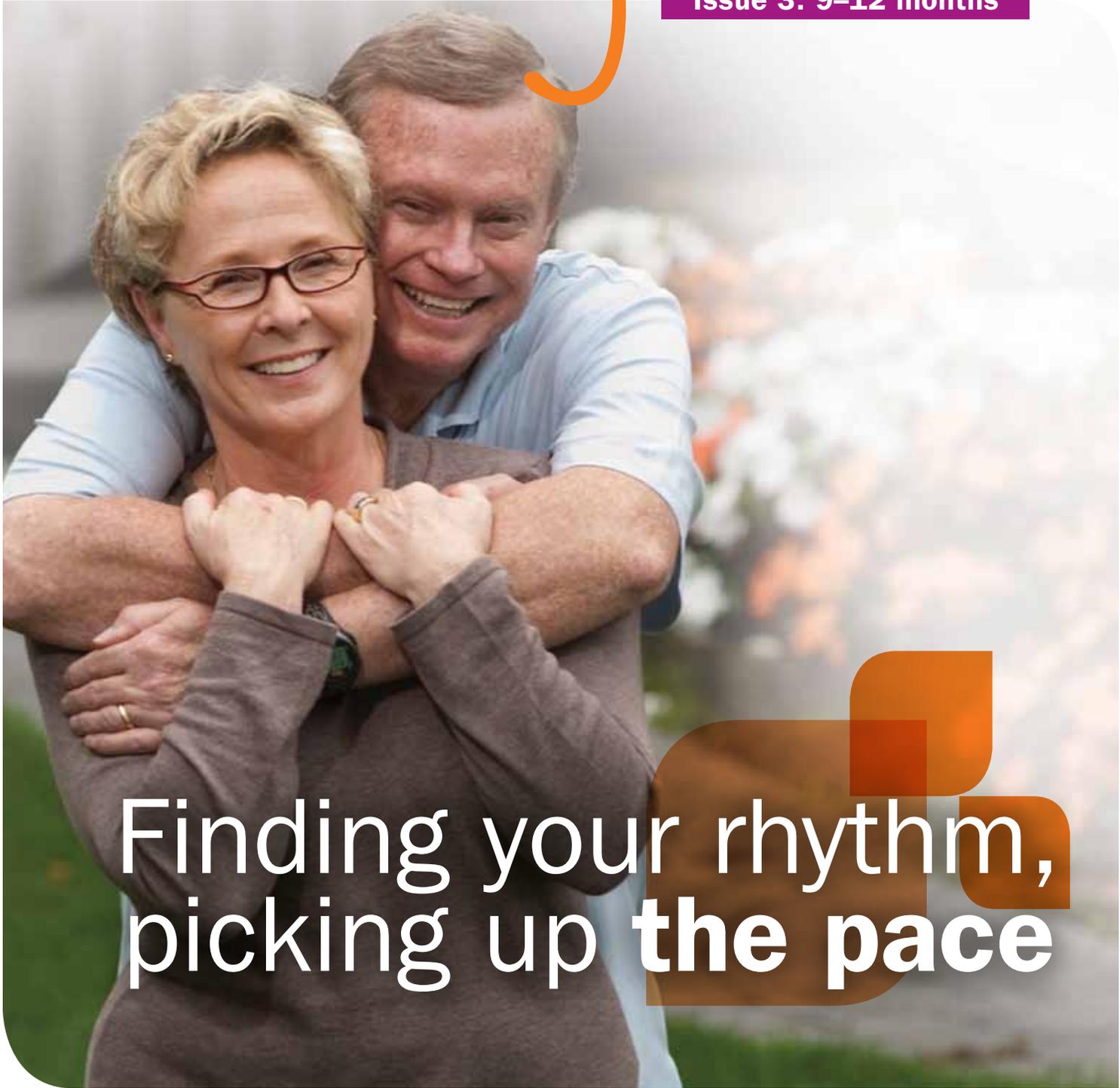


Living **now**

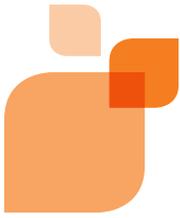
A guide to life after transplant

now

Issue 3: 9–12 months



Finding your rhythm,
picking up **the pace**



On the cover: Dan, transplant recipient, with his wife, Deb

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Welcome to *Living Now*

This newsletter is the third 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

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Finding your rhythm, picking up the pace

Recovery after a transplant can be a lengthy process for patients and their families. It might seem like steady progress, or it might feel like “two steps forward, one step back.” Everyone’s experience is different. But over time, you may find that there is a certain rhythm to your recovery.

