

Living **now**

A guide to life after transplant

Issue 5: 18–24 Months



Adjusting to the
“new normal”



On the cover: Danielle, transplant recipient, with her son, Jaylen

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Welcome to *Living Now*

This newsletter is the fifth of six issues produced by Be The Match® patient services. Each issue addresses various aspects of life after transplant, from three months post transplant, to two years and beyond. Every person's experience is unique. This is not a timeline against which to measure yourself. This collection of observations, tips and resources is designed to help you make the most of living now.

Be The Match offers free educational resources, confidential one-on-one support and financial guidance to support patients, families and caregivers, before, during and after transplant. We can help you learn more about transplant as a treatment option, plan for a transplant and learn what to expect after transplant.

Note: Information in this newsletter is based on input from marrow and cord blood transplant experts and represents general principles and recommendations. This information is not intended to replace, and should not replace, your doctor's medical judgment or advice. Always consult your own medical team regarding your specific situation.

Information for caregivers

A special caregiver issue of *Living Now* is available for spouses, partners, parents or anyone else who helps care for a loved one after transplant. It includes valuable information and resources on self-care, getting help from family and friends, finding emotional support and more. If you have not received a copy, you may order it online from BeTheMatch.org/patient (click on Order Materials), or by calling 1 (888) 999-6743. Caregiving information is also available online at BeTheMatch.org/patient (click on Caregiving).

To unsubscribe

We make every effort to keep our mailing list current. If you have received this newsletter in error, or do not wish to receive future issues, you may unsubscribe by calling 1 (888) 999-6743 or e-mailing patientinfo@nmdp.org.

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Moving forward

Now that you've passed your one-year milestone, many of the difficult parts of your transplant experience may be behind you. Your medical concerns may be more chronic and less urgent. As you continue to adjust to your "new normal" you may be won-

dering what lies ahead. At this point in recovery many recipients begin to shift from looking back at how things were to planning for the future.

This issue addresses ongoing self-care, strategies for dealing with changes to memory and concentration, tips for healthy relationships and more. ■

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During transplant, you have a mindset of "if" as in, "if my counts are good." After transplant, your lifestyle shifts from "if" to "when." The planning of vacation or planning of college changes from a thought to an action."

—Danielle, transplant recipient



Danielle, transplant recipient, with her family

► Don't let your guard down

Maintaining your health



José, transplant recipient, with his doctor

It's important to follow your transplant doctor's recommendations carefully, even if you feel healthy.

Stay on your medications

Taking your prescriptions exactly as directed can be critical to your health.

If side effects from your medication make you want to stop taking it, talk

to your doctor about options. Never stop or change a medication without consulting your doctor. It could be very dangerous.

If the cost of your prescription is a problem, contact your transplant center or Be The Match patient services for information or referrals to financial support and assistance.

Keep doctors appointments and get tested as needed

It is often easier to treat problems when they are detected early. The recommended care guidelines noted at the right are available to monitor for problems that may occur after transplant. It is possible that you will never experience any of these problems, or experience only a few.

In addition to transplant-specific testing, you should also continue to see your doctor to receive the same tests recommended for the general public:

- High blood pressure
- High cholesterol
- Diabetes
- Colon cancer
- Prostate cancer (men)
- Breast and cervical cancer (women)
- Sexually transmitted diseases
- Osteoporosis (women)

Details for these guidelines can be found at the U.S. Department of Health and Human Services' site, [hhs.gov](https://www.hhs.gov)

To further support your health and healing after transplant, follow the same health guidelines recommended to the general public:

- Eat a healthy diet
- Be physically active
- Maintain a healthy weight
- Wear sunscreen
- Avoid excessive sun exposure
- Discuss all medications with your doctor, including herbal supplements or alternative remedies you may be considering
- Use seat belts
- Wear helmets and other safety equipment when riding a motorcycle, bike, or playing sports
- Don't use tobacco
- Don't use illegal drugs
- Avoid second-hand smoke
- Avoid alcohol or use in moderation, usually fewer than two drinks per day ■

Recommended post-transplant care

Some side effects might not show up for months or even years after transplant. *Allogeneic Transplant: A Guide to Protecting your Health After Transplant* lists tests to help detect post-transplant problems at six months, at one year, and yearly, thereafter. It also lists medicines you may need to take to help prevent problems from occurring. The guidelines are a publication from the Center for International Blood and Marrow Transplant Research (CIBMTR) and the NMDP.

