Caring for Those Who Care for Others

A Caregiver Resource Guide
You may be this person’s partner, adult child, relative or friend and now you have taken on a new role as a caregiver.
Introduction

Are you among the many adults across our community who are trying to juggle work and family life while caring for a loved one’s special needs?

If so, you are part of the rapidly growing community of people responsible for caring for an aging or sick loved one. You may be this person's spouse, partner, adult child, relative or friend and now you have taken on a new role as a caregiver. More and more, caregivers are called upon to manage the increasingly complicated world of health care. In the struggle to navigate the maze of medical and social services, trying to get help and coordinate these services can be overwhelming. This booklet provides guidance and resources that will enable you to find the best care for your loved one while balancing your work and family life. Here are three important things to remember:

Plan Ahead

It cannot be said enough that planning ahead is critical to easing caregiver stress. Anticipating future medical, legal and financial issues before a crisis or hospitalization can eliminate the need to make critical and difficult emotional decisions during a terribly stressful time.

Take Some Time Away

Caregiving can lead to physical and emotional ailments, relationship stress, job issues and financial burdens. Caregivers often put their own needs aside, and more often than not, go on to suffer exhaustion, burn-out, social isolation and depression. Taking time to soothe your body and replenish your spirit will help you sleep better and restore your sense of well being.

We Are Here to Help

The North Shore-LIJ Health System joins with community partners to create a path to better communication and connection so that we may provide you with support in caring for your loved one. This guide will help you ask the right questions, find services and learn how to use them. We believe that, given good resources, you will be better prepared to face the challenges that lie ahead.
You Are an Important Part of the Health Care Team

As a caregiver, you are part of a team made up of the patient, the medical staff and the family. You will find yourself working closely with doctors, nurses, pharmacists, social workers, and physical or occupational therapists. You manage communication and services among the medical specialties and coordinate the care of your loved one. You are the source of the best and most reliable information about your loved one. The other members of the team must have your input in order to evaluate and make critical decisions, so it is very important to keep the lines of communication open.

In your role as a caregiver, you may often need to be the voice of your loved one and advocate on his or her behalf. Remember that you may also be the voice to him or her—the one who explains what a health professional has said or prescribed. Through your care and guidance, your loved one can have better care and quality of life.
Communication with the medical team is one of the most important factors that affect the care of your loved one. Here are some suggestions for speaking with medical providers:

- Keep all medical information, contacts and test results in one place or in a binder so that it may be found easily.
- Learn who the members of the health care team are, what they do and how to contact them.
- Tell the staff if you or your loved one has difficulty speaking or understanding English, or have problems with hearing or vision.
- If you do not understand something, let the staff know and ask them to explain it until you understand.
- Bring a notebook to medical visits and write down important information. Ask for written copies of information and test results.
- Know your loved one’s diagnosis and what care and medications he or she receives.

If results of medical tests will not be ready for a few days, ask the doctor:

- How will results be returned to you?
- Who will be available to explain results?
- If you have questions after you receive the results, is there someone you can talk to and what is the best time to reach them?
Plan Ahead for Emergency Department and Hospital Admissions

Many emergency department and hospital admissions are unexpected. In order to make the situation less stressful, a little organization goes a long way. You can prepare ahead of time by creating your own hospital emergency information packet and having it readily available.

The packet should contain the following current information:

- Loved one’s identification (i.e. copy of a drivers license)
- Allergies/drug sensitivities
- Emergency contacts
- All medical team members’ contact information
- Health insurance information
- Medical history summary
- Advance directives
- Recent test results and x-rays
- List of current medications, including prescription, over-the-counter drugs and herbal supplements
When Your Loved One’s Circumstances Change

When your loved one needs help with daily living and medical care at home as a result of a worsening medical condition or transition from a health care facility to home, below are some questions to ask your medical provider or case manager.

- What medical services are needed, such as home care, physical or speech therapy?
- Where are these services found?
- Is a medical order necessary to obtain these services?
- Will the services be covered under insurance?
- What transportation to medical services is available?
- If the person is unable to travel, what home services are available?
- Who will help manage medications?
- Who will order medical supplies?
- How can I arrange for help in the home? What are the options available?
- Is my loved one eligible for Medicaid?
- If prepared meals are needed, what services are available?
- Do they need a Personal Emergency Response System?
- If my loved one is homebound and alone, what social services and networking are available?
Planning for Long-Term Care

When taking care of a loved one, it is important to know the daily care, housing and options available for him or her in order to plan financially for that person and their spouse. Medicaid may be available to cover the cost of home care in the home, an assisted living facility or a nursing home.

Careful legal planning should be done in order to avoid the impoverishment of their healthy spouse. Estate planning tools such as a Power of Attorney, which is the authority to act on behalf of another person in a business or legal matter, allows you or someone else to handle their affairs while they are unavailable or unable to do so.

