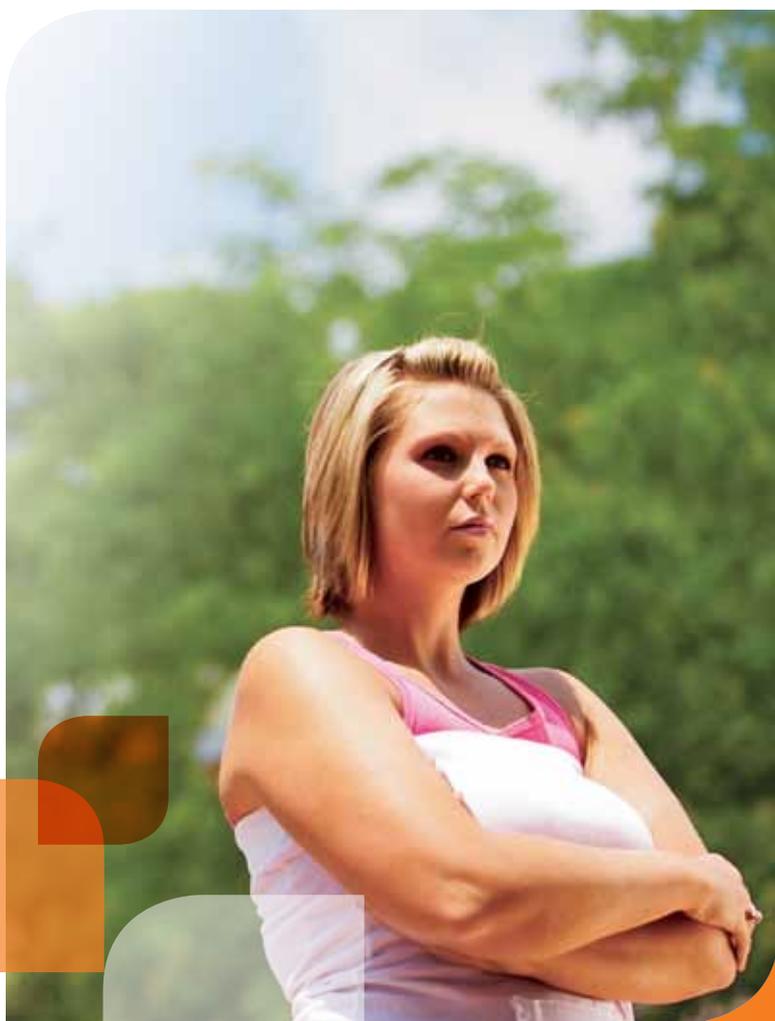




Emotional health for transplant recipients and caregivers



1.888.999.6743 | BeTheMatch.org/patient

Emotional health after transplant for survivors and caregivers

We are here to help.

Be The Match® has a team dedicated to supporting patients, caregivers and families before, during and after transplant.

We offer you confidential one-on-one support, financial guidance and free educational resources — DVDs, booklets, online tools and more. Our goal is to get you what you need, when you need it. We can help you learn more about transplant as a treatment option, plan for a transplant, and learn what to expect after transplant.

We offer support in more than 100 languages, including Spanish bilingual staff, and translated materials.

- Learn: **BeTheMatch.org/patient**
- Request information: **BeTheMatch.org/request**
- E-mail: **patientinfo@nmdp.org**
- Call: **1 (888) 999-6743**

If you need information in another language, we can help. When you call, you will need to say — in English — what language you speak. It will take four to eight minutes for an interpreter to join the call. Please stay on the line until you are greeted by the interpreter.

Be The Match is operated by the National Marrow Donor Program®, which also works with hospitals and physicians to help patients who do not have a matching donor in their family.

On the cover: **Ashley**, transplant recipient



“Life after transplant is a different challenge than treatment. Paving the road to your new normal has its emotional ups and downs. However, if you lean on your support system and listen to your doctors, your road will be much smoother.”

— **Matt**, transplant recipient (with wife Cori)

Now that you've completed your transplant, it's time to focus on healing. Paying attention to your emotional health is just as important as taking care of your physical health. It's common for transplant recipients and their caregivers to feel a range of emotions, such as relieved, happy, sad, worried and frustrated. All are normal emotions, but if worry, anxiety and sadness prevent you from enjoying life or doing the things you want, it may be time to ask for help.

