

Living **now**

A guide to life after transplant

Issue 4: 12–18 months



Taking stock, looking forward



On the cover: Brent, transplant recipient with his wife Heather and daughter Madeline

Contents

Issue 4: 12–18 months



Late complications
page 4



Overcoming fear
page 6



Recognizing depression
page 8



Complementary and alternative medicine
page 10

Welcome to *Living Now*

This newsletter is the fourth 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.

Oversight of medical content provided by:

Dennis Confer, M.D., chief medical officer,
National Marrow Donor Program

Willis Navarro, M.D., medical director,
National Marrow Donor Program

Mary Horowitz, M.D., M.S., scientific director,
Center for International Blood and Marrow Transplant Research

J. Douglas Rizzo, M.D., M.S., associate scientific director,
Center for International Blood and Marrow Transplant Research

One year and beyond:

Taking stock and looking forward

However challenging your journey has been, you can celebrate having achieved and passed the one-year milestone. It is a good time to take stock of how far you have come — physically and emotionally.

Some survivors report that their quality of life after transplant is similar or even better than their life before. Others have to learn to cope with lingering or ongoing side effects of treatment. A smaller number find the quality of their lives compromised in significant ways. Whatever your recovery has been like, it is certain that the experience has changed you. ■

“

The challenges we face as survivors of this experience will be a benefit in our lives and the lives of others. Keep taking the next steps forward and upward! I am getting there and won't ever quit!”

—**Brent, transplant recipient**



Brent, transplant recipient, with his daughter Madeline

Coping with late complications



Kathleen, transplant recipient, with her doctor

You may experience some late complications related to your transplant, such as graft-versus-host disease (GVHD). Eye, mouth and lung problems may first appear or worsen as you begin to reduce your immunosuppressants. These side effects are common, but they may vary in severity among individuals.

▼
Continue to monitor early warning signs carefully. Let your health care provider know of any changes you experience so you can work together to address the situation quickly and effectively.

One-year follow-up exam

It is so important to get regular follow-up exams. If you have not been back to your transplant center for your one-year, follow-up examination, don't put it off. Contact your center today.

Managing Complications

Eyes

Cataracts

For early or mild cataracts, you might find new glasses or better lighting beneficial. If vision becomes seriously impaired, cataract surgery may be an option. Talk to your health care provider to determine the best treatment option for you.

Dryness, itching, irritation

Avoid eye strain and rest your eyes. Some people find relief through frequent use of artificial tears, a humidifier or warm compresses. For more problematic symptoms, ask your health care provider about lacrimal duct occlusion, a surgical procedure to reduce draining of tears.

Severely dry eyes

People suffering from severely dry eyes, who have not benefited from other treatments, might be candidates for the Boston Scleral Lens (BSL). The BSL prosthetic device creates a space between the cornea and the lens where artificial tears can continually lubricate the eye. Additional information about BSL can be found in the Post-Transplant Resources section on page 15.

Heart and Circulatory System

Some treatments prior to or during transplant can speed up the process of atherosclerosis, a buildup of fatty deposits inside an artery. Atherosclerosis, when severe, can result in heart attack, stroke or poor circulation. Treatments include diet modifications, exercise, lipid- and cholesterol-lowering drugs, and drugs to control blood pressure.

Liver

Chronic GVHD may involve the liver, with severity ranging from lab test abnormalities to severe liver problems.

Symptoms of liver GVHD include fatigue, loss of appetite, nausea and jaundice (yellowing of the skin). Liver GVHD may be treated successfully with immunosuppressants.

Lungs

Some patients with chronic GVHD develop an inflammation of the lungs, which can lead to breathing problems. Immunosuppressants, including corticosteroids, when used early on, can help resolve problems caused by inflammation and minimize long-term lung damage.

Mouth

Immunosuppressants, rinses and lubricants may relieve the sores and raw patches some people experience.

Skin and joints

Rashes

GVHD of the skin often shows up as a red sunburn-like skin rash that may or may not be dry and itchy. Immunosuppressants, including corticosteroids, may be used to treat the GVHD causing the rash.

Scleroderma (hard skin)

Scleroderma is a disorder that results in excess collagen deposits that may affect the skin, joints and blood vessels, making them less flexible. GVHD can sometimes result in similar findings; when this happens it is termed sclerodermatous GVHD. In addition to medications, proper diet, exercise and physical therapy may help increase circulation, strength and flexibility.

Avascular necrosis

Avascular necrosis is a process where the part of a bone involved in a joint loses adequate blood flow, causing that area of bone to break down. This

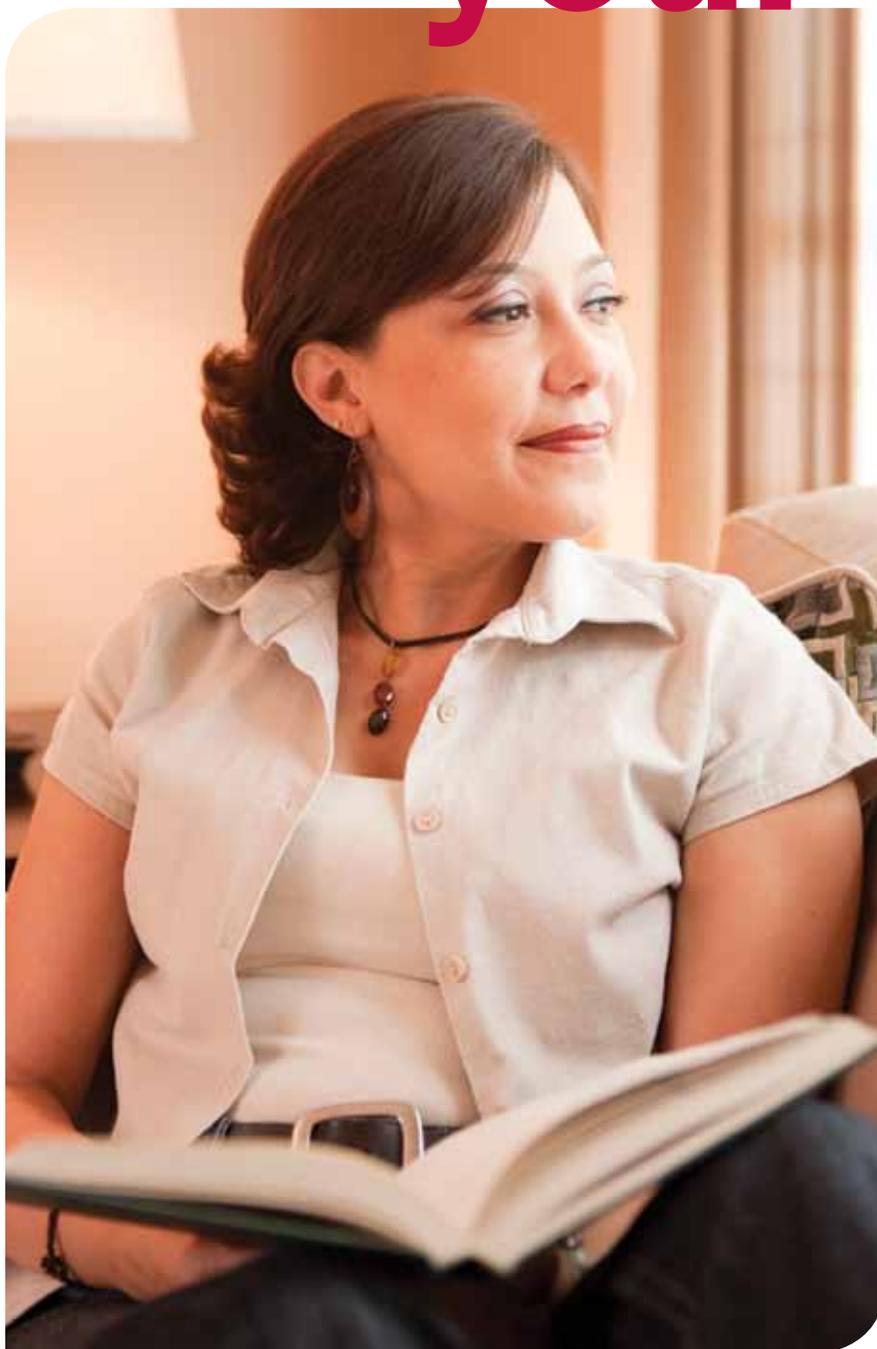
results in a joint with rough rather than smooth bone, causing joint pain. Your health care provider may prescribe medication, use of crutches or braces, and range of motion exercises to reduce pain and prevent further damage. More severe cases may require surgery to repair or replace the joint. ■

Signs of late complications

Watch for and report any of the following changes to your health care provider:

- **Digestive system:** Nausea, vomiting, diarrhea, loss of appetite, unexplained weight loss
- **Energy level:** Unusual or progressive fatigue
- **Eyes:** Dryness, itching, irritation
- **Hair:** Thinning
- **Joints:** Unable to fully extend fingers, wrists, elbows, ankles or knees
- **Mouth:** Dryness, pain, sensitivity, difficulty swallowing
- **Nails:** New texture changes, brittleness
- **Skin:** Rash, discoloration, tightness, thickening, texture changes
- **Temperature:** Chronic low-grade fever
- **Vagina:** Dryness, irritation

Overcoming your fears



Maritza, transplant recipient

Even though you may be beating your disease physically, you may continue to deal with it emotionally. Many people worry that their disease will return; in fact, this feeling might never go away completely. Some days the fear may be manageable, almost forgotten, and other days it might seem overwhelming. There are ways to cope.

Stay informed

The more you understand about your disease and recovery, the greater your sense of control. Logic cannot control emotions completely, but knowledge, access to resources and a well-defined emergency action plan can help calm nagging fears.

Studies have shown that informed patients are more likely to follow their treatment plans and recover more quickly than patients lacking information or living with unanswered questions.

Process your feelings

People have different coping styles and most people use a variety of strategies to cope with the emotional challenges of transplant. The important thing is to take time to process your feelings. If you are uncertain about what helps you manage fear, explore different approaches to see what works for you:

- **Share your fears with others:** Many people benefit from talking about their fears, anxiety and concerns with family, friends, other survivors or a counselor. Expressing your feelings can make it easier to let the feelings go.
- **Seek help through a support group:** You might consider participating in a local or online support group to share your feelings and get feedback from other people who understand your situation.
- **Maintain a journal:** If you want to explore your feelings, but it's hard for you to talk to others, consider writing down your thoughts. You can keep your journal private, or share it with someone you trust.

Remember that you do not need to be upbeat all the time. Give yourself permission to have a bad day if that's what you need.

Reduce stress

During treatment, you may have put parts of your life on hold – the demands of family, school, work and finances. As you move into your “new normal,” you'll likely find that these challenges have not gone away. It can be stressful if you worry that you are not up to dealing with these demands.

Some survivors become anxious or worry that stress in their lives may have caused their illness and renewed stress will bring it back. While stress can

contribute to some health problems, diseases like cancer can and do strike anyone. If you feel responsible for your illness, talking to a counselor may help. ■

Some people prefer to process their feelings quietly, on their own. For them, focusing on anxieties or sharing their fears with others only increases negative feelings. If you prefer to process feelings on your own, people with a different style might worry that you are in denial or accuse you of “bottling up” your feelings. You can remind them that there are different ways to cope, and reassure them that your method works for you.

Tips to reduce Stress

Exercise

Research has shown that exercise helps many people manage stress. So, find a physical activity that you enjoy, check with your health care provider and begin an exercise program.

Express your creativity

Activities such as drawing, painting, dancing, playing a musical instrument or singing often help relieve stress, even if you've never participated in these activities before.

Tell your story

Sharing your experience with other survivors, and hearing their stories in return, may help you feel more hopeful by connecting with others in a meaningful way.



Mike, transplant recipient



Recognizing depression

Many people feel sad, tense and angry as a result of their illness and treatment. Even people who were very upbeat throughout their treatment can become depressed. This can be a natural response to stress, which typically decreases over time.

For some people, however, the feelings get worse, until they interfere with daily life. Depression is more than “feeling down.” It is not something you can simply dismiss or shake off. It may be a medical condition that requires treatment.

Getting help for depression

If you think you may be depressed, contact your health care provider to discuss any symptoms of depression you are experiencing and ask about treatment options. Your health care provider might recommend prescription medication or refer you to a therapist

experienced in treating depression in people recovering from a life-threatening illness.

If you are having thoughts of hurting yourself or others, seek help immediately.

- You can contact 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 room (ER).
- If you think you may be depressed, contact your health care provider (HCP). Don't wait for your HCP or others to ask how you're doing. Tell your HCP about any symptoms of depression you are experiencing and ask about treatment options. ■

Symptoms of depression

Use this checklist to identify any symptoms that you experience for most of the day every day for two weeks or more:

- Constant sad, anxious or “empty” mood
- Changes in sleep patterns
- Changes in appetite and weight, either loss or gain
- Loss of pleasure and interest in activities you used to enjoy, including sex
- Restlessness, irritability
- Persistent physical symptoms that do not respond to treatment
- Difficulty concentrating, remembering or making decisions
- Fatigue or loss of energy
- Feeling guilty, hopeless or worthless
- Thoughts of suicide

More than stress: post-traumatic stress disorder

When stress significantly interferes with daily life, it may indicate a condition known as post-traumatic stress disorder, or PTSD. This condition may occur after a very difficult life experience, such as going through a transplant. Left untreated, PTSD may affect a person's ability to interact with others and function at home, work or school.

Symptoms of PTSD

According to the National Institute of Mental Health, PTSD symptoms are typically grouped into three categories:

- 1. Re-experiencing symptoms** – bad dreams, frightening thoughts or reliving the trauma over and over
- 2. Avoidance symptoms** – feeling emotionally numb, guilty, depressed or worried; losing interest in activities that were enjoyable in the past; staying away from places, events or objects that are reminders of the experience; or having trouble remembering the dangerous event
- 3. Hyperarousal symptoms** – easily startled, feeling tense or “on edge”; having difficulty sleeping or angry outbursts

Whether your symptoms appear early or later in the recovery process, it's important to monitor the duration of these symptoms. When symptoms last more than a few weeks and become an ongoing problem, they might be PTSD.

If you think you might have PTSD, talk to your health care provider about your symptoms. Many people with PTSD have benefited from drug therapy to treat their depression and anxiety and to help them cope. Counseling and group therapy may also be effective. ■

Emotional Health Checklist

If you or your loved ones have concerns about your emotional health, take a few minutes to ask yourself the following questions and write down your thoughts. Your answers can help you and your health care provider identify areas where you may need help.

Quality of life and general well-being

- How do I feel overall? Better or worse than I expected?
- Am I eating well?
- Am I sleeping well?
- How is my energy level?

Emotional well-being

- How is my overall mood?
- Am I worried? Angry? Depressed?
- What makes me feel better or worse?

Relationships

- How are my relationships — with my spouse or partner, family, friends?
- Am I dealing with relationship problems?
- Am I asking for and getting the help I need?
- Who could help?

► For additional information about emotional health after transplant, visit [BeTheMatch.org/patient](https://www.BeTheMatch.org/patient) or call Be The Match patient services at 1 (888) 999-6743 to request a copy of *Emotional Health after Transplant for Survivors and Caregivers*.

Complementary and alternative medicine

Could it help? Could it hurt?

Decisions about your health care are always important. This is especially true if you are considering complementary or alternative medicine (sometimes referred to as “CAM”) as part of your treatment and recovery.

Complementary medicine refers to non-traditional practices used in conjunction with treatment prescribed by your health care provider. Alternative medicine refers to practices used in place of conventional treatment.



Penny, transplant recipient

When complementary medicine is used appropriately — in combination with conventional therapy — many people report that their complementary approaches help them manage symptoms, reduce stress and improve their sense of well-being. Others do not experience a benefit.

There is a wide range to the relative safety and effectiveness of some complementary and alternative practices — especially for transplant recipients. If you have a weakened immune system,

have GVHD or are taking prescription drugs, you need to be careful about how some of these practices could impact your health.

Health care providers understand that many people explore a variety of healing techniques, so feel free to bring it up without fear of being judged.

Research any products or equipment not recommended by your health care provider to minimize risk and avoid scams.

Always talk with your medical team before changing your treatment, or trying any new approach to your health care. Don't wait to be asked. Tell your health care providers everything about your self-care so they can coordinate your overall care to be safe and effective.

Complementary and alternative medicine safety gauge

Generally safe

Practices that promote relaxation and well-being:

- Meditation, prayer
- Guided imagery
- Chiropractic manipulation
- Massage
- Art and music therapies

Practices that promote movement, stretching and exercise:

- Yoga
- Tai chi

Use caution

Practices outside of the self-care guidelines you received from your transplant center:

- **Special diets** Work with a dietitian to make sure any special diet meets your nutritional requirements and don't pose a risk. For example, if you are immune compromised, a diet of all raw foods could be dangerous. In addition, some fruits and juices, such as grapefruit, can cause dangerous reactions with certain medications.
- **Acupuncture** Check with your health care provider before trying acupuncture. If you do seek service from an acupuncturist, make sure to work with a licensed specialist.
- **Special products or equipment** This could include suspension exercise devices

Potentially dangerous

Practices that contradict or reject your health care provider's (HCP) advice:

- Quitting or substituting a prescription or HCP-recommended treatment.
- Starting vitamins, supplements or herbal products. (These could cause harmful interactions with your prescription medications.)
- Exposing yourself to light, sun or lotions that could aggravate GVHD of the skin.

Questions to ask your health care provider when considering complementary or alternative medicine as part of your treatment:

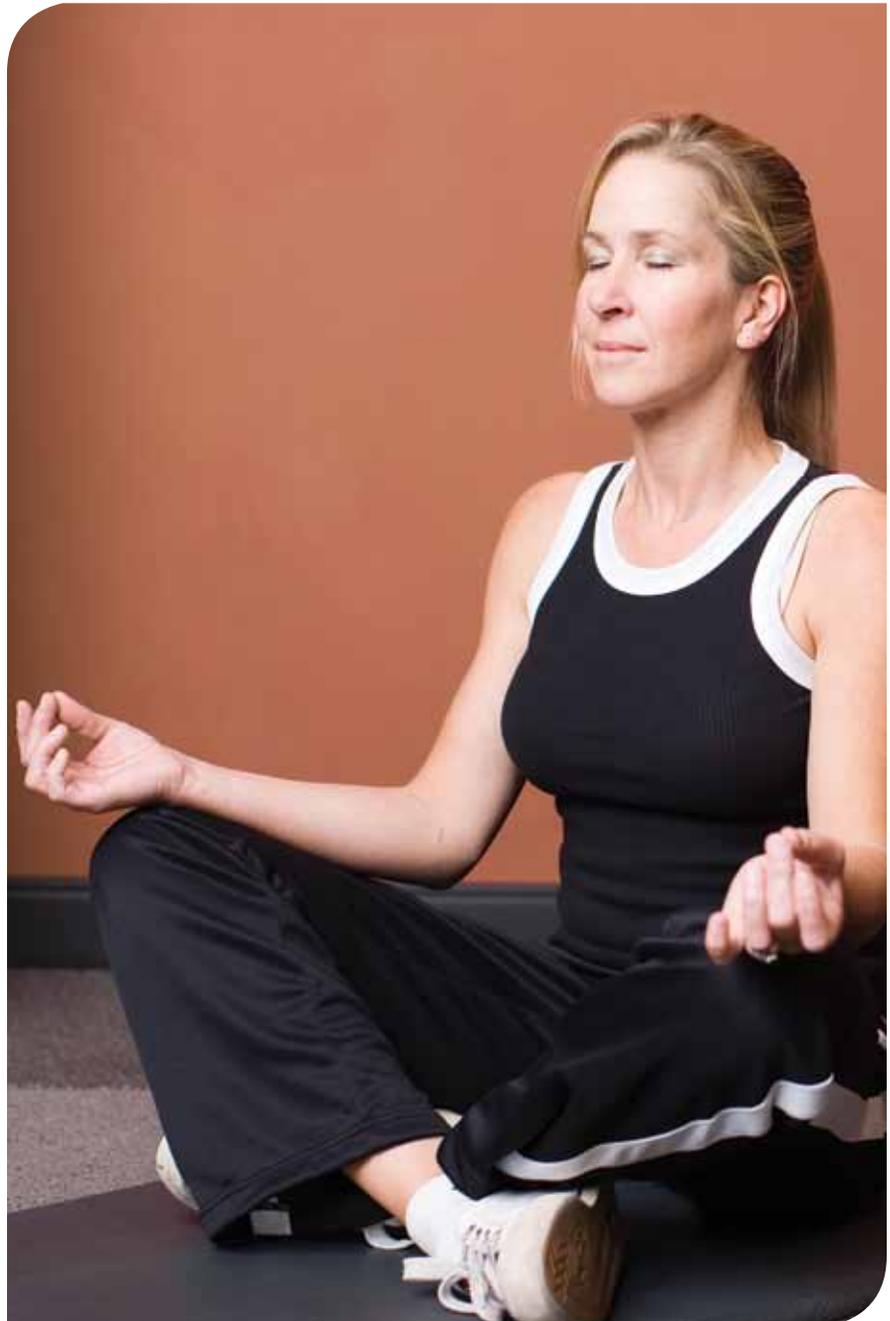
- What benefit could I expect from this therapy?
- What are the risks associated with this therapy?
- Do the known benefits outweigh the risks?
- Are there any potential side effects?
- Would the therapy interfere with my current treatment?

Take time to research health claims of potential products and services

Be skeptical of any products or services that make extravagant health claims, like promising to heal or cure. Keep in mind that products that claim to be “all natural” are not necessarily safe. Products that are not regulated by the U.S. Food and Drug Administration (FDA) have not been tested by an independent agency for effectiveness or safety.

You can learn more about any of these practices at the National Center for Complementary and Alternative Medicine (NCCAM), part of the National Institutes of Health: nccam.nih.gov. ■

▶ Beware of unethical “healers” and sales people who may profit by exploiting people’s hopes and fears. Do your research, check references, trust your instincts and always talk to your medical team before making any changes to your care.



Stacey, mother and caregiver of Kelsey, transplant recipient

Caring for caregivers

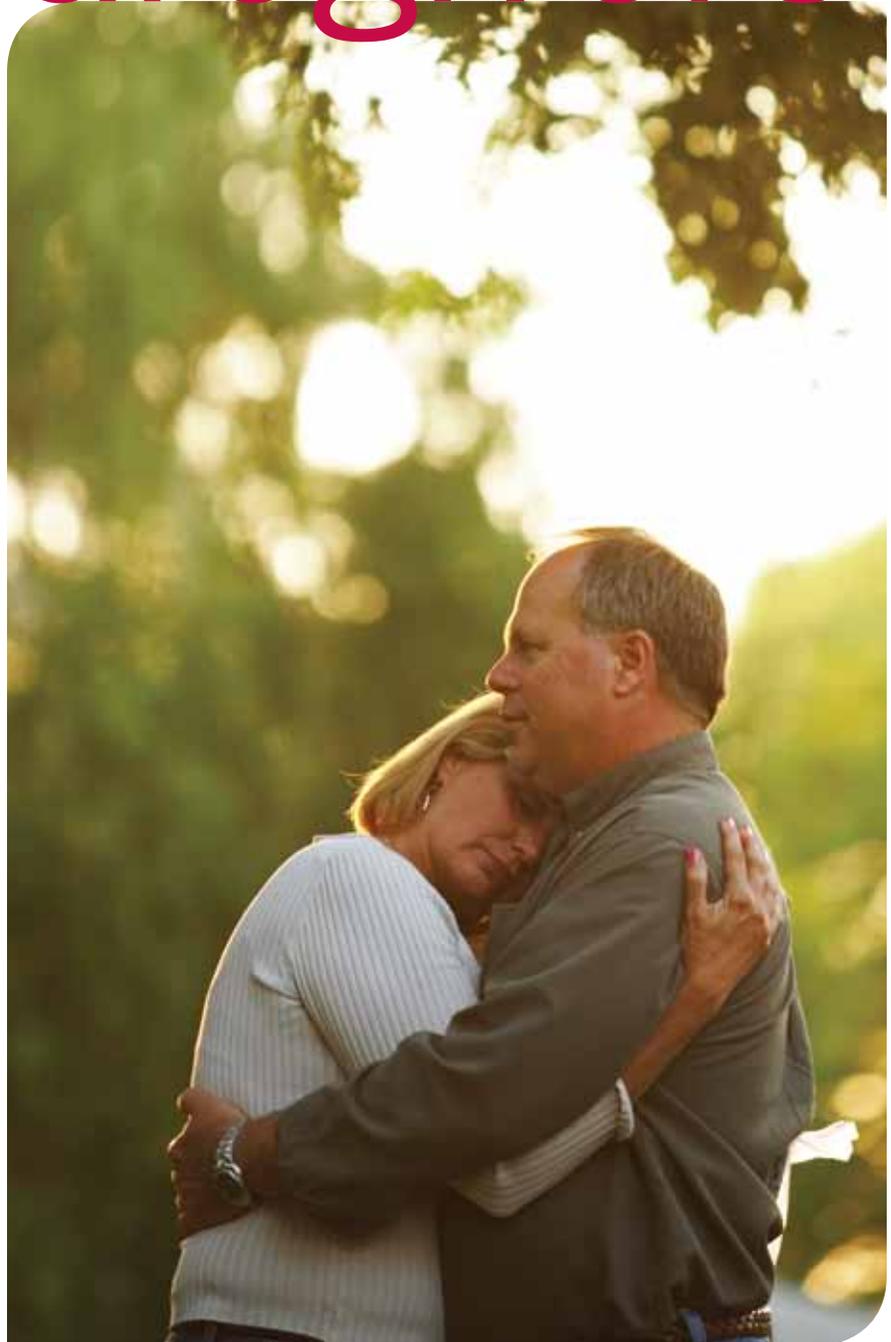
Many families do grow closer after a transplant, but it's the result of confronting and working through their difficulties, not by denying or ignoring the things that bother them.

Recognizing and managing conflict

Every relationship has some conflict. Personality clashes, misunderstandings, differences of opinion, tension and resentment can all contribute to conflict. Some people imagine that when serious illness strikes a family, everyone will set aside their differences and come together in love and support.

In stressful situations, people tend to rely on their preferred coping techniques. While this allows them to continue functioning, it can also exaggerate negative personality traits. People who are controlling may become overbearing. People who avoid conflict may become withdrawn.

People who are judgmental may become even more critical. People might develop addictions or rely on substances



Terry and Debra, parents and caregivers of Ashley, transplant recipient



Susan, mother and caregiver of Betsy, transplant recipient

more heavily. Physical and emotional challenges remain even after the most intense period of treatment and recovery are over. You might feel like “it’s finally over,” but the effects of the experience still linger. This can be frustrating. Even caregivers who have been on top of things throughout it all, can suddenly find themselves overwhelmed by accumulated stress. You might feel like you’re going to snap or lash out.

Consider talking to someone you trust and respect to get guidance and support. It could be someone in your family, a member of your faith community, close friend or a professional counselor. Self-help books may also help you understand and resolve issues that cause conflict.

Addressing family issues

If your family thought things would “get back to normal,” you may have

trouble getting used to “the new normal.” Some family members might be unhappy about the changes. Some families choose to work through problems on their own, others get professional help. You might consider asking your health care provider or social worker to refer you to a counselor who specializes in working with families who have been affected by illness.

Tips for avoiding conflict

- When something rubs you the wrong way, think about the person’s intent
- Ask for clarification to avoid misunderstandings
- Tell people how you feel
- Discuss how things could be done differently
- Build yourself up by spending time with people who help you stay positive
- Reduce your stress by taking good care of yourself

Tips for helping children adjust

Help your younger children or grandchildren understand your illness and recovery. Explain medical equipment, conditions and routines in terms they will understand. Children of survivors offer these suggestions:

- Be honest with your children; they often fear something worse than the truth
- Speak as directly and openly as possible
- Educate children about your illness, and involve them in your recovery
- Spend extra time with your children
- Encourage other family members to be open and honest about your treatment and recovery ■

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.

BMT Support Online, Inc.

Interactive chat area, and two online support groups — one for marrow and cord blood transplant patients and survivors, and the other for caregivers. Both groups meet weekly at scheduled times.

Web site: bmtsupport.org

Boston Foundation for Sight

Learn more about the Boston Scleral Lens, or BSL, prosthetic device online at the Boston Foundation for Sight Web site.

Web site: bostonsight.org/aboutlens.htm

Cataract Surgery

Visit www.medem.com and search medical library for “cataract surgery”

Web site: medem.com

Depression Screening

The mission of the Depression Screening Web site is to educate people about clinical depression, offer a confidential way for people to get screened for symptoms of the illness, and guide people toward appropriate professional help if necessary.

Web site: depression-screening.org

GVHD Online Support Group

To subscribe, visit www.acor.org. Click on Mailing Lists, select “G” and scroll down to GVHD List.

Mental Health Services Locator

This site provides comprehensive information about mental health services and resources; it is useful for professionals, consumers and their families, and the public.

Web site: mentalhealth.samhsa.gov/databases

National Family Caregivers Association

NFCA is a nonprofit organization dedicated to supporting and empowering the lives of America's family caregivers.

Web site: thefamilycaregiver.org

Office of Cancer Complementary and Alternative Medicine (OCCAM)

OCCAM is responsible for the National Cancer Institute's research agenda in complementary and alternative medicine (CAM) as it relates to cancer prevention, diagnosis, treatment and symptom management.

Web site: cancer.gov/cam

The National Center for Complementary and Alternative Medicine (NCCAM)

NCCAM is part of the National Institutes of Health, and NCCAM is the federal government's lead agency for scientific research on complementary and alternative medicine (CAM). NCCAM's mission is to explore complementary and alternative healing practices in the context of rigorous science, train CAM researchers, and disseminate authoritative information to the public and professionals.

Web site: nccam.nih.gov

Living Now e-newsletter:



SUBSCRIBE NOW

BeTheMatch.org/patient-news

The National Center for Post-Traumatic Stress Disorder (PTSD)

The National Center for PTSD seeks to advance the science and promote understanding of traumatic stress. The site provides resources associated with the psychological effect of trauma and tools to help with assessment and treatment of PTSD.

Web site: ncptsd.va.gov

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

A guide to life after transplant
Issue 4: 12–18 months

A time of adjustment

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.



Living now

Issue 4: 12–18 months

Inside this issue:

Taking stock, looking forward

- Late complications
- Overcoming fear
- Recognizing depression
- Complementary and alternative medicine

P0384; OCT 2011



Brent, transplant recipient,
with his family