Planning for Medical Decision-Making

Caregivers are frequently called upon to make very difficult decisions, especially at the end of life. Misunderstandings about your loved one's treatment preferences and end of life care can be avoided during a stressful time by assuring that he or she has an Advance Directive. An Advance Directive clearly states what they want done if they become incapable of making their own health care decisions. In New York State, a document that appoints another adult to make those health care decisions is a Health Care Proxy. Health Care Proxy forms are available in many places and an attorney is not necessary. While your loved one is capable of making informed decisions, you should discuss what their treatment preferences are in the event they are unable to make their wishes known.

Important terms to know:

- Power of Attorney
- Advance Directive
- Health Care Proxy
- Living Will
For example:

- Do they want to be brought back to life (resuscitated) if their breathing or heart stops?
- Do they want to be put on a breathing machine if they cannot breathe on their own?
- Do they want to be fed by tubes (receive artificial nutrition and hydration) if they cannot be fed otherwise?
- Do they want medications, such as painkillers, even if they might make them die more slowly?

If you know what your loved one’s wishes are at end of life you are better prepared to make these decisions. Having these discussions with your loved one ahead of time can avoid conflict or confusion among family members and/or significant others. If your loved one does not want to appoint someone as their Health Care Proxy, they can still give specific instructions about treatment in advance. Those instructions should be written and are often referred to as a **Living Will**. Putting things in writing is safer than simply speaking to people, but neither method is as effective as appointing a Health Care Proxy.

If a Health Care Proxy has not been chosen in advance, New York State’s Family Health Care Decision Act appoints a family member, domestic partner or a designated other the ability to make decisions for a loved one after that person loses capacity. The decision-maker (or surrogate) can be a spouse, partner, child or designated other, according to an order determined by law.
Additional Tools to Help Honor Your Loved One’s Treatment Preferences

MOLST Forms – Medical Orders for Life Sustaining Treatment:
The MOLST form is a bright pink sheet that tells others the patient’s wishes for life sustaining treatment. It is based on the patient’s current medical condition and must be ordered and signed by a doctor. All health care professionals are required to follow these medical orders as a patient moves from one place to another, unless a doctor reevaluates the patient and changes them. If the patient is unable to make decisions, the orders should reflect the patient's wishes as understood by the Health Care Proxy or surrogate.

DNR – Do Not Resuscitate:
The DNR is a medical form that tells others what the patient wishes in the event of a cardiac or respiratory arrest. It must be signed by a doctor. If the patient is unable to make decisions, the decision can be made by the Health Care Proxy or surrogate after a discussion with the physician about the patient's condition. Keep in mind that a DNR is not permanent and may be changed.
Taking Care of You – Self Care

Caring for yourself is one of the most important and overlooked things you can do as a caregiver. Although taking time for you can seem unimportant or selfish when you are taking care of someone that is ill or disabled, you can only take proper care of others by taking care of yourself. Self care is not a luxury—it is a necessity. Take care of your physical health. Eat a balanced diet, exercise and make sure you get enough sleep. Rest when you are sick and keep your regular appointments with your own health professionals.

In addition to the good feelings that can come from helping someone you love, caregivers may also experience frustration, sadness and anger. Be realistic about your loved one’s illness and about your level of stress. Don’t be afraid to admit when you need physical or emotional help. There are even some things you can do every day to help alleviate some of the stress of care-giving. Take a small amount of time every day to de-stress by doing something you enjoy such as taking a short walk, listening to music or meditating. You can also join a support group for people in similar situations. Make arrangements for your loved one to be in a program that gives you some time off or arrange for someone else to help once a week. What works for you may not necessarily be the same as what works for others; but whatever you choose to do should make you feel relaxed and recharged. When you feel better, the person you are caring for benefits as well. The resources listed later in this guide will help you find support services that can help.

Self care is not a luxury—it is a necessity:

- Take care of your physical health.
- Eat a balanced diet.
- Make sure you get enough sleep.
- Take a small amount of time every day to de-stress.
- Don’t be afraid to admit when you need physical or emotional help.
Community Resources

Many organizations provide a wide range of information on different types of services and support for loved ones as well as their caregivers. Resources to help you find programs and services located in your neighborhood can be found at the end of this booklet. Some examples of these community services are listed below.

**Care Coordination Services and Case Management**

Case management allows a professional to coordinate services from different social agencies and staff. One agency takes primary responsibility for the client and assigns a case manager, usually a social worker, to coordinate services and advocate for the client. This relieves some of the responsibility for the caregiver and can improve the quality of life for both the patient and caregiver.

**Home Health Care**

Patients often recover faster in a familiar atmosphere, surrounded by family and friends. Home health care is individualized care, supervised by a physician and provided by skilled professionals in the comfort of a patient’s own home. Anyone who is under a physician’s care and requires the services of a registered nurse and/or other therapists on a part-time, intermittent or even long-term basis may be eligible. Prior hospitalization is not necessary to qualify for home health care. Services can include wound and skin specialists, physical therapy, occupational therapy, speech/language therapy, infusion services, social work and home health aides. Quality care in a place that a person feels most comfortable can help to reduce the stress that a caregiver may experience on a day-to-day basis.

**Palliative and Hospice Care**

Palliative care includes pain and symptom management for patients with advanced illness, and it offers support for their loved ones. Palliative care can be provided along with other appropriate treatments to cure illness or prolong life. Ask your doctor for more information.

Hospice provides palliative care including pain and symptom management as well as psychosocial, spiritual and bereavement support to a patient and family. Hospice care is provided by a team of professionals at home, in a nursing home or inpatient setting. Services include nursing, home health aides, medications, medical equipment and supplies. Physician consultation and visits are available when needed.

**Emotional Support**

Caring for an aging loved one can make you feel lonely, frightened or depressed. Counseling, support groups, and other types of programs are available to help you cope with
these feelings. Caregiver support groups are available for specific groups such as spouses and adult children. They can be held using traditional face to face discussion groups, as well as new and innovative settings such as teleconferences and online forums.

Financial/Legal Needs
There are companies and organizations that help with medical billing, insurance coverage, reimbursement, Medicaid planning, access to free and low cost services and advance directives.

Transportation Needs
Many people have trouble getting to medical appointments and social services. In many communities, transportation services are available to help.

Respite
Some organizations provide day care and overnight care for your loved one. These programs offer safe, quality care while providing respite and peace of mind for you.

Nutrition Support
Nutrition plays an important role in physical and social well-being. Several community food service options are available. These include home delivered meals or congregate meal service, which is served to a group of people at a community location. Both options provide your loved one with an opportunity to interact and socialize with others on a daily basis.

Exercise
Daily physical activity can improve strength, balance and reduce stress for both loved ones and caregivers. Some examples include Tai Chi, yoga, and water exercise.

Self Care
Community programs offer support groups, exercise, meditation, yoga and other stress management techniques for caregivers.

Bereavement
Loss of a loved one can have many emotional and psychological consequences. Bereavement counseling and support groups are available in the community to help people cope with the death of a loved one.

Advocacy
In order to improve the quality of life and protect the rights of you and your loved one, there are community organizations that advocate for individuals as well as groups to raise awareness, support services and promote legislation for these important issues.

Community Volunteer Services
Community volunteers are available to provide “friendly visits” either in person or by telephone. These volunteers are members of community organizations and provide social interaction as well as emotional support for those who are homebound.
North Shore-LIJ Health System Resources

Fall and Injury Prevention
northshorelij.com/preventfalls
Falls are the leading cause of emergency room visits and home injury. Each year, one out of three seniors suffers moderate to severe injuries, leading to nursing home placement. Many falls, however, are preventable. Taking simple steps to prevent falls can help you and those you love stay active and maintain independence.

Support Groups
northshorelij.com/community
North Shore-LIJ Health System provides multiple support groups to the community, free of charge, on a wide range of topics. Support groups are organized by each hospital, and include, but are not limited to, such topics as bereavement, cancer, cardiac, diabetes, nutrition and stroke.

CPR and Emergency First Aid
(516) 465-2500
northshorelij.com/community
Courses are designed for families, friends and the general public to learn the core skills of adult CPR, principles of first aid, injuries and medical/environmental emergencies.

Senior Navigator
(888) AGEMAP2 (243-6272)
Need help navigating the maze of services available as you or a loved gets older? The Senior Navigator program is a free information, referral and assistance center designed to help seniors and their families find and access services. A team of professional social workers and trained volunteers are here to provide you with support, comfort, information and guidance.

North Shore-LIJ Home Care Network
(866) 651-4200
northshorelij.com/homecare
One of the largest home care agencies in New York State, North Shore-LIJ Home Care Network provides medical care, nursing services and therapy – all within the comfort of the patient’s own home. Home Care Network helps patients manage their condition and maintain a sense of independence.

North Shore-LIJ Rehabilitation Network
(888) REHAB-03
northshorelij.com/rehab

North Shore-LIJ Rehabilitation Network offers a full range of inpatient and outpatient rehabilitation services to help patients find relief from pain and get moving again after an accident, injury, illness or surgery. Easy-to-access locations are found throughout Long Island, Queens and Staten Island. Each location offers state-of-the-art equipment and is staffed by licensed, friendly therapists experienced in the latest rehabilitation techniques.

Senior and Geriatric Services
northshorelij.com/NSLIJ/AgingGuide

The North Shