kristina, transplant recipient

Cancer wasn’t ever supposed to happen to me. I was attracted to living life on the edge and suddenly, I was told I was dying. Did they know who they were talking to? Maybe it was the New Yorker in me, but there was no way this was getting me down.

Going into treatment, I knew I wouldn’t be able to be the individual I have always been or lead the lifestyle I was so passionate about. I knew I had to accept the transition and take my recovery one day at a time. Simplifying my perspective helped me make it through that time in my life. Just as I had packed my backpack for countless trips, I decided to pack my emotional backpack and get through it. The sun will always rise again in the morning and set the next day.

After transplant, the biggest thing for me was getting back my quality of life. I knew I would get there no matter what. Though my recovery went well, I had a flare-up that was a devastating setback. I developed graft-versus-host disease (GVHD) and spent so much time on the couch watching TV that it scared me. It made me realize how easy it was to curl up in a ball every day, how easy it would be to slip into feelings of self-pity.

As post-transplant survivors, we have to drag ourselves out of it. It took a lot of self-motivation. The initial step of recovery is to just get moving. It sounds cliché to say, ‘just get up,’ but it’s true. Whether you do this alone, with a caregiver or through a program, little steps make a big impact.

I joined Team Survivor Northwest, an organization that provides fitness programs for women cancer survivors, and attended every class to help regain my quality of life. I succeeded in getting stronger and bonding with other women whose lives were affected by cancer. My ‘new normal’ included my mindset, physical changes, how people reacted to me and my emotional well-being. And while I experienced many changes and realized new things about myself, I was able to get back the part of my life that I loved.

It’s amazing to live through such an experience. Look at what we, as transplant recipients, have done already! If we can beat a disease, we can get through the recovery as well.
Your sense of self

You may feel like you’re balancing the life and person you know now and who you were before your disease. Think about the emotional, physical, spiritual and social changes you’ve experienced and use these changes to assess your sense of self. Ask:

• In what ways have I remained the same? In what ways have I become someone new?
• What have I gained and what have I lost through my experience?
• What can I do now to help me adjust my expectations and goals? What can I do to help my family accept these changes?
Peer Connect Program

Hardly anyone understands what this process means and all the medical procedures unless you’ve been through it yourself. When you meet someone who’s traveled your path, you bond and connect with every word.

—Transplant recipient

Talk with someone who’s been there

• “How soon will I be able to do the things I used to do?”
• “What will it be like when I go back to work after being gone so long?”
• “As a caregiver, how do I ask for help?”

If you’ve had these questions, and many more, you’re not alone. After transplant, sometimes you just need to talk to someone who’s been there.

Our Peer Connect program can help. We’ll put you in touch with one of our trained volunteers—who are transplant recipients and caregivers—to answer your questions and share tips from their own transplant experience.

Peer volunteers are available to talk by phone or email.

To request a connection, visit BeTheMatch.org/peerconnect

About Be The Match*

For people with life-threatening blood cancers—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.