A patient checklist

Getting ready for your transplant

This checklist is a guide to help you prepare for your transplant. Some items will not relate to your situation. Although the list is long, please do not let it overwhelm you. You might use this list to help you develop questions for your transplant center coordinator, social worker or financial representative.

Self advocacy

- ❒ Identify what works best for you in terms of understanding information on your upcoming treatment. You might want things explained in writing or you might want to have a friend or family member present to hear information with you. A tape recorder is an option if you want to play back important information later.
- ❒ Ask your doctor about how long he or she thinks you will need to stay at the transplant center. Identify someone to be your caregiver during and after your inpatient stay at the transplant center. This could include immediate family members or friends. Most transplant centers expect that you have a caregiver to stay with you when you return home.
- ❒ To help your caregiver in understanding his or her role, ask your physician what is expected of the caregiver. How long will you need a caregiver? When do they need to be with you? What types of activities will they be asked to perform? Could more than one person serve as a caregiver?

Choosing a caregiver

- ❒ Sometimes you might feel that you do not have a choice in who will be your caregiver. If you have more than one option, ask yourself how comfortable he/she feels in the hospital/clinic setting.
- ❒ Does your caregiver have the patience needed to wait for long periods (e.g., for procedures or doctors' visits)?
- ❒ Are you and your caregiver able to resolve differences?
- ❒ Will your caregiver understand your health care choices?
- ❒ Are there a number of support people within your family/friends network that could rotate the caregiver role?
- ❒ Is your caregiver able to get Family Medical Leave for an extended absence from work?
- ❒ Discuss with your spouse or significant other the ways in which your relationship might change after the transplant. You will have to depend on him or her for more help with your care. That might put a strain on the relationship. Think about how you can work to make these changes less stressful.

Personal care

- ❒ Both you and your caregiver might need to complete routine dental and medical appointments prior to transplant if your transplant center is far from home. Your caregiver might need a plan to get prescriptions renewed.
- ❒ If you or your caregiver are under a specialist's or therapist's care, discuss the care plan to follow while away and arrange for possible follow-up care near the transplant center. Ask your current doctor what you should do if you need professional care while you are in another city or state.

Family and friends

- ❒ Set up family meetings to talk openly about the transplant and the plans you and your family need to make.
- ❒ If you have children or grandchildren, explain to them in words they can understand why you are going to the transplant center. You might use books, photos or videos to help them understand.
- ❒ Talk to your children about what will happen to them while you are in the hospital. Identify who will be with them, how their schedules will be kept and how you will communicate with them if you are separated. If you want assistance in talking to a child, contact your hospital social worker or child life specialist.
- ❒ Discuss your own needs and concerns with your spouse, partner or significant other.
- ❒ Consider setting up an appointment with a counselor to assist you and your family in preparing for transplant.
- ❒ Participate in a send-off gathering with family and friends. Have pictures taken to bring with you.
- ❒ If friends and family want to know how they can help or what they can send, consider long-distance calling cards, snacks, meal certificates, notes of encouragement and videos of family and friends.

Finding support

- ❒ Support groups for adults or family members often help during stressful times by providing answers to commonly asked questions and mutual support from others who have been in similar circumstances. See Patient resources on pages 51 through 56 for organizations that provide these resources.
- ❒ Support comes from many sources. Reach out to work colleagues, neighbors, community organizations, religious or spiritual groups, extended family or supportive friends. Some might offer to provide meals for family members at home while you are at the hospital. Others might offer to provide rides for children to school activities.
- ❒ Online support can be found for information, connecting with transplant survivors or talking electronically with others. Remember that medical opinions shared by others or information received over the Internet does not substitute for advice given by your doctor or transplant team.

Financial

- ❒ Veterans should contact their Veteran's Administration office to inquire about eligibility for any programs based on service record and disability.
- ❒ Fundraising might be done locally on your behalf. You might want the experienced advice of a fundraising organization if you anticipate uncovered medical expenses (National Foundation for Transplants, 1 (800) 489-3863, or The National Transplant Assistance Fund, 1 (800) 642-8399).
- ❒ Some organizations offer limited financial assistance to help with costs not covered by insurance. Check with your transplant center for additional resources.
- ❒ The Federal government has two income insurance programs available for adults: Social Security Disability and Supplemental Security Income. Eligibility is based on a determination by your physician that your disability will last one year or longer. You might qualify to start

receiving benefits at an earlier date. You should talk to your transplant social worker or contact Social Security at 1 (800) 772-1213. Those who qualify for Supplemental Security Income, (SSI) based on meeting minimum income requirements might also be eligible for Medicaid, which can help cover medical care costs.