In this booklet you'll learn how:

- to recognize fatigue, anxiety, post-traumatic stress disorder and depression
- to share your emotions – with your health care team, family and friends to get the help you need
- your relationships and your coping style can affect your emotional health

In addition, you'll find questions to ask your doctor, a depression checklist and tips for developing healthy habits that can improve your emotional well-being.

Whether you're a survivor or a caregiver, getting help for emotional issues can make you feel better, improve your relationships and speed recovery.



“As a mother of a sick child, I felt like I had to take on the world to make sure that everything was done correctly. [But] I actually had to take a step back and talk to someone. A good friend of mine helped me by being a great listener and giving me positive feedback.” — **Tennille**, caregiver

Understand your emotions

Fatigue, anxiety, PTSD and depression

Fatigue, anxiety, depression and post-traumatic stress disorder (PTSD) are common experiences and emotions after transplant. Recognizing what they are can make it easier for you to take action to help you feel better.

Fatigue is a constant lack of energy and extreme tiredness that does not go away with sleep or rest. Almost all transplant recipients feel weak, exhausted, or slow for some time. But it's important to recognize the difference between fatigue and tiredness. Remember these key points and talk to your doctor if you think you may be experiencing fatigue. Fatigue:

- Is typically not caused by too much activity
- Can be caused from changes in your body due to transplant
- Can be caused by emotional stress
- Can develop into chronic fatigue – which is defined as extreme tiredness lasting six months or longer
- Can also lead to anxiety or depression

Anxiety can be described as excessive worry. Transplant recipients and caregivers spend a lot of time thinking about illness and potential challenges ahead. But you should talk to your doctor if constant worry disrupts your daily life or interferes with recovery.

Post-Traumatic Stress Disorder (PTSD) can be triggered by a traumatic or stressful event. The physical and mental shock of having a life-threatening disease and receiving treatment for the disease can be traumatic experiences for many patients. Some people may experience trauma-related symptoms similar to symptoms experienced by people who have survived highly stressful situations, or life-threatening events. Post-traumatic stress disorder includes symptoms such as avoiding situations related to the trauma, continuously thinking of the trauma, and being overexcited. Post-traumatic stress disorder:

- Can occur in people of any age, including children and adolescents
- Can also develop in caregivers
- Can interfere with relationships and a person's ability to function

Depression is ongoing feelings of sadness, despair, loss of energy, and difficulty dealing with normal daily life. It is more than feeling sad or "down" from time to time. If these feelings interfere with your daily life, it's time to seek help.

For Caregivers

Caregivers can experience the same anxiety and signs of depression as survivors, but are less likely to have their symptoms noticed and addressed. As a caregiver, it's important that you also have people you can turn to for emotional support.

Caregivers may also experience something known as emotional or compassion fatigue. The stress of caregiving can be overwhelming, and your attitude can change from feeling compassionate to frustrated and angry. It's important to not feel guilty about taking a break from your caregiving responsibilities to take time for yourself and take care of yourself. If you're feeling this type of fatigue, here are some ideas for coping:

- Find a trusted friend you can talk to about what you are experiencing
- Ask for and accept help from others
- Accept your feelings – feeling frustrated and angry is normal and does not make you a bad person or caregiver

Learn more – Review the resources included in this booklet to learn more about emotional health and how to access support resources designed for you.

Depression Checklist

Below is a general list of symptoms of depression. If you have any of the following symptoms for most of the day, every day for two weeks or more talk to your doctor about being screened for depression. If you are diagnosed with depression, getting help is important for your health.

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

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

You can contact the National Suicide Prevention Lifeline at **1-800-273-TALK** (8255) any time – 24 hours a day, 7 days a week. Contact them to talk with someone who can help.

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

An interactive depression screener is also available from Mental Health America. Please visit: [mentalhealthamerica.net](https://www.mentalhealthamerica.net) and search “depression screener.”



“For the first three months after transplant I was severely depressed. I was in a ‘why me’ state for a while. I didn’t want to [get] out of bed. My doctor prescribed anti-depressants. That, along with the support from my mom, really helped. She literally took my hand and got me up, helped me take a shower and helped me get dressed. She did it one day at a time, but her consistency was what was beneficial for me.” — **Danielle**, transplant recipient



“I dealt with uncertainty and helplessness. I tried to be there for my wife, to do whatever I could to help her through the difficult times, but at the end of the day I had to recognize that I could only do so much. On the positive side, we had a lot to celebrate, and made a point of acknowledging every milestone we could.” — **Brian**, caregiver (with his family)

Getting help from your health care team

Your health care team is there to help you through every stage of recovery. Some people think they should be able to control their emotions and behavior through self discipline. But it's not realistic to think that you can just "get over it" and move on. There may be physical causes or side effects that can be treated.