Download at:
[BeTheMatch.org/yourhealth](https://www.BetheMatch.org/yourhealth)

Returning to work

Returning to work may require a period of trial and error as you test your abilities and ease back into a regular work schedule.

It's important to stay on disability while you transition back to work. Social Security Disability Insurance (SSDI) allows for a trial work period that lets you test your ability to work for at least nine months. During the trial work period, you continue to receive your full disability benefit. The nine months do not need to be consecutive. If your disability benefits stop after successfully completing the trial work period because you achieved the earning limits, Social Security can automatically reinstate your benefits without a new application for any months your earnings drop below that earning limit.

For more information on Social Security benefits, visit [ssa.gov/disability](https://www.ssa.gov/disability).



Herschel, transplant recipient

Traveling after transplant

Whether you are planning an elaborate vacation or just a weekend away, visiting new places and experiences can be fun and exciting. To get the most enjoyment out of traveling after a transplant, there are a few things to keep in mind.

Check with your transplant doctor

Share any travel plans with your doctor. Make sure that your doctor is comfort-

able that you are healthy enough to travel and ask if there are any precautions you should take while you're away from home.

Carry a summary of your medical condition and treatment plan

For international travel, consider translating your medical summary into the language of the country you'll be visiting, and find out where the nearest hospital is in case of an emergency.

Vaccination requirements

If planning a trip overseas, find out which vaccinations or precautionary medications might be required. Check with your doctor to make sure you can meet the requirements and remember to carry your vaccination records.

Traveling with medications

If flying, pack essential medicines and supplies as carry-on luggage and keep it with you. Consider bringing extra in case medication is lost. Carry copies of prescriptions, medical treatment and insurance information.

If you have medicines that need to be kept cool, get small cold gel packs from your pharmacist. Make sure there is a convenient and secure refrigerator you can use at your destination.

If you carry pain medication—especially opiates—make sure you understand any legal restrictions that might

apply, particularly if you are traveling to another country.

Have fun, but play it safe

It's natural to want to do and see everything, but it's important to be realistic about your energy level and physical ability when planning activities. Make sure to build in time to rest and relax so you don't over exert yourself.

You may be tempted to let your guard down and "just have fun," but you should follow your regular precautions as much as you can. Take your medications on schedule, eat and drink according to your doctor's recommendations and protect yourself from the sun and bug bites. If you are immune compromised, avoid dirty or crowded locations as well as lakes, pools and hot tubs.

Ask a traveling companion to support you in making good choices so you can have fun without taking unnecessary risks with your health. ■

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I was able to travel to Europe, Mexico and Hawaii, and experience fascinating cultures, cities and foods.

To experience and live life and everything that comes with it—the good and the bad—all this I wouldn't trade for the world.”

—Valerie, transplant recipient



Valerie, transplant recipient

► Managing relationships

Reconnecting with your partner



Everett, transplant recipient, and his wife Jeanette

The emotional stress of illness and recovery affects both survivors and caregivers. It can change how people feel about themselves, each other, and their relationship. Some people develop a deeper appreciation for each other and their bond gets even stronger. Others become frustrated or depressed about the changes in their relationship. Both partners might feel the same way, or they might see their relationship differently. A survivor might report a happy marriage, but his or her caregiver spouse might be unhappy. A caregiver might be looking forward to “getting back to normal,” but the survivor part-

ner might have a different vision for the future, based on new priorities.

Good communication is essential to a healthy relationship. Resolve conflicts and strengthen your connection by sharing your feelings with honesty and compassion. Stay positive by focusing on how you’d like things to be. Avoid blame by focusing on your own feelings and actions you can take.

Sexual health

Many transplant survivors have some sexual problems, such as loss of interest in sex, or pain, or sexual dysfunction. These side effects can be temporary.

“It’s important for couples to talk about all the changes they’ve been through, how they feel about it, how it affects their priorities and plans for the future.”

—Susan Francis,
Patient Services Coordinator, Be The Match

Learning to cope with these changes is an important part of recovery.

If talking about sexual health is difficult for you, remember that most doctors and clinical nurse specialists are used to answering questions about this subject.

Seek help

Support groups can be safe places to discuss relationship concerns with people who understand.

A professional counselor or therapist can help facilitate difficult conversations, identify issues and suggest problem-solving strategies. ■

Issues to consider, topics to discuss

- How is your communication? Has it changed?
- Do you feel like your partner understands you?
- Do you feel emotionally close, or distant?
- How do you manage conflict?
- Do you share the same expectations about recovery?
- Do you share the same priorities?
- Do you share the same goals for the future?
- Have your roles changed? How do you feel about that?
- How have physical or emotional changes affected your relationship?
- How do you feel about your sexual intimacy? How might you want it to change?

For more information on sexual health after transplant, see Living Now #2, or visit [BeTheMatch.org/relationships](https://www.bethematch.org/relationships)

Parenting and discipline



Murray, transplant recipient, with his mother, Jill

Disciplining a child who has been seriously ill can be one of the most difficult aspects of parenting. It can be hard for parents to enforce rules when they think about everything their child has been through. But children depend on their parents and other adults to teach them appropriate behavior. Setting clear expectations—and consequences—can be reassuring for your child. It shows that you expect them to grow and develop and behave just the same as any other child.

Understand what causes poor behavior

Stress, pain, and certain medications can all cause undesirable behavior. Acting out is often a sign of frustration and discomfort. Steroids can cause anger and aggressiveness that can be difficult or impossible for your child to control. In these situations, your child needs your guidance and support as well as clear limits.

Changes in how you relate to your child can also affect mood and behavior. It can be hard for a child who has gotten used to receiving special attention to return to a more typical routine.

Be a positive role model

Children learn coping skills from their parents. Demonstrate the behaviors you expect from your child. Talk respectfully, discuss your feelings honestly, take time outs when you need to and apologize when you have been wrong. Use and discuss the techniques you use to manage your feelings and behavior.

Set clear rules and appropriate expectations

Consider writing and displaying “house rules” that apply to everyone. Let children help develop the rules and consequences. Set age-appropriate limits and be consistent in enforcing consequences. Common rules might include cleaning up after yourself, treating each other respectfully, no hitting, name-calling, throwing things, etc. Make sure that rules are appropriate and realistic. Rules like “no crying” or “no arguing” would not be appropriate.

Help children understand their feelings

Talk about feelings. Acknowledge and validate them. Let your child know that everyone has all kinds of emotions and that is OK. Explain that there are ways to deal with your feelings so they don't control your behavior. Help them understand that they are not allowed to be hurtful or destructive. Help them find other ways to express strong feelings.

Offer options

Loss of control contributes to anger and frustration. Give children age-appropriate options as often as you can. Having choices helps improve decision making skills and provides opportunities to feel more in control.

Develop coping strategies

Explore a variety of acceptable ways for your child to express and release anger and frustration, like expressing feelings through words, art, physical activity or calming exercises.

Enforce consequences

Establish clear consequences for violation of the rules. Make sure the severity of the consequence matches the severity of the violation. Time outs can be very effective for younger children. Loss of privileges works well with older children. Don't make empty or exaggerated threats or you won't be taken seriously. Be as consistent as possible with enforcement of the rules. Consistency contributes to an overall sense of stability, trust, safety and comfort.

Praise good behavior

Reinforce positive behavior with praise and attention. Reassure your child that you love him or her unconditionally. Provide plenty of hugs and physical affection.

Get professional help

For emotional and behavior problems that are serious and ongoing, ask your child's physician, nurse or social worker to recommend a mental health care professional. ■

“There were many times when we were unsure how Murray was going to pull through, so we tended to spoil him. Later, when he was feeling better, he could be difficult to discipline, especially while he was on steroids. He was easily upset and he'd get so mad—say bad words and even become violent! Our coping mechanism was to give him lots of hugs and love and just hold him. He is extremely loving since all of this.”

—Jill, Murray's mom



Murray, transplant recipient

tips for memory and concentration



Jodi, transplant recipient

Many survivors say that they don't seem to be able to think as clearly as they did before treatment. They report trouble remembering names and conversations, being unable to recall words, or following multiple-step instructions. Some people report that it takes longer to complete tasks.

Many people who experience these problems fear that it might get worse, like Alzheimer's disease. Fortunately, that is not the case. A few specific cognitive functions might be affected, but these difficulties are not always permanent and can improve over time.

Family and friends might dismiss your difficulties, blaming it on being tired, distracted or under stress. They might think they are being reassuring, but it can be frustrating if your concerns are not taken seriously. People might also misinterpret your forgetfulness or confusion as laziness, uninterest or hostility.

It can help to educate friends and family members about memory and concentration issues so you can work together to identify the problem and find solutions.

Possible causes

Radiation and chemotherapy can affect memory, concentration, organizational skills and more. The medical term for this syndrome is "cancer-therapy associated cognitive change," but it is commonly called "chemo brain." The cause is not yet well understood, and may not necessarily be associated with chemotherapy. Other causes might include medications, depression or anxiety, and hormonal shifts.

Define the problem

Make a list of specific difficulties you have experienced. Ask people close to you to share their concerns and obser-

ventions. Look for patterns. What tasks are most difficult? What factors make a situation easier or more difficult? Understanding the problem makes it easier to identify causes and contributing factors.

Coping tips

If you have memory and concentration problems, talk to your doctor. You might be referred to a specialist for additional testing or for help developing an individualized coping plan.

Below are general tips for dealing with memory and concentration problems.

Use memory aids

- Use a calendar or daily planner to schedule your days
- Carry a small notebook or electronic organizer with you
- Use a bulletin board or dry erase board to post large reminders
- Post small reminders where you need them – on the phone, in the kitchen, on the front door, etc.
- Bring someone with you to appointments to help listen, ask questions and take notes

Simplify

- List things you would like to get done and choose those that are most important to you
- Write yourself simple, step-by-step directions for tasks that are difficult
- Ask for help making plans or decisions, even if it's just to review and confirm your plans

Reduce stress

- Stress can make it harder to think clearly. Find ways to relax. Exercise and relaxation techniques like yoga, meditation and guided visualization can help reduce stress
- Eat well and get adequate sleep

Stay safe

- Avoid multitasking when it could prove dangerous, as when driving, cooking or watching children ■

Post-transplant support & resources

One of the most important things to remember throughout the recovery process is that you are not alone. **Be The Match**[®] is dedicated to supporting patients, caregivers and families. We offer you confidential one-on-one support, financial guidance and free educational resources. We're here for you.

Call: 1 (888) 999-6743 **Learn:** BeTheMatch.org/patient

Order: BeTheMatch.org/request **Email:** patientinfo@nmdp.org

In addition to the national organizations below, you can also explore local community resources or online communities. Ask if your transplant center offers a buddy program that can connect you with other transplant recipients or caregivers interested in sharing their experiences and seeking solutions.

Beyond the Cure

A program of the National Children's Cancer Society, the mission of Beyond the Cure is to help childhood cancer survivors integrate the cancer experience into their new life as survivors, successfully handle the challenges that are ahead of them and to celebrate survivorship.

Web site: beyondthecure.org

CancerCare

CancerCare is dedicated to helping people face the many challenges of a cancer diagnosis. Through counseling, education, information and referral, and direct financial assistance, free professional help is provided to help people with all cancers.

