

Living **now**

A guide to life after transplant

Issue 1: Returning home



A new
beginning



On the cover: Jackie (left), donor to Paizley (right) transplant recipient

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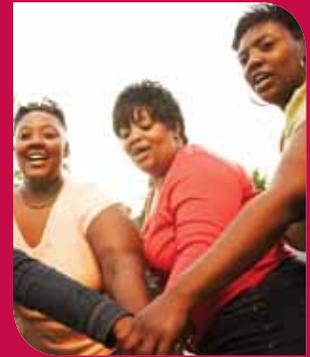
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Welcome to *Living Now*

This newsletter is the first 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.

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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A new beginning



Paizley, transplant recipient (right), with her donor, Jackie

After all the preparation, receiving your transplant may seem like reaching the top of a mountain. You have much to celebrate in reaching this milestone! As you move through recovery over the coming months and years, there will be many things you can do to promote your health and healing.

- Learn what to expect during recovery.
- Take precautions to protect your health.
- Learn the early warning signs and symptoms so you can act quickly to minimize complications.

During the first three to four months after your transplant, your immune system will be suppressed or slowly rebuilding. This immunosuppression makes you especially vulnerable to infection, which can range from mild to life-threatening. It is critical during this period for you to take extra precautions

“ Since the transplant, I’m getting better. I don’t have to go to the hospital as much as I used to, and I can now enjoy doing many things that I couldn’t before. Thanks to Jackie and all the other people who helped me, I will be able to make my hopes and dreams come true.” —Paizley

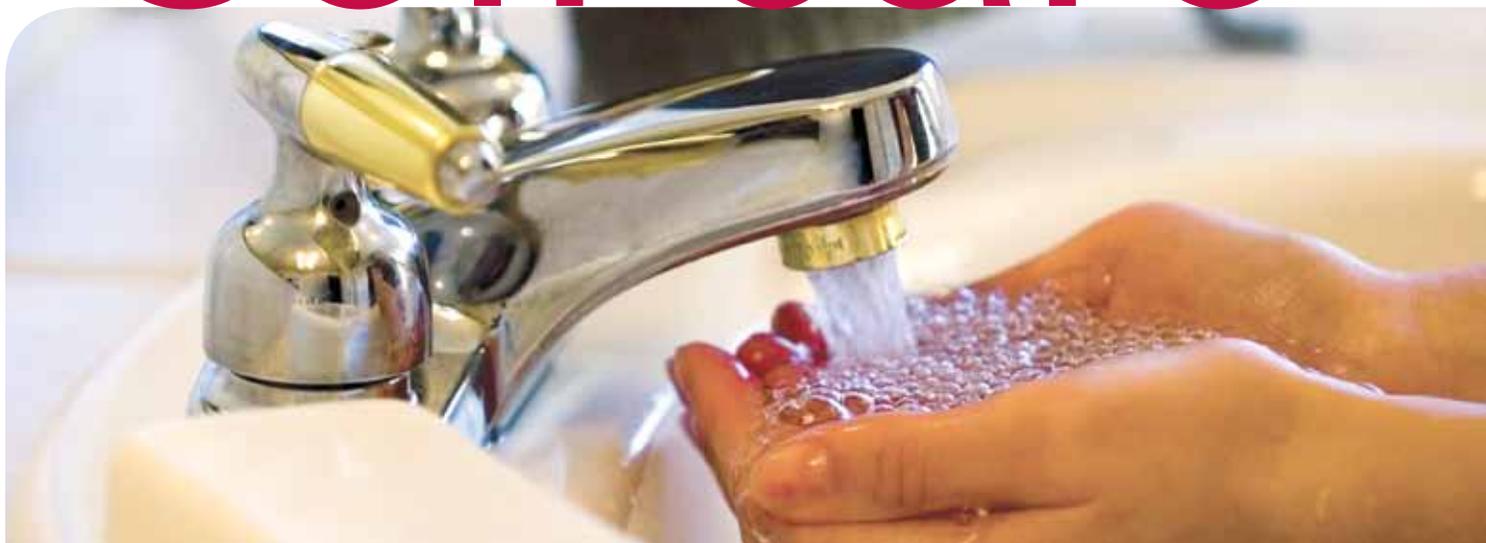
to protect yourself from the germs that are around us all the time in the environment, on our food and spread by animals and other people.

Until your immune system is able to protect you more thoroughly, you will need to take conscious control of your health. Many of the changes in your daily life are restrictions. These can be frustrating and difficult at times. It might help to focus on how your

choices are strengthening your body, restoring your health and nurturing your spirit. Concentrate on what you can do versus what you cannot do. Remember that most changes are temporary.

The more careful you are in following your doctor’s orders, taking precautions and watching for warning signs, the better it will be for your long-term recovery. ■

Keys to self-care



be your best

There are many things you can do related to self-care that will help you be your best. Some important suggestions are listed on the following pages, including information on food choices.

Keep your hands and body clean

Frequent hand-washing and daily bathing with soap and shampoo are two of the best ways to prevent infection. Follow your doctor's recommen-

dations for soaps and shampoos that are both mild and effective.

Be especially aware of washing hands after using the bathroom, touching telephones, doorknobs or other shared objects. Wash your hands before eating, drinking or taking medications. Make sure all family, friends and visitors follow a strict hand-washing policy. Insist that they wash upon entering your home and don't be shy about enforcing the policy.