“With low energy levels after transplant, it is easier to rest and relax than to get back to normal activity,” said Dan. “Sometimes just the thought of doing an activity is difficult.” Dan, like many transplant recipients, knows you may have to push yourself to do normal activities while not overdoing it.

As you begin to feel better, you will be able to gradually resume some of your old activities, take on greater responsibilities and become more independent.

If you feel better than you expected, you might be tempted to rush your recovery to get back to your usual routine. That might cause you to ignore your medical team’s instructions or take chances with your health. It is very important to continue following your medical team’s directions and not make any changes regarding your medications, diet or other restrictions without their advice.

If your recovery has been slower or more difficult than you expected, try not to get discouraged. Eating well, exercising and doing things you enjoy can help you stay motivated on the path to recovery.

This issue includes tips for celebrating milestones, preparing for your one-year follow-up exam, contacting your donor, returning to work or school, and managing pain. ■

“

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



Dan, transplant recipient

Your one-year anniversary



Penny, transplant recipient, with her doctor

Celebrating milestones

Many transplant recipients celebrate the anniversary of their transplant, which is often referred to as a first “birthday.” It can be a good opportunity to reflect on how far you have come, and thank everyone who helped you. Setting goals, tracking your progress and celebrating achievements can be fun and motivational.

As you approach this first anniversary and you continue to get stronger and healthier, you will have opportunities to celebrate other milestones. These might include:

- One-year follow-up exam
- Contacting your donor
- First day back at work
- Child’s first day back at school

When you reach a milestone, reward yourself with a special activity, gift or vacation. Attending social events such as weddings, birthdays, anniversaries and graduations can be both a goal and a reward. Use your imagination and have fun with it.

Building momentum, gaining stamina

Physical activity is important to building strength and endurance while fighting fatigue. Regular exercise may help reduce pain and improve overall quality of life. Talk to your doctor about exercise goals:

- Go for a walk every day.
- Increase your distance (or time).
- Exercise with a friend.
- Try different activities, such as cycling, weights or yoga.
- Keep track of your progress.
- Celebrate your achievements.

Following dietary guidelines

Continue to eat well and follow your dietary guidelines. Good nutrition is important to avoiding weakness, gaining strength and maintaining proper weight.

As your appetite and sense of taste returns, you may experience food cravings. Do not be too disappointed if an item you craved does not live up to expectations. Improvement in your sense of taste might be slow, but will return to normal for most patients.

Preparing for your one-year exam

A significant milestone is your one-year follow-up exam at your transplant center. This appointment is important for determining how well you are doing overall and addressing any late complications.



Most foods are okay to add back into your diet, but certain foods such as grapefruit can interact with important post-transplant medications. Check with your transplant team to be sure new additions to your diet are okay.

Some people are nervous about their one-year exam, hoping for the best, but worrying about what tests might find. Others look forward to seeing their doctors and nurses again, and getting answers to their questions. Whatever your attitude, the one-year exam is a significant event in your recovery.

As you near the one-year anniversary of your transplant, it's time to plan for your one-year follow-up exam:

- Work with your medical team to find out if your transplant center will be contacting you to arrange your one-year exam, or if you need to make the appointment.
- Confirm with your medical team that all of your most recent medical records are available as needed, or complete any paperwork required to release your records.
- Prepare a detailed list of questions and topics to cover with your doctor (e.g., symptoms of GVHD or infection, side effects, sexual health, emotional health, medications and any complementary or alternative medicine you are using or are considering).
- Arrange to have a friend or family member attend this appointment with you to take notes and provide support.
- Make travel and lodging arrangements as needed. ■

Guide for recommended tests and procedures

The more you know about your health, the better prepared you will be to protect and maintain it. Be The Match provides guidelines that patients and physicians can use to schedule long-term, follow-up care after a transplant. *A Guide to Protecting Your Health after Transplant: Recommended Tests and Procedures*, includes:

- Information about side effects that may occur months or years after transplant.
- Charts with recommended tests and procedures for patients' six-month, twelve-month and yearly post-transplant check-ups.
- Space for patients to record important information about their own post-transplant care.

You are encouraged to:

1. Download or order a free printed copy of the guidelines online at: cibmtr.org/posttransplant.
2. Review the recommended tests and procedures for your one-year follow-up exam.
3. Bring a copy of the guidelines with you to your one-year follow-up exam.

Returning to work is a personal decision. Doctors usually recommend that people not return to work until at least one year after transplant. That's because it can take nine to 12 months for the immune system to recover sufficiently. For some people recovery may take longer. When you feel up to it, talk with your doctor about going back to work.

You may need to wait longer before returning to work if your job is physically demanding or puts you at higher risk for infection (such as construction work or working with animals). Some people need to find a different kind of job until their strength and energy return and their immune system has rebounded.

If you experience ups and downs in your energy level, it is best to return to work gradually, working part time if possible, before taking on the demands of full-time work. It may be helpful to monitor your activities throughout the day to determine when you have the most energy and how often you may need to take breaks.

Remember that you do not need to try to do more than you can handle or settle for less than you deserve. Research shows that survivors who return to work are as productive on the job as other workers.

Returning to work and disability benefits

It is important to consider how returning to work will affect your Social Security disability benefits and any long-term disability insurance benefits. There are many factors to consider when returning to work, including your physical ability. The Social Security Ad-

Returning to work



Herschel, transplant recipient

“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**

ministration (SSA) offers a number of incentives to encourage people who are receiving disability benefits to work:

Trial work period

A trial work period lets you test your ability to work. You can receive your full Social Security benefits for up to nine months even though you are earning an income. The nine months do not need to be consecutive, but must occur within a five-year period. If you lose your job during a trial work period, your benefits will continue.

Extended period of eligibility

After you exhaust your nine-month trial work period, you have 36 months during which you can work and still receive benefits for any month in which you earn less than the stated maximum. If you lose your job during the extended period, you can call the SSA to have your benefits reinstated.

Expedited reinstatement

If you find yourself unable to continue working because of your condition, you can have your benefits reinstated immediately without having to reapply. You can do this at any time up to five years after your benefits were initially discontinued.

Work expenses related to your disability

Eligible expenses may be subtracted from your earnings when the SSA calculates your benefits.

Continuation of Medicare

You must complete a two-year waiting period from the time your disability is determined before you can receive any Medicare benefits. If your Social Security disability benefits stop because of your earnings, but you are still disabled, your free Medicare Part A coverage will continue for at least 93 months after the nine-month trial work period. After that time, you can pay a monthly premium to continue Medicare coverage.

Plan for Achieving Self-Support (PASS)

A PASS lets you set aside money to go back to school, get job training, start your own business or achieve other goals to reduce your dependency on Supplemental Security Income and become self-supporting.

Compassionate Allowances

Social Security provides “compassionate allowances” to fast-track applications for people with cancers and rare diseases. Compassionate allowances allow the SSA to process disability claims for people with certain conditions in a matter of days rather than months or even years. For more information and to view a list of diseases covered, visit www.ssa.gov/compassionateallowances.

To learn more or get new and revised information on Social Security disability benefits, visit the SSA Web site at www.ssa.gov/disability/ or call (800) 772-1213.

Individual plans vary. Be sure to review current social security disability benefits and check with your plan administrator regarding your specific situation.

Keeping your health insurance

Do not let your health insurance coverage lapse. If you lose coverage, it can be hard to get new insurance. If you face losing insurance coverage through your employer because of the loss of your job or a reduction in your work hours, look into:

- Adding yourself to your spouse’s insurance policy.
- Continuing insurance benefits through COBRA (the Consolidated Omnibus Budget Reconciliation Act). COBRA gives people the right to keep their health plan for a certain amount of time after leaving a job. COBRA payments may seem high, but the cost of losing insurance would be higher.
- Joining a state risk-pool program. Some states have risk pools that serve people who have trouble getting insurance because of a pre-existing health condition or other reasons.

There may be other state programs that can provide access to health care. Contact your state’s department of health or health commission for more information. ■

Tips for returning to work

- Before you return to work, contact your human resources 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., flex time, regularly scheduled breaks, working from home or special equipment).
- Work out clear expectations about your schedule and work load.
- Document each request and the response for your records.
- Consider asking your employer to discuss your situation with your co-workers, and make sure you are comfortable with the information and the way it will be presented.

Helping your child return to school

Returning to school is a huge milestone on the road to recovery. Your child may be eager to get back to a normal routine, but it can be hard. There are things you can do to help prevent problems and resources you can use to help find solutions.



We couldn't be more excited to see Elias grow and explore and learn new things. We are really lucky that his health is very good, and it doesn't impede him in any way. We found that communication is key. When everyone is on the same page, we are all more successful."

—Sheila, mom of
transplant recipient Elias



Elias, transplant recipient

Getting ready: Educating the educators

Most teachers and school administrators have little or no experience with cancer survivors or students who have had a transplant. Be proactive about helping them understand your child's unique challenges and what they can do to meet your child's needs. When teachers and staff understand your child's special circumstances, it is easier to work together to find solutions and stick to a plan.

Create a team

Create a support team of doctors, child life specialists, teachers and school administrators. As your child's biggest advocate, it may be up to you to introduce these people to each other and help them understand your child's special circumstances and how long-term effects of treatment might affect learning. Working together, you can make sure your child gets all the educational support entitled by law.

Be aware of potential issues

Your child may have cognitive difficulties caused by treatment. Radiation and chemotherapy can affect the brain in many ways. It can impair fine motor skills, and it can make it hard to plan and organize or process visual information. Teachers may find that your child has trouble paying attention and may appear to "space out" at times and miss important information or experience difficulty with organization.

Ask if your school has special accommodations to support reading and writing, such as an audio recorder or receiving more spoken direction. Let school staff know that fatigue and physical weakness may be a problem. Make sure teachers, nurses and physical education instructors understand the seriousness of your child's challenges. Educate your team so they have realistic expectations and adjust goals accordingly. By understanding these limita-



About 20 percent of young people who graduate from college go on to graduate school. In our cancer survivorship population, that number is about 50 percent. Most of those children go into careers and fields that involve helping other people. They're in medicine, psychology, education, nursing and law advocacy. We are producing not only survivors, but major contributors to the well-being of our world."

—Daniel Armstrong, Ph.D.

director, Mailman Center for Child Development; associate chair, Department of Pediatrics, University of Miami Miller School of Medicine; associate chief of staff, Holtz Children's Hospital, UM Jackson Memorial Medical Center

tions, teachers can be more supportive of your child's educational needs.

Detail your child's medication

Inform the team of your child's medications. If side effects from steroids or other medications cause a problem with your child's mood or behavior, work with the school to develop a plan that is tailored to your child's special circumstances.

Listen and involve your child in planning

Always listen to your child as well as teachers and counselors. Be aware that your child might make excuses rather than admit to having problems and needing extra help. Your child probably just wants to fit in and may deny needing special accommodations. But it can be very scary and frustrating for your child to be accused of not paying attention, held accountable for behaviors that feel out of control, or labeled slow or lazy.

CONTINUED ON PAGE 10

Back-to-school checklist

As your child prepares to return to school, remember to do your homework:

- Research necessary resources, accommodations and services.
- Establish a support team to help your child.
- Create a list of your child's medications, including any side effects or behavior issues associated with these medications.
- Meet with your child's teacher to develop a plan.

And remember, once your child is back in school, keep lines of communication open and stay involved.

CONTINUED FROM PAGE 9

Talk to your support team about age-appropriate ways for your child to participate in discussions and decisions. Involving children in problem solving can improve their willingness to try different plans.

Find out what is going on and take action

While planning ahead is important, be proactive about learning how your child is doing in different circumstances, with different people—teachers, staff and other students. Don't wait for regularly scheduled conferences. If issues are identified, develop a plan to support your child. Remember, you are your child's advocate; insist on what is right for your child.

Know your rights

Your child may be entitled to special education services through IDEA (Individuals with Disabilities Education Act), which allows for an Individual Education Program (IEP). Your child might also be eligible for accommodations through Section 504 of the Rehabilitation Act of 1973.

These services and accommodations generally require an evaluation to determine if your child qualifies. Talk to your child's teacher or school administrator to find out what is required to schedule an evaluation. If your child meets state and federal guidelines, the school will be legally required to address the areas of difficulty. This might include such accommodations as:

- Extended time to complete assignments
- Reduced homework demands
- Help organizing materials
- Use of calculators and recorders
- Dictation of tests and reports

Know your alternatives

Many schools do a good job meeting students' needs and making accommodations to help them succeed. Unfortunately, some schools lack resources or the commitment to fulfill their obligations to your child. If you believe your child is not getting the necessary support, there are several options you can pursue:

- Work with the administration, elevating your concerns from teacher to principal to superintendent, as needed.
- Find other resources—such as tutors or therapists—to compensate for services the school is not providing.
- Take legal action to make the school fulfill its legal obligations to your child.
- Change schools or home school your child.

It's important to explore all your options to find solutions that work for you and your child.

Stay optimistic and be creative

Physical and cognitive side effects are not always permanent. Function can improve over time. Recent studies by the National Cancer Institute suggest that the brain can recover and adapt to new ways of learning. Many people find their own ways of dealing with cognitive challenges. Find support groups and explore different ideas to find solutions that work for your child. ■

A Guide to the IEP

For a guide on Individual Education Programs (IEP), visit: ed.gov/parents/needs/spced/iepguide/index.html

Finding success in college

The Individual Education Program (IEP) and Section 504 do not carry over to college. Even if your child has good grades from high school, low scores on standardized tests such as the SAT can make it harder to get into college. Once there, it might be difficult to keep up with the demands. Make sure to use all of the services available through the school's disabilities office. If at all possible, enlist the support of a senior staff member who can advise your child and be an advocate on your child's behalf. An appeal to the head of the psychology or education department can help resolve conflicts with other professors.



Ashley, transplant recipient

Initiating contact with your donor

If you received an allogeneic transplant from an unrelated adult donor, you may or may not have a strong desire to meet your donor. Contact between donors and recipients can have a profound effect on everyone involved. It can be wonderful, or it can be stressful.

Some donors look forward to being contacted, while others choose not to be contacted. Every person is unique.

If you wish to reach out to your donor, start by contacting your transplant center. Some centers allow patients and donors to send anonymous cards or letters to each other as long as no identifying information is shared. Such anonymous communication must be reviewed by the transplant center and the donor center.

“

We are so grateful to Alan and to everyone else who helped us—the doctors, nurses, and Be The Match. If it wasn't for them, we wouldn't be here today.”

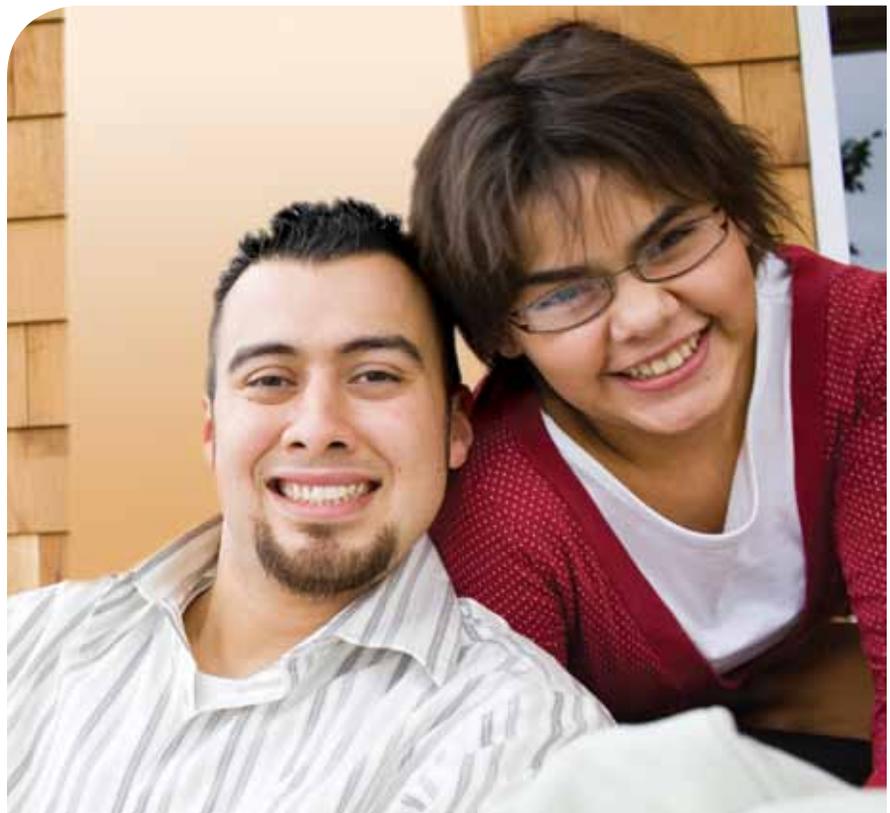
—Michelle, mom of transplant recipient
Clarissa

In addition, each center establishes specific rules about direct contact between patients and their donors. Some centers require one year, two years or even three years following transplant before any contact. Some centers never allow contact between donors and recipients.

Finally, donors and recipients both have the same rights to privacy. Either of you may choose not to be contacted. However, if you do want to connect, both of you must agree and sign a consent form. Contact your transplant center to learn more. ■



Many patients want to express gratitude to their donor. Whether or not you choose to, or are able to connect, rest assured that donors know their donations are valued and appreciated.