Web site: cancercares.org

Cancer Support Community

Men, women and children with cancer and their families and friends can join with others to build social and emotional support as a supplement to medical care.

Web site: CancerSupportCommunity.org

National Coalition for Cancer Survivorship

NCCS advocates for quality cancer care and provides tools that empower people affected by cancer to advocate for themselves. Resources include the award-winning Cancer Survival Toolbox[®], a self-learning audio program created by leading cancer organizations to help people develop essential skills to meet the challenges of their illness.

Web site: canceradvocacy.org

Supersibs!

Supersibs! is a national not-for-profit organization that serves to honor, support and recognize the brothers and sisters of children with cancer. Supersibs! provides free, ongoing services to children between the ages of 4 and 18, who reside in the United States and Canada, and who had (or have) a brother or sister with cancer.

Web site: supersibs.org

Find more resources with ExploreBMT[™]

To find trusted resources from other organizations that can help you in your situation, visit ExploreBMT.org. ExploreBMT is a one-stop resource for patients, families and caregivers impacted by a disease treatable by a blood and marrow transplant. This easy-to-search online tool provides direct access to information about blood and marrow transplantation from many patient-focused organizations.

Living Now e-newsletter:

Staying connected after transplant just got easier



This free e-newsletter is designed just for transplant recipients and their families.

- **Hear stories** and experiences from others.
- Be the first to know about **new resources** and research.
- Get **tips and ideas** for healthy living after transplant.
- **Share** your experiences.

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Adjusting to the “new normal”

Invitation to submit stories

Do you have tips or information about your post-transplant experience that you would like to share with other patients? If so, please contact us at: mystory@nmdp.org or 1 (888) 999-6743.



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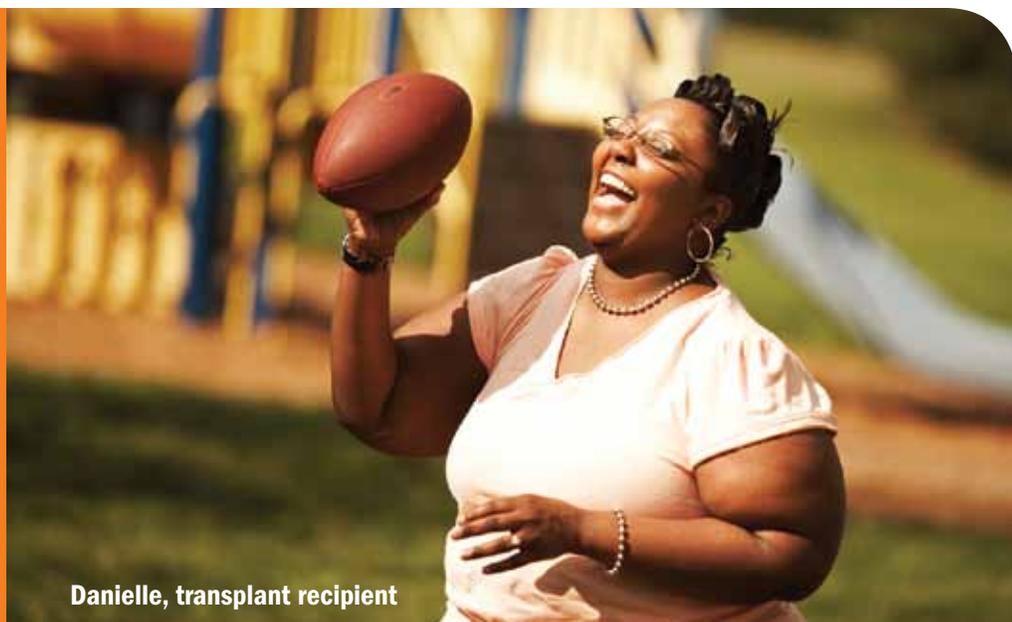
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Danielle, transplant recipient