- ❒ Keep extra checks, deposit slips, and your ATM/debit/cash card on hand. Make sure you and your caregiver know your Personal Identification Number (PIN) number in case you need to access cash from an automated teller machine (ATM). Do not store these things in your hospital room or hotel room. Your caregiver should keep these for you.
- ❒ See a financial counselor for longer term financial planning.

Employment

- ❒ Contact your employer to make arrangements regarding absence from work. Seek out your employee human resources representative to help you understand your benefits and responsibilities in order to qualify for disability and continuation of insurance. Know your rights regarding COBRA insurance benefits, work disability and Family Medical Leave.
- ❒ If you are covered under your employer's disability plan (short or long term), the employer will assist you in determining when to apply for Social Security Disability.

Legal

- ❒ Many employers have employee assistance programs that include access to legal advice. You might be interested in completing a will, a trust, planning guardianship (if you are a single parent), completing a living will or designating power of attorney. If you do not share a joint checking account, you might want to designate someone to handle your financial affairs temporarily.
- ❒ Depending on how complicated your financial or legal affairs are, you might want to consult a financial or family law attorney. Contact your local bar association for referral.
- ❒ You might want to know your rights under the Americans with Disabilities Act, which protects you against discrimination upon your return to work.
- ❒ If you have children under the age of 18 who will be separated from both parents, you need to give permission for another adult to take them for medical care (emergency or routine) in your absence. Generally, a signed statement will suffice, but you should check with your child's doctor.

Travel & lodging

- ❒ Check with your insurance carrier to see if your benefits cover travel, meals and lodging for yourself and a caregiver.
- ❒ Ask your transplant center about lodging resources near the transplant center. Ask for costs and whether you need to put your name on a waiting list. The National Association of Hospital Hospitality Houses Inc. might also list lodging options in the area. Call 1 (800) 542-9730.
- ❒ If you will have to travel to a transplant center, make travel arrangements. You might want to ask family members if they have frequent flyer miles available to assist you. If you need assistance for travel, you might contact the National Patient Travel Helpline at 1 (800) 296-1217 for resource information or patienttravel.org.

Faith and spirituality

- ❒ If consistent with your beliefs, arrange ways to keep in touch with your faith community. Other members might want your address to send cards and give encouragement.
- ❒ p Many faith communities have rituals for healing or have other important ways of offering support. You might want to discuss this with your faith leader.
- ❒ There might be connections to your faith community in the city where your transplant will take place. You might want to have a local contact for additional support.

Before leaving home

- ❒ Prepare a packing list. Think of clothes for different temperatures and seasons, if appropriate. Include some family photos or posters that might brighten your hospital room or temporary living space.
- ❒ Bring phone lists, addresses, e-mail addresses and a phone card to use for long-distance calls while you are away from your home phone.
- ❒ Arrange for someone to look after your home or apartment while you are away.
- ❒ Consider how bills will be paid in your absence. When possible, pay ahead. You might consider checking with certain loans (such as car, student loan, etc.) about the possibility of temporary deferment (grace period) of payments due to medical disability.
- ❒ Have your mail forwarded, or arrange to have someone screen your mail for you while you are away.
- ❒ Make arrangements for someone to care for your pet during your intensive treatment. Most temporary lodging facilities do not have accommodations for pets.

Special Contributions

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For further assistance, please contact the Office of Patient Advocacy toll-free at 1 (888) 999-6743 or (612) 627-8140.

Available in the following languages: English.

The National Marrow Donor Program® (NMDP) helps people who need a life-saving marrow or cord blood transplant. We connect patients, doctors and researchers to the resources they need to help more people live longer and healthier lives. Be The Match Registry℠ is the new name of the NMDP's registry. If you do not have a matching donor in your family, your doctor can contact the NMDP to search our Be The Match Registry and other registries worldwide to access more than 12 million donors and 300,000 cord blood units. In addition to growing the registry, Be The Match also recruits volunteers to support our mission, and raises funds through Be The Match Foundation℠ to help patients and their families.

The NMDP's Office of Patient Advocacy (OPA) offers resources and services to help patients and their families throughout the transplant process. OPA can help you:

- Understand your treatment options
- Answer your questions about the transplant process
- Choose a transplant center
- Learn about insurance coverage and financial options
- Prepare for life after transplant

In addition to print, audio and visual materials (offered in several languages), OPA has bilingual (Spanish/English) case managers and LanguageLine interpreter services available for callers. All OPA materials and services are free and confidential.

To Contact the Office of Patient Advocacy:

Call toll-free at 1 (888) 999-6743
Outside the United States call (612) 627-8140
Reach by e-mail at **patientinfo@nmdp.org**
Visit online at **marrow.org/patient**