Soap and disposable wipes should be conveniently located throughout the home. Buying antibacterial soaps in fun dispensers can help kids get in the habit of hand-washing.

Consider using **disposable towels** and wipes. Do not share towels or washcloths. Change clothing and towels daily. Change sheets once a week.

It is best to **avoid "dirty work"** while you are immunosuppressed. Have someone else clean up after pets.

If you have to change diapers or handle similar materials, use disposable gloves and wash after discarding them.

Your skin may be dry and sensitive.

Frequent washing and bathing might contribute to the problem. Discuss this with your medical team. They might prescribe special lotions or recommend products you can buy at your local drug store. If you notice a rash, tell your medical team right away, as it might be an early sign of GVHD.

Keep your mouth clean

Doctors recommend daily home use of fluoride brush-on gels, or custom fluoride trays to help prevent bleeding and infection. If you notice mouth sores, call your doctor.

Keep your environment clean

To lessen the risk of inhaling fungus and molds, stay away from areas while they are being vacuumed and stay indoors when anyone is mowing the lawn, using a leaf blower or doing anything else that stirs up dust.

You can reduce your risk of infection by keeping your house clean and disinfected. The goal is to reduce dust as much as possible. **Arrange for someone else to do as much of the house-keeping as possible.** You should avoid being in a room while it is being cleaned. Disposable cleaning wipes and paper towels are recommended. Apply cleaners to wipes to avoid spraying mist into the air. You can minimize dust in the air by using a floor sweeper instead

of a vacuum, and a damp mop instead of a broom.

Plants and soil contain bacteria, molds and fungi, so they should also be avoided until your immune system is back in action. As with pets, established plants in the home can stay, but do not bring in any new ones.

Ask family and friends to explain to well-wishers that you cannot accept any plants or flowers as gifts. Real Christmas trees and other holiday plants should also be avoided.

It is best to move plants to an area of the home where you will not be spending much time and have someone else take care of them. Many doctors recommend that you avoid outdoor gardening and yard work for the first year post transplant.

Breathe clean air

You do not need to wear a mask at home, but it is a good idea to **change the air filters on your furnace** once a month. Air purifiers such as a HEPA filter are OK to have, but not necessary.

Don't smoke and avoid second-hand smoke. To avoid soot, don't use fireplaces, candles, oil lamps or incense. If you enjoy candles, consider getting some safe and realistic, battery-operated LED candles.

Avoid new construction, sawdust and environmental chemicals such as glue or paint.

Pets & animals

Many people have strong attachments to their pets, and having them around can be important for a person's emotional well-being. Most established dogs and cats can stay in the home, but no new pets should be brought in. Arrange for someone else to do the feeding and cleanup, and limit your physical contact with pets as much as possible during your recovery.

Dogs: Do not let dogs sleep with you or lick you. Wash yourself after any contact.

Cats: Do not allow cats to go outside. Do not clean the litter box. Do not allow cats into areas where you eat, sleep or spend extended periods of time.

Fish: A home aquarium is fine as long as someone else cleans it regularly.

Birds: Many transplant centers do not recommend birds. However, if you would like to keep an established bird, have someone else clean the cage.

Reptiles: Not recommended.

Patients in rural areas: You should avoid barns, fields and contact with farm animals.



Ashley, transplant recipient, with her dog

A strong offense...

- Clean hands & body
- Clean environment
- Protection from the sun
- Clean air
- Safe foods

...is the best defense



Ed, transplant recipient (middle), with his family

► Relax! Arrange for someone else to do as much of the housekeeping as possible.

Protect yourself in public

Try to avoid crowds by visiting public places like stores, restaurants and theaters at times when they are less busy. Follow your doctor's advice about when to wear a mask, and visiting public places.

Bring several pairs of protective gloves and disinfectant wipes with you to use in public restrooms or other locations where you might be at increased risk of infection. Always wash your hands again when you return home.

Additionally, avoid swimming in lakes, pools and hot tubs, both public and private.

Protect yourself from the sun

Exposure to the sun's ultraviolet rays increases your risk for developing GVHD. The best way to avoid GVHD is to take your medications as prescribed and stay out of the sun. When you go out during the day, limit your time in the sun as much as possible. Wear a hat, long sleeves and long pants. Apply sunscreen (SPF 30 or higher) to any exposed skin. Do not forget your face, back of neck, hands and feet. Some patients also wear special clothes with SPF in them.

Remember that ultraviolet light is invisible: Daylight on a cool, overcast day can be just as damaging as hot, bright sunlight.

Protect yourself from injury

Your new marrow also makes platelets that help with clotting. If your platelet count is below normal levels, you might be at increased risk for bleeding. If this is the case, you need to be careful to avoid injuries that could cause bleeding.

- Do not use knives, scissors, nail clippers or other sharp objects until your platelet count is greater than 50,000.
- Use an electric razor, rather than a straight-edge razor.
- Dab at your nose gently. Do not blow your nose forcefully.
- Use a stool softener if you tend to be constipated. Don't strain.
- Do not use rectal thermometers or suppositories, enemas, tampons or douches.
- Avoid strenuous activities that have potential for injury.