Share your emotions and learn where you can turn for support

If you're concerned about emotional health issues, don't wait for your doctor to bring it up. Talk with your doctor about what's bothering you and find out what help is available. There may be things you can do for yourself, adjustments in medication, counseling resources, or groups of peers who can help you find solutions.

Your doctor might refer you to a therapist or counselor who is experienced in treating people recovering from a life-threatening illness. You might also ask about prescription medication to help you feel less afraid and tense.

To find a counselor, contact your insurance company for a list of practicing counselors in your area. If you do not have insurance, talk with a social worker at your transplant center or contact a community clinic in your area to identify other resources.

““ My health care team was great. They really understood what I was going through. They listened to me and validated that what I was experiencing was normal.”

— **Kathy**, transplant recipient



Things to consider when talking to your health care team

Talking honestly with your doctor about your feelings can be hard, but it's the first step to uncover problems and find solutions. You can use these questions to identify potential issues you'd like to discuss with your health care team.

Quality of life and general well-being

- How am I feeling overall? Better or worse than I expected?
- How is my appetite?
- How am I sleeping?
- How is my energy level?
- Am I able to enjoy activities the way I want to?
- How is my sexual health? Any concerns about desire, enjoyment or physical difficulties?
- How is my short-term memory, recall, and ability to concentrate?

Emotional well-being

- How is my overall mood?
- Do I often worry? Feel angry? Guilty? Depressed?
- Have I noticed what things make me feel better, or worse?
- Have I considered attending a support group or talking to a counselor?
- Have I talked about treatments for anxiety or depression?

Relationships

- How are my relationships – with my spouse or partner, family, friends?
- How am I dealing with any challenging issues or concerns?
- Am I asking for and getting the help I need? From whom?

Helping yourself

Eating well, exercising and getting enough rest are good for both emotional and physical health. Work at developing healthy habits that are fun and will help you stay on track. It may be hard at first, but the more you do the easier it can be. Here are some things you can do for yourself:

Make a plan

My favorite way to exercise: _____

Other activities to try: _____

If I want company, I can invite: _____

I will track my progress by using: _____

My best time of day is: _____

To make sure I am eating well, I will: _____

Activities that may make you feel better could include:

- Going for a walk
- Taking a yoga class
- Getting a massage
- Reading
- Listening to music
- Enjoying a favorite hobby
- Going out with friends

Benefits of developing healthy habits include:

- Strengthened immune system
- Improved sleep
- Reduced injury and illness
- Increased stamina and concentration
- Improved appearance
- Improved emotional health

Getting practical help from others

Think about who you could talk to for emotional and practical support: family, friends, clergy or trusted members of your community. Many people appreciate the opportunity to help. Getting help on some of the practical things in your life (such as transportation, housework, gardening or childcare) allows you to focus on your own emotional health needs. Make a list of tasks people can sign up for.

You can also get support from other transplant recipients and caregivers. Talking to people who understand your experience can help you sort out your feelings and find new ways to improve your situation.

How your relationships affect your emotional health

Many people rely on close family and friends for emotional support before, during and after transplant. It's not uncommon for some roles and relationships to change. For some people, this can be especially stressful. These changes can also cause stress and depression. You may feel grief or anger over someone who was not there for you. You might feel guilty about accepting support, or resentful of someone who has taken on your old responsibilities. It is important to deal with these issues and find ways to minimize the stress they cause.

Have your relationships changed since transplant? In what ways? Try these tips to help you communicate with those around you.

Tips to improve communication

- Ask for clarification to avoid misunderstandings.
- Tell people what you need.
- Tell people how you feel.
- Try to keep things in perspective and pick your battles.
- When something rubs you the wrong way, think about the person's intent. Can you just let it go?
- Look for the humor in situations. What's annoying one day might seem absurdly funny the next.
- As much as you can, avoid people and situations that aggravate you, and spend more time with people you enjoy.



“ My relationships became stronger with my family. But I actually had a lot of friends distance themselves from me. It taught me that during major changes in life, you realize who will stick by you. I was never mad at them, though. [I understand] it’s difficult to see someone go through a major illness.”