Clarissa, transplant recipient and her donor, Alan

Managing pain

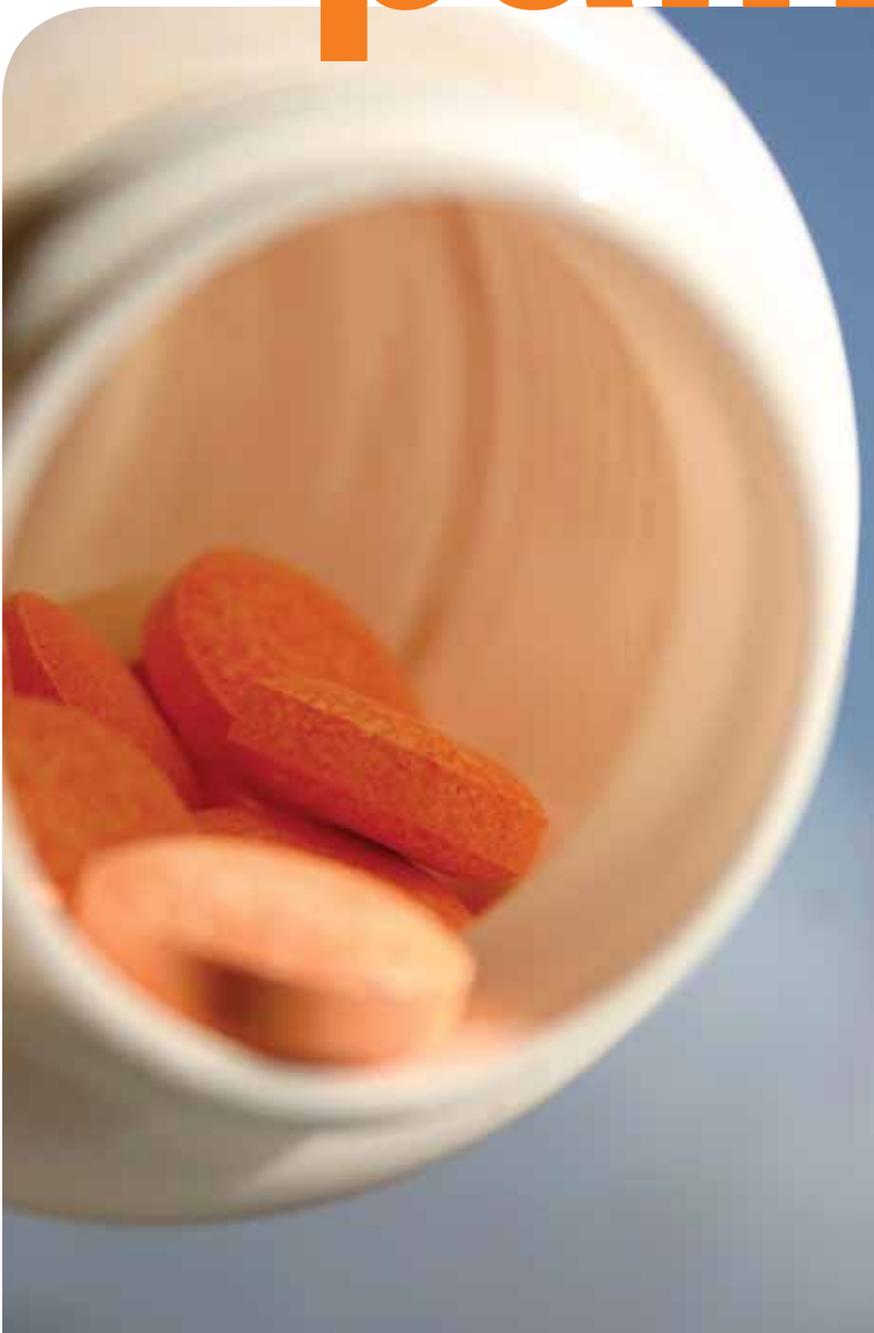
Effective pain control is important to healing

How well you feel affects your mood, energy level and ability to function. In fact, pain can actually slow your recovery. Therefore, if you experience pain it is important to talk to your doctor about treatment options and take action early.

Some patients experience good results from treatments such as physical therapy, massage, hot or cold compresses, relaxation and guided visualization. Other times, over-the-counter medications provide relief.

If medications such as ibuprofen and naproxen don't help, your doctor may prescribe more powerful pain-relieving medications as necessary. These could include opiates, which are sedative narcotics such as Percocet® Vicodin® and Demerol®, that contain opium or one or more of its natural or synthetic derivatives. These medications are very effective at relieving pain, making it possible for people to enjoy a better quality of life and take an active role in their recovery.

Some people worry that they might become dependent or addicted if they take opiates. Learning about the issues associated with opiates can help you understand how they might fit into



Issues associated with the use of opiates

your treatment plan.

Addiction is a psychological reaction, not a physical response. Addiction is rare among people taking opiates to manage pain. Before an opiate is prescribed, your doctor will determine if you are a good candidate. You should have no prior history of substance abuse or other condition that would indicate risk for addiction.

Dependency can happen to anyone who takes an opiate for more than a few weeks. It simply means that if a person suddenly stops using the drug, he or she could experience physical side effects. When people are ready to

stop using an opiate, they are carefully weaned off of it under a doctor's close supervision.

Tolerance describes a patient's need to take greater amounts of the drug to get the same benefit. Tolerance requires adjustment in the amount or type of pain medication prescribed or adding a non-opiate pain reliever.

If you need to use opiates, you are encouraged to involve family members in helping monitor use and watching for any side effects such as changes in behavior or judgment. If you have questions or need help with pain management, talk to your doctor. ■

While opiates are highly effective for pain management and beneficial to healing, their use needs to be carefully monitored. Take only as directed by your doctor.

Pain may be a symptom of GVHD

Symptoms of graft-versus-host disease (GVHD) vary significantly, ranging from mild to life-threatening. For some people, symptoms are painful or hard to manage. Talk to your doctor about symptoms you experience, and report any new or worsening symptoms immediately.

To learn more about signs, symptoms and treatment of GVHD, visit BeTheMatch.org/patient. From the main menu, select the *You and Survivorship* section, which includes important information about the cause, prevention, warning signs and treatment of GVHD.



José, transplant recipient, with his doctor

Tips for caregivers



Theresa, caregiver

Moving through the stages of recovery requires you and your loved one to continually adjust to changes. You might just be getting used to additional responsibility, when you find that you have to start letting go to allow your loved one to achieve independence. It helps to be aware of specific changes and to discuss them openly to ease transition.

Pay attention to your emotional health

You may feel grief about your situation or anger over someone who was

not there for you. You might feel guilty or resentful about needing help. It's important to take care of yourself:

- Do things that relax and refresh you.
- Ask for and accept offers to help.
- Do not ignore symptoms of stress.
- Set priorities based on your own values.
- Seek out a support group and/or professional counseling.

See the special issue of *Living Now for Caregivers* for more information. Caregiving information is also available online at BeTheMatch.org/caregiver. ■

Next steps

Reclaim your independence

As you recover, it is important for your well-being to resume your usual activities. Set goals, build on your abilities and develop strategies for coping with challenges. Some days will be better than others. Consider your progress week-to-week or month-to-month.

Be aware that conflicts might arise if family members have different expectations about your abilities. Caregivers might worry or become frustrated if they think you are doing too much or

too little. You might get upset if you feel like you are being pushed too hard or coddled too much. Talk with your family and friends about your expectations, and remember to focus on your shared goals of health and recovery.

Adjusting emotionally

Recovery is more than a physical process. It requires a mental shift from seeing yourself as sick to seeing yourself as healthy. Some people feel vulnerable or depressed because they cannot stop thinking about their illness and

treatment. Some people have second thoughts about the decisions they've made. Others live in fear of a relapse. If these kinds of worries upset your life, consider speaking to a professional therapist or to members of a support group.

Look ahead

Plans for the future are often put on hold during treatment and early recovery. But as you feel better, it can be motivating to re-evaluate your goals and make plans for what you want to do next in your life. ■

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.

American Childhood Cancer Organization

Provides information and awareness for children and adolescents with cancer and their families, advocates for their needs, and supports research. They offer the free booklet, *Educating the Child with Cancer: A Guide for Parents and Teachers*, written by both parents and educators and edited by Nancy Keene.

Web site: candlelighters.org

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

Cancer Legal Resource Center

The Cancer Legal Resource Center provides information and education on cancer-related legal issues.

Web site: cancerlegalresourcecenter.org

CareerOneStop

CareerOneStop is a U.S. Department of Labor-sponsored Web site that offers career resources and workforce information to job seekers, students, businesses and workforce professionals.

Web site: careeronestop.org

Health Insurance Consumer Guides for the Fifty States

Provides information on individual health insurance coverage after a major life event.

Web site: healthinsuranceinfo.net

Learning Disability Online (LD Online)

LD Online provides information about learning disabilities in children, including resources for parents wanting to learn more about the IEP process.

Web site: ldonline.org/indepth/iep

The Leukemia and Lymphoma Society's Trish Greene Back to School Program for Children with Cancer

The Trish Greene Back to School Program for Children with Cancer was developed to foster communication among health care professionals, parents, young patients and school personnel in preparation for the return to school and other activities.

Materials, videos and literature are available through local chapters of The Leukemia and Lymphoma Society.

Web site: lls.org

Patient Advocate Foundation

Patient liaison representatives work with patients and their caregivers to educate and empower them as well as mediate on their behalf to resolve denial of access to quality care, job retention and financial issues related to diagnosis.

Web site: patientadvocate.org

Living Now e-newsletter:

Staying connected after transplant just got easier



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

SUBSCRIBE NOW

BeTheMatch.org/patient-ews

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 3: 9–12 months

Finding your rhythm picking up the pace

- Preparing for your one-year exam
- Returning to work and school
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Dan, transplant recipient, with his wife, Deb