If you have an injury that bleeds, apply pressure over the injured area. Keep applying pressure until the bleeding stops, which might take several minutes (5 to 10 minutes). If the bleeding does not stop, apply ice, maintain the pressure and call your doctor or go to the emergency center. ■

Take precautions around visitors

- Alert visitors to your needs before they come over.
- Do not allow contact with anyone with symptoms of a cold, flu or rash, or people who have been in close contact with sick children.
- Avoid children who have been immunized within the previous four weeks.
- Ask visitors to remove their shoes to avoid tracking in dirt.
- Insist that everyone wash their hands as soon as they arrive.
- It is OK to trust your instincts, keep your distance, cut visits short and wash afterward.
- Teach visitors the "elbow bump" greeting used in hospitals.

food choices

Choose foods carefully

Eat only foods that are clean and safe

Good nutrition is important to regaining your strength and health, but until your immune system is fully functioning, all non-sterile foods and drinks pose a dangerous risk for infection.

Follow your medical team's instructions for safe eating and food handling. Use the menus and recipes they provide. Talk to your medical team about favorite foods and preparation techniques that might not be covered in their guidelines. Your dietitian might be able to help you modify your recipes to minimize any risks.

When grocery shopping

Use your knowledge about foods that are safe for an immune-suppressed person. Shop for items that are healthy, convenient and meet your personal requirements.

Safer choices

- Buy mostly prepared, packaged foods in boxes, cans or frozen.
- Buy pasteurized foods.
- Check freshness and expiration dates.
- Check that packaging is not damaged.
- Make sure frozen foods are frozen solid.

Note: Most tap water is safe, but if you have concerns about your water quality or get your water from a well, use bottled water instead.

Fresh foods require extra precaution

This includes meats and poultry, eggs, fruits, vegetables, beans, grains and herbs.

This restriction can be especially difficult for people with a strong personal or cultural preference for using fresh

ingredients. If ready-made versions of your favorite foods are not available or just do not work for you, talk to your dietitian. He or she can help you figure out ways to safely prepare your favorite foods or come up with alternatives.

Items to AVOID

Do not buy:

- Bulk foods or items from self-service bins
- Deli meats, cheeses, pre-made salads, entrees, etc.
- Unpasteurized versions of honey, milk, cheese or yogurt
- Unroasted nuts or nuts in the shell
- Aged cheeses such as certain sharp cheeses or moldy cheeses such as brie and blue cheese



Jenny, transplant recipient

Caffeine and alcohol

Caffeine can dehydrate you, putting extra strain on the kidneys. Caffeinated and carbonated drinks can also contribute to diarrhea and gas. If you do drink colas, coffee, tea, etc., enjoy them in moderation and make sure to drink extra water or other hydrating beverages to offset the effects.

Avoid alcoholic beverages for at least the first six months after transplant, and discuss it with your doctor before you resume drinking. Alcohol's negative effects increase after transplant, and it can cause dangerous interactions with medications.

Dining away from home

Talk to your doctor about when it is safe to visit restaurants. Avoid crowds by calling ahead and visiting during off times.

When eating in a restaurant, request that your food be brought to you as soon as it is ready, even if it arrives before your companions' food. Explain to your server that it is important that your food does not sit under the warming lights.

Foods and venues to AVOID when dining out:

- Foods that you don't know how they were prepared or stored
- Ice from ice machines and soda fountains
- Sodas from fountain machines
- Salad bars and delis
- Soft-serve ice cream and frozen yogurt from machines
- Free samples
- Unrefrigerated cream
- Foods from sidewalk vendors
- Foods containing raw eggs (Caesar salads, custards, cookie dough)
- Sushi, raw fish, smoked fish
- Buffets

Ideas to make eating easier and more enjoyable

Many transplant recipients experience a decrease in their appetite or a change in their taste buds. These are usually temporary side effects of treatment. **Work with your dietitian to plan meals** that are both satisfying and meet your nutritional needs.

- Use pre-packaged, single-serving foods that are safe and easy.
- Rinse your mouth with a solution of water and baking soda before eating.
- Try chilled or frozen foods.
- If food tastes metallic, use plastic utensils and try mint or ginger to cover the taste.
- Eat small amounts throughout the day instead of larger meals.
- Drink six to eight glasses daily of fluids such as water, sports drinks, juice or clear broth.
- If your stomach or GI tract is irritated, avoid fried, fatty, spicy and acidic foods, such as tomato juice.
- Help prevent diarrhea by eating low-fiber foods like white bread, rice, eggs, potatoes, cooked fish and chicken without skin.



Everett, transplant recipient (right), with his family

Store and prepare foods safely

Safe food storage

- Take your groceries home directly from the store and put them away immediately.
- Make sure refrigerated foods stay cold and frozen foods stay frozen.
- Pay attention to freshness dates and throw away expired foods.
- Date foods once they are opened.
- Make and store foods in small portions so they get used more quickly.
- Do not eat refrigerated foods that have been left out for more than two hours.
- Do not eat any foods that have been in the refrigerator for more than three days.

Safe food preparation

- Use hot, soapy water to clean surfaces where foods are prepared.
- Use disposable paper towels instead of sponges or rags.
- Use separate cutting boards, plates and utensils for raw foods and cooked foods. Especially avoid contact between cooked meats and raw meat juices.
- Clean cutting boards in a solution of one part bleach to ten parts water.
- Thaw frozen foods (including turkey) in the refrigerator, not on the counter or in the sink.
- Wash all fruits and vegetables before cutting them.
- Wash the tops of cans and can opener with hot, soapy water before use.
- Use a side-opening can opener so lids don't fall inside. (This also eliminates sharp edges.)
- Avoid handling raw meats, poultry and fish.
- Cook meats and poultry to a safe internal temperature.

► Follow your medical team's instructions for safe eating and food handling.

Use a kitchen thermometer to help prevent food-borne illness

According to the USDA, changes in color and texture are not reliable indicators of when foods are safe. A thermometer lets you know when the internal temperature is high enough to kill bacteria. Keep it clean and make sure it is designed for meat and poultry. Candy thermometers will not work.

Types of thermometers:

- Regular, oven-proof thermometers that go into food before cooking
- Digital thermometers used to test foods after cooking
- Pop-up thermometers, most often found in turkeys
- Microwave-safe thermometers that can only be used in microwave ovens ■

Safe temperature recommendations from the USDA

Ground meat and meat mixtures

Beef, Pork, Veal, Lamb160°
Turkey, Chicken165°

Fresh Beef, Veal, Lamb

Medium160°
Well Done170°

Poultry

Chicken and Turkey, whole180°
Poultry breasts, roast170°
Poultry thighs, wings, legs.....180°
Duck and Goose180°
Stuffing (cooked alone or in bird)..165°

(Temperatures in Fahrenheit.)

Fresh pork

Medium160°
Well Done170°

Ham

Fresh (raw)160°
Pre-cooked (to reheat)140°

Eggs and egg dishes

Eggs: Cook until yolk and white are firm
Egg dishes160°

Leftovers and casseroles....165°

Be on the lookout

early warning signs of infection & GVHD

Despite your best precautions, it is likely that you will experience some setbacks as an unavoidable part of the recovery process. Stay on the lookout for symptoms and take prompt action to get anything unusual diagnosed and treated. Early treatment can minimize complications.

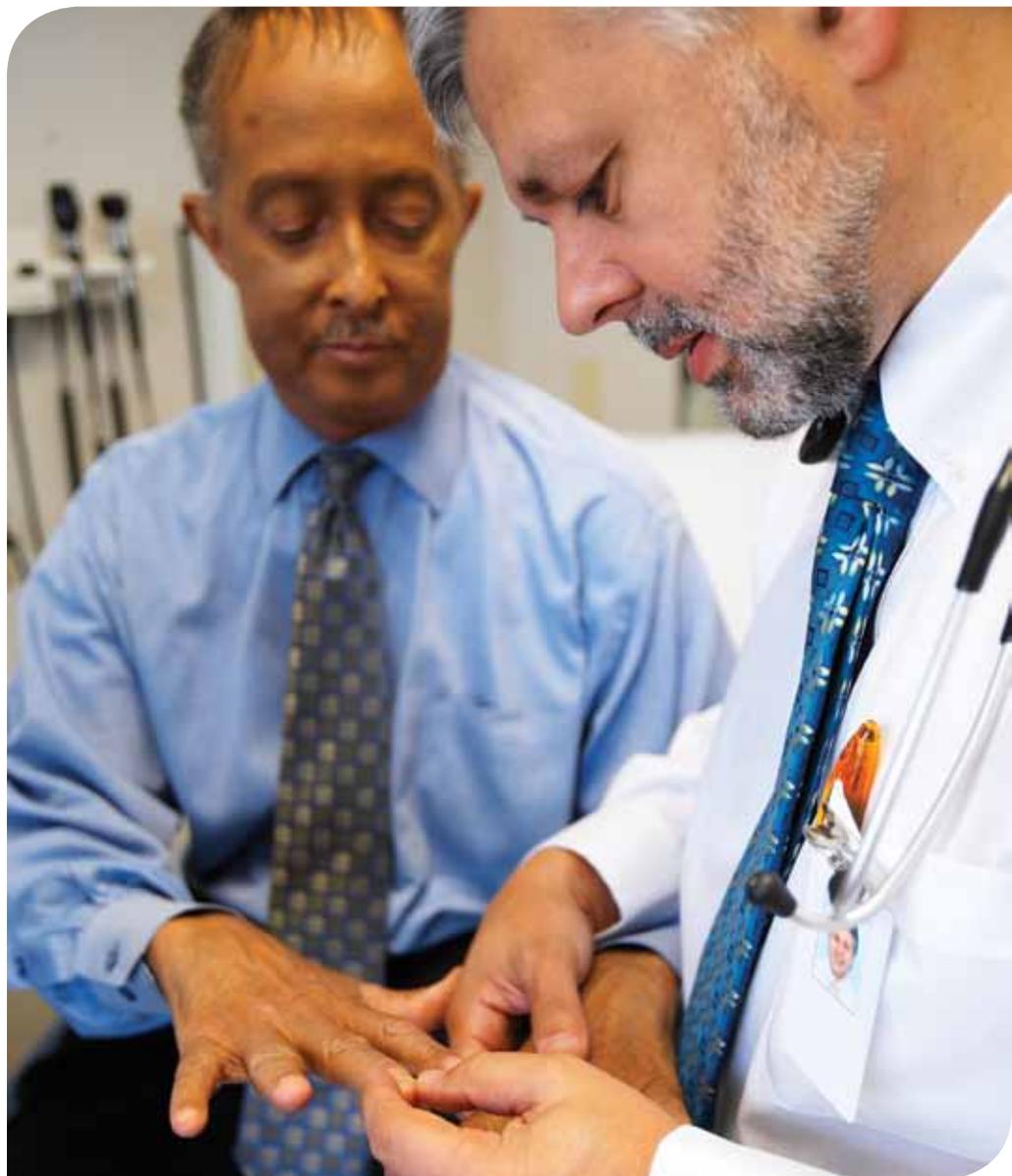
Take your temperature twice a day, and any time you feel ill or suspect a fever. Fever is an early sign of infection.

Weigh yourself twice a week. Let your doctor and dietitian know if you lose five pounds or more in seven days. Parents should check with their child's doctor as to what kind of weight loss to watch out for.

Graft-versus-host disease (GVHD)

Because of genetic differences between you and your donor, your new immune system might recognize your body's cells as foreign and attack them.

About half of all patients receiving a transplant from an unrelated donor develop some GVHD.



Everett, transplant recipient, with his doctor

Having GVHD might not be all bad. It has been found that for some diseases, patients who experience some GVHD have a lower risk of the disease returning after transplantation than patients who do not develop GVHD.

There are two forms of GVHD:

- Acute GVHD usually develops in the first three months post transplant.
- Chronic GVHD usually develops after the first 100 days post transplant, but signs and symptoms can appear earlier.

Act fast to address early warning signs

The early stages of recovery are tricky and early treatment can make a big difference in your long-term recovery. Many of the early warning signs listed below can be caused by an infection OR GVHD OR a side effect from treatment, which is why you cannot be too careful.

Keep your medical team’s phone list where it is easy to find.

- Call your medical team as soon as you notice any of the warning signs.
- Provide as much detail as you can about what you’re experiencing, noting the circumstances, the timing, etc. This will help your team figure out the cause of the symptom, and the best way to treat what is causing the symptom.
- Anytime you become seriously ill, call your medical team immediately.

Consider wearing a medical alert bracelet to let others know you have received a marrow or cord blood transplant. In case of an emergency, this bracelet can provide your contact information and important medical information.

A note to parents

If your child has received a transplant, refer to the list of early warning signs

every day and ask your child specific questions about any changes or problems. Stress to your child how important it is that he or she tell you right away about any changes. ■

► **Call your medical team as soon as you notice any of the warning signs below.**

Watch for early warning signs and take action

Do not ignore or underestimate early warning signs of infection, GVHD or side effects from treatment. Getting treatment early may prevent more serious complications. Call your medical team to report any symptoms you experience.

* may represent a medical emergency
 + symptoms that make it hard to swallow or digest medication require immediate attention

Whole body

- Fever (above 101°F)*
- Bleeding*
- Severe or long-lasting (more than 24 hours) headache*
- Confusion*
- Changes in memory or concentration
- Changes in weight
- Stiff, painful joints
- Weakness or fatigue

Stomach/digestive

- Difficulty swallowing+
- Stomach upset+
- Sudden or severe nausea/vomiting*
- Sudden or severe diarrhea*

Skin, mouth, nails

- Dry mouth, chapped lips, mouth sores*
- Changes to skin or nails
- Dry, irritated eyes

Lungs

- Dry cough, coughing*
- Shortness of breath*

Urinary/genital

- Painful urination*
- Blood in urine*
- Painful or difficult intercourse
- Symptoms of early menopause (hot flashes, mood shifts, etc.)

Not everyone experiences all of these warning signs or complications, but most people experience some of them. Some of these symptoms might develop into long-term challenges. Most are temporary and will go away with proper medical attention.

Understand your medications

uses and side effects



Ed, transplant recipient, with his doctor

Your immune system is your body's main defense against infection. It recognizes anything foreign in the body and attacks it. That is a good thing when it is attacking germs or diseased cells. But if the immune system you got from your donor thinks your body is the enemy, it needs to be suppressed so it does not do more harm than good.

It can be a complicated balancing act between strengthening your immune system to fight infection, and suppressing your immune system to control GVHD. Because each person's experience is unique, it is often a case of trial and error to get the balance of medications right.

Pay attention to symptoms (listed on page 11) and report them early to get the most effective treatment possible.

Treating infection

If your medical team suspects an infection, they will take cultures (blood, urine, stool, saliva) and might do other tests, such as a chest X-ray, to find out if the infection is bacterial, viral or fungal. Each type of infection requires specific treatments that your doctor will tailor to your needs.

Treating GVHD

The drugs used to prevent the immune system from attacking the body are steroids and immunosuppressants. These drugs prevent or treat GVHD by suppressing your body's immune system. Unfortunately, they also increase your risk for developing

Always remember

- Do not change or stop taking your medications without first consulting your doctor. Continue taking the medication even if you feel better. Stopping medications suddenly can make your condition worse or lead to life-threatening complications.
- Do not take less medication than your doctor prescribes in order to save money. You have to take the full amount in order to get the full benefit. If medication costs are too high, talk with your doctor about ways to reduce the costs.
- If you miss a dose, take it as soon as you remember. However, if it is almost time for the next dose, skip the missed dose and go back to your regular schedule. Do not take two doses to make up for a missed dose.
- Do not take any over-the-counter medications or herbal therapies or supplements until you have consulted with your doctor or pharmacist. These may cause harmful interactions with your prescribed medications.
- Refill medications before running out. Call in your refill right away, allowing four to five days for shipping if necessary. Check to see if your insurance carrier has a mail-order program for a 90-day supply of your medication at a reduced cost.

infections because they prevent your body from fighting off germs. These drugs help many patients, but not all.