— **Kristin**, transplant recipient

Your coping style affects your emotional health

Some people thrive on staying positive. Others take comfort in accepting their situation as it is. Some feel better when they express their fears and frustrations. No one approach is best, and most people use a variety of coping styles.

Many people benefit from talking about their feelings with family, friends, other survivors or a counselor. Expressing your feelings can make it easier to let the feelings go. You might also consider participating in an online support group to get feedback from other people who understand your situation.

Other people prefer to process their feelings on their own. For them, focusing on anxieties or sharing them with others only increases the negative feelings. Trust your instincts and do whatever works best to help you feel better.

Stay open to exploring different resources. For example, many people who initially resist counseling or peer support later find it to be very helpful.

Remember that you are your own best advocate. Talk to your health care team, and to your family and friends, to get the help you need for your emotional health and well-being.

Helpful organizations and resources

This resource list was compiled by Be The Match. There may be additional resources for people living with cancer, transplant recipients and caregivers through your local hospital and community centers, or faith communities.

Marrow and cord blood transplant resources

Be The Match

We offer one-on-one support, financial guidance and free educational resources including emotional support for patients, families and caregivers before, during and after transplant.

(888) 999-6743

Email: patientinfo@nmdp.org

Website: BeTheMatch.org/patient

Blood & Marrow Transplant Information Network (BMT InfoNet)

Provides opportunity for transplant patients to connect with survivors and high-quality medical information in easy-to-understand language.

(888) 597-7674

Email: help@bmtinfonet.org

Website: bmtinfonet.org

BMT Support

Offers online peer-support groups for transplant patients, survivors and caregivers.

Email: bmt_support@bmtsupport.org

Website: bmtsupport.org

ExploreBMT

A one-stop online portal that provides transplant resources and support from a variety of patient-focused organizations for patients, families and caregivers.

Website: explorebmt.org

National Bone Marrow Transplant Link (nbmtLINK)

Offers information and support services for transplant patients, caregivers, families and the health care community.

(800) 546-5268

Email: info@nbmtlink.org

Website: nbmtlink.org

Emotional support resources and one-to-one support

American Cancer Society (ACS)

Provides online message boards and support groups for patients on maintaining physical and emotional health after cancer treatment.

(800) 227-2345

Website: cancer.org

American Psychosocial Oncology Society's (APOS) Toll-Free HELPLINE

Helps people with cancer and their caregivers find counseling services in their own communities. To request a confidential referral, please call.

(866) 276-7443

Website: apos-society.org/survivors/helpline/helpline.aspx

Cancer.net

Provides oncologist-approved cancer information from the American Society of Clinical Oncology to help people with cancer and families make informed health care decisions. It also offers emotional support to people living with cancer, caregivers and survivors.

(888) 651-3038

Email: contactus@cancer.net

Website: cancer.net

CancerCare, Inc.

Offers support to people with cancer, survivors, and caregivers through counseling, education, information, referral and financial assistance, and specialized programs.

(800) 813-4673 (HOPE)

Email: info@cancercare.org

Website: cancercare.org

Cancer Hope Network

Connects people with cancer to each other and provides links to general information on cancer and cancer treatment.

(877) 467-3638 (HOPENET)

Email: info@cancerhopenetwork.org

Website: cancerhopenetwork.org

Cancer Information and Counseling Line (CICL; AMC Cancer Research Center)

Helps people with cancer, survivors and their families by providing current medical information, short-term counseling and resource referrals.

(800) 525-3777

Cancer Support Community

Offers emotional and social support for people with cancer, family members and friends through networking groups, lectures, workshops and social activities.

1 (888) 793.9355

Email:

help@cancersupportcommunity.org

Website: cancersupportcommunity.org

Cancer Wellness Center

Provides counseling, information and support for people with cancer, families and survivors through open networking groups and support programs.

(866) 292-9355

Website: cancerwellness.org

Center for Mental Health Services (CMHS)

Offers information and free publications on mental health.

(800) 789-2647

Website: mentalhealth.samhsa.gov

Leukemia & Lymphoma Society (LLS)

Provides information and materials to improve the quality of life for people with cancer and their families, financial assistance, and patient-to-patient support.

(800) 955-4572

Email: infocenter@lls.org

Website: lls.org

LIVESTRONG SurvivorCare

Provides free professional support in English and Spanish to help you:

- Cope with emotional concerns through counseling
- Address your financial, insurance and job concerns
- Find clinical trials and new treatments in development
- Locate and access local resources
- Learn about physical, emotional and day-to-day concerns
- Get brochures about cancer issues

(866) 673-7205 – English

(866) 927-7205 – Spanish

Website: Livestrong.org/CancerSupport

National Cancer Institute (NCI)

Provides health information and programs for the continuing care of people with cancer and their families. It also provides support and resources for life after cancer treatment.

(800) 422-6237 (1-800-4-CANCER)

Website: cancer.net.gov/cancertopics

National Coalition for Cancer Survivorship (NCCS)

Offers educational publications and programs for people with cancer. It also provides referrals and advocacy for the rights of people with cancer and survivors.

(888) 650-9127

(877) 622-7937 (to order publications)

Email: info@canceradvocacy.org

Website: canceradvocacy.org

Caregiving resources

BeTheMatch

Provides tips and resources to help caregivers understand and cope with the challenges and feelings that come with being a caregiver.

Visit: [BeTheMatch.org/companion](https://www.bethematch.org/companion) to view or download PDFs that address topics such as emotional well-being, social support, communication, physical health and more.

Or visit: [BeTheMatch.org/patient-survive](https://www.bethematch.org/patient-survive) to download or order the caregiver issue of our *Living Now* newsletter.

Cancer Caregiving

Provides tools to help caregivers care for themselves, get help when needed, and plan for the future.

Website: [cancercaregiving.com](https://www.cancercaregiving.com)

Caregivers4Cancer

Educates and assures caregivers and oncology teams through support services, guidebooks and information.

(972) 513-0668

Email: betty@caregivers4cancer.com

Website: [caregivers4cancer.com](https://www.caregivers4cancer.com)

Family Caregiver Alliance

Offers support to families who are caring for a loved one through information and advice, fact sheets and publications, newsletters and support groups.

(800) 445-8106

Email: info@caregiver.org

Website: [caregiver.org](https://www.caregiver.org)

Family Caregiving 101

National Family Caregivers Association (NFCA) and the National Alliance for Caregiving (NAC) developed this online resource to provide caregivers with the basic tools, skills and information – such as how to care for themselves, assess their abilities, navigate the health care system, and find help – in order to protect their own physical and emotional health.

Website: [familycaregiving101.org](https://www.familycaregiving101.org)

National Alliance for Caregiving (NAC)

Offers research and programs to address family caregiver issues and strengthen state and local caregiving efforts.

Email: info@caregiving.org

Website: [caregiving.org](https://www.caregiving.org)

National Family Caregivers Association (NFCA)

Educates and supports caregivers by providing reports, statistics, information and links to further caregiving resources.

(800) 896-3650

Email: info@thefamilycaregiver.org

Website: [nfcares.org](https://www.nfcares.org)

National Institutes of Health (NIH) Clinical Center for Caregivers

Provides resources, events and research for caregivers.

Website: clinicalcenter.nih.gov/wecare

Strength for Caring

(owned by Johnson & Johnson)

Offers information for caregivers on how to care for themselves and others, provides a place for caregivers to connect with each other, and directs caregivers to additional resources.

Website: [strengthforcaring.com](https://www.strengthforcaring.com)

Well Spouse Association

Provides emotional support for partners of the chronically ill and/or disabled through support groups and information on practical issues facing partner caregivers.

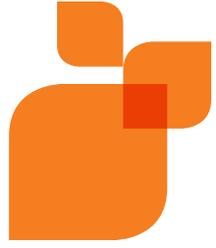
(800) 838-0879

Website: [wellspouse.org](https://www.wellspouse.org)

Young (Cancer) Spouses

Brings together young spouses of adults with cancer to share information, support and experiences online.

Website: [youngcancerspouses.com](https://www.youngcancerspouses.com)



About Be The Match®

Be The Match helps patients with leukemia, lymphoma and other diseases who need a marrow or umbilical cord blood transplant. People can join the Be The Match registry – the largest listing of potential marrow donors and donated cord blood units – contribute financially, and volunteer.

Patients and their families can also turn to Be The Match for support and resources 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: [BeTheMatch.org/patient](https://www.BeTheMatch.org/patient)

Order: [BeTheMatch.org/request](https://www.BeTheMatch.org/request)

Email: patientinfo@nmdp.org

Call: 1 (888) 999-6743

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



Patient Services, National Marrow Donor Program
3001 Broadway St. N.E., Minneapolis, MN 55413-1753
1 (888) 999-6743 | [BeTheMatch.org/patient](https://www.BeTheMatch.org/patient)