Understand side effects

For any drug, whether for infection, GVHD or other reason, you will need to understand possible side effects.

- Ask your doctor what side effects you could expect with your medications.
- Ask if any side effects could be warning signs of an emergency.

It is especially critical to take drugs that treat GVHD or infection exactly as directed. If you change or stop taking your medication, it could lead to serious, life-threatening consequences. If you cannot take your drugs for some reason, contact your doctor immediately.

▶ It is especially critical to take drugs that treat GVHD or infection exactly as directed. If you change or stop taking your medication, it could lead to serious, life-threatening consequences.



Rob, transplant recipient

Tips for keeping track of your medications

You must take medications as directed to get the most benefit and minimize risks. Creating an organized system can make it easier to manage your medications.

Consider the following suggestions and pick what works for you.

Tip 1: Keep a master list of all the medications you are currently taking and all the medications you have ever taken. It is good to keep a list like this on a

computer if you have one, making it easier to update. Include the dates and dosages for any medications you are taking. You may also want to include color, shape, how the medication should be taken and pharmacy source.

Tip 2: Take your list with you to doctor's appointments to help you remember which drugs you're taking. You should also keep a copy in your wallet or purse in case of emergency.

► Use any combination of these tips to create your own system to take your medications correctly.

Tip 3: Use a medication check-off chart to keep track of when and how to take your medications. A bulletin board or dry erase board works well. Keep the chart where your medications are stored and display it so it is easy to read. (NOTE: Do not keep pills in the bathroom. Heat and humidity can have an adverse effect on your medications.)

Write out the times of day on the board and the medications you should take at that time. Check off each medication as you take it. Erase your check-marks and start fresh each day.

Consider color-coding your chart, especially if it is hard to read the prescription labels. Use different colored labels or markers to code the labels of the medication containers. When you take a medication, mark your chart in a color that matches the color on the label of the container. It is not recommended to mark the caps, as caps can be returned to the wrong containers. When refilling a prescription, give the new container its proper color code.

Tip 4: Use a pill case that works with your schedule, preferably one that you only have to refill once a week. Talk to your doctor or pharmacist about what products they recommend. Make sure that individual compartments are large enough to easily hold multiple pills. Consider using an electronic organizer with a built-in alarm as a backup reminder. ■



Danielle, transplant recipient (second from left), with her sisters

Emotional recovery, coping and relationships discover what helps YOU feel better

Recovery after transplant is more than just a physical process. It also affects you mentally, emotionally and spiritually. Practicing your preferred coping style to manage stress can help support healing as well as improve your quality of life.

Different people have different coping styles. Some people are fighters. Some people thrive on maintaining a positive attitude. Others take comfort

in accepting their situation as it is. Some release stress by expressing their hopelessness and despair.

Some people use a consistent coping style but most people rely on a variety of strategies. You might be upbeat one day and need to vent the next.

Trust your instincts and pay attention to what works best for you. Well-meaning family and friends who urge you to simply “look on the bright side”

- ▶ **Build your own support team.** Ask trusted friends and family members to help keep an eye on you and be your advocate.



Betsy, transplant recipient, with her donor, Tobias

or “be more positive,” might actually add to your stress if “being positive” is not the style that is working for you at that time. Let people know what you need from them in terms of emotional support.

Regardless of your coping style, there are common things you can do to promote healing and improve your quality of life.

Eat well, exercise as much as you can and rest when you need to. Even if you do not feel like exercising or eating, keep in mind that every little bit helps, and the more you can make yourself do, the more you will benefit.

Energize yourself with activities you enjoy. Anything that relaxes you and that you enjoy can be beneficial. If your temporary restrictions stop you from doing your favorite activities, explore new interests and develop new skills.

You might **set a goal for yourself** to learn one new activity or explore one

new interest during your first three months at home. Encourage a family member or friend to try a new interest with you. Remember your safety precautions when exploring new activities, and check with your medical team if you have any questions.

Exploring different relaxation techniques

Many people find that they can reduce stress by using exercises that involve breathing, muscle relaxation and imagery. Check out a variety of books, tapes and articles until you find an approach that appeals to you. Keep in mind that it will probably take some practice before you begin to feel the benefits. Sample relaxation exercise: While sitting comfortably, breathe in deeply while thinking, “I am,” then exhale slowly while thinking, “relaxed.” Repeat.

Get in touch with your spirituality. Many people benefit from spiritual practices such as prayer, meditation and rituals that help them feel connected to a healing energy or higher power.

“

Accepting my emotions, addressing them, and trying to maintain my optimism whenever possible are strategies that have been essential to my survival.” — **Betsy**

Whether or not you feel “religious” or follow any particular faith tradition, you might want to explore spiritual practices that appeal to you—even if they are different from the practices of your friends or family.

Dealing with friends, family and others

Your illness and recovery might change how you relate to your family and friends. It might affect your outlook on life or how you see yourself. Changes in roles can put stress on the family. This is especially true when people have conflicting expectations about caring for children, maintaining the home or returning to work.

During treatment, your caregiver and support network take on a tremendous amount of additional responsibility. Things get put off. Some things might even fall apart. When pushed to such extremes, feelings of guilt, resentment, anger and frustration are common.

It might be a long time before you are

able to resume your old activities. Roles and responsibilities within your family might even be changed permanently. It is important to deal with these issues and find ways to make the “new normal” work.

Remind people around you that you want to contribute. Come up with creative ways to do things. Remember that having something to do, and getting it done is more important than the speed and efficiency with which it gets done. You may have to relax your standards and give up some control. No two people cook the same, clean the same or even fold laundry the same. It is not unusual for differences over these simple activities to cause frustration.

Try to keep things in perspective, pick your battles and practice letting go. Keeping your sense of humor and getting support from someone who understands your situation can really help.

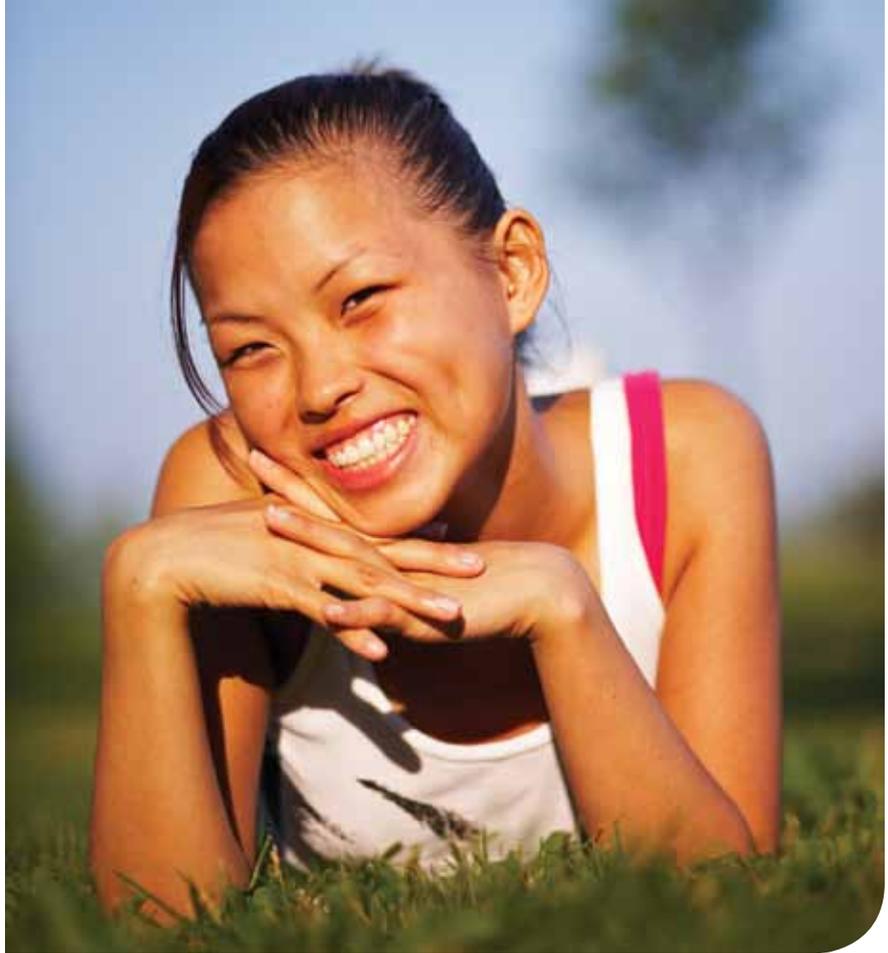
Getting help for family conflict

Everyone has some “negative” personality traits that can get worse when they are under stress. Controlling people tend to become more demanding, judgmental people tend to become more critical. People with addictions or dependency issues tend to use their substance more. Excessive conflict and negativity can interfere with your recovery.

If you are worried about stress and conflict in your family, tell your medical team. They can refer you to counselors who understand illness and recovery.

Dealing with changing relationships

Friendships can also change or take on new meaning. Many people are afraid of illness and choose to avoid it. They might not know what to say or do around you. Some people are unwilling or unprepared to deal with the emotions involved.



Mary, transplant recipient

Celebrate your achievements

If your progress seems slow, or if you experience a series of setbacks during your recovery, it can be discouraging. Setting goals and celebrating your achievements can help you see the bigger picture of your recovery. Celebrate special dates like your first 100 days, six months and one year. Celebrate improvements in your blood counts, strength, stamina and appetite. Celebrate your returning hair or anything else that reminds you of how far you have come.

Don't believe everything you worry about. Despite your efforts to maintain a healing attitude, there might still be times when worries and fears seem overwhelming. It might help to remember that your brain is just offering up different ideas it thinks might be helpful. Feel free to simply disregard those ideas if they do not contribute to healing. Talk to your health care team to see how realistic—or not—your fears are.

Acknowledging your fears and reminding yourself that you have done everything you can to address them, can give you a greater sense of control and help keep fears manageable.

Sometimes friendships dissolve. Sometimes they become stronger. It is likely that you will also make new friends and find new sources of support. As with all other aspects of recovery, it is best to take it one day at a time, look for the best in the present moment, and let go of the past.

Separating from your medical team

No matter how much you looked forward to leaving the hospital and returning home, the transition can be stressful. In the hospital, expert care was available at the touch of a button. Your daily routine was clear. While time in the hospital can be boring or frustrating, it can also be comforting to know that other people are responsible for your well-being.

Leaving the hospital can feel like venturing onto a tightrope without a safety net. It is important to remember that

your medical team would not discharge you unless they thought you were ready, and they are still just a phone call away.

You might also miss your doctors and nurses on a personal level. It is common to develop an emotional bond with the people who have cared for you. You might want to send a letter or postcard to let them know what they have meant to you. As you adjust to life at home, family members, friends and neighbors can help provide the emotional support that you might have gotten from your medical team.

Coping with separation anxiety

If you feel anxious about being separated from your medical team, talk to them about what would be appropriate if you just want to check in from time to time. It can be a comfort just knowing you may call.

Take advantage of support groups and counselors. Athletes rely on professional coaches and trainers to help them avoid injury and maximize their abilities. In the same way, you can rely on counselors and support groups to aid in your recovery. Many transplant recipients find that talking to people who really understand the experience can inspire and motivate them in ways no one else can.

Recognize and treat depression. Almost everyone who has dealt with a serious illness experiences some anger, sadness, fear and anxiety. These feelings usually lessen and go away over time. But for some people, these emotions do not go away. They interfere with daily life. This kind of depression is a medical condition. Some medications are known to contribute to depression. Let your medical team know if you feel depressed so your condition can be evaluated and treated. ■

Nurture yourself with family and friends



Ashley, transplant recipient (lower left), with her family

Continue to follow your medical team's advice about visitors, but stay connected as best you can. Corresponding by phone, letters or e-mail can be a great alternative to face-to-face contact.

Many people feel uplifted and energized by visiting with people who love and care for them. But if socializing is draining to you, feel free to set limits and end visits before they exhaust you. Limit your contacts as much as you can to people who make you feel better. Your first priority is to your health and well-being, not to satisfying other people's expectations.

To get the most out of your social visits, set good boundaries and ask your caregivers to help you enforce them.

Post-transplant resources

One of the most important things to remember throughout the recovery process is that you are not alone. Be The Match patient services is here to help (see back cover). 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 Cancer Society® (ACS)

As a cancer survivor you have special needs and interests. Learn to develop healthy habits now that your treatment is over. Connect with other survivors and find opportunities to volunteer.

website: cancer.org

Blood & Marrow Transplant Information Network (BMT InfoNet)

BMT InfoNet strives to provide high-quality medical information in easy-to-understand language, so that bone marrow and blood cell transplant patients can be active, knowledgeable participants in their health care planning and treatment. BMT InfoNet's Patient-to-Survivor program links patients to survivors who can share information and provide emotional support.

website: bmtinfonet.org

CancerCare

CancerCare is dedicated to helping people face the many challenges of a cancer diagnosis. Provides free professional help to people with all cancers through counseling, education, information and referral and direct financial assistance. CancerCare has an online forum for post-treatment cancer survivors.

website: cancercare.org

Facing Forward Cancer Survivor Series

Includes publications on life after cancer treatment.

website: cancer.gov/cancertopics/life-after-treatment

LiveStrong®

Information that helps you to live strong through the physical, emotional and practical challenges of your survivorship.

website: livestrong.org

Lotsa Helping Hands

An easy-to-use, private group calendar, specifically designed for organizing helpers.

website: lotsahelpinghands.com

National Bone Marrow Transplant Link (nbmtLINK)

The mission of the National Bone Marrow Transplant Link is to help patients, caregivers and families cope with the social and emotional challenges of bone marrow/stem cell transplant from diagnosis through survivorship by providing vital information and personalized support services. Peer Support On Call program offers emotional support through one-on-one conversations with volunteers who are transplant survivors, caregivers and donors.

website: nbmtlink.org

Office of Cancer Survivorship, National Cancer Institute

Office of Cancer Survivorship, National Cancer Institute—dedicated to enhancing the length and quality of life of cancer survivors.

website: survivorship.cancer.gov

Living Now e-newsletter:

Staying connected after transplant just got easier

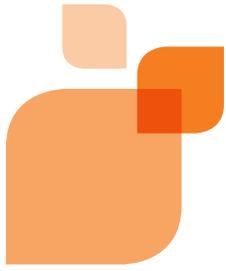


This free e-newsletter is designed just for transplant recipients and their families.

- **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.

SUBSCRIBE NOW

BeTheMatch.org/patient-news



Living **now**

A guide to life after transplant

Issue 1: Returning home

Support for patients

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. Our goal is to help you learn more about transplant as a treatment option, the overall transplant process and what to expect after transplant.

No question is too big or too small; we can help you find answers. If we don't have what you need, we'll connect you to someone who does. We're here for you.

Call: 1 (888) 999-6743

Learn: BeTheMatch.org/patient

Order: BeTheMatch.org/request

E-mail: patientinfo@nmdp.org



Three years after her marrow transplant, Betsy is cancer-free and active. Along with raising their two young daughters, she and her husband now volunteer to help educate patients about transplant and to raise awareness of our Be The Match Registry®.

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. This information 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

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 more at BeTheMatch.org/patient or call 1 (888) 999-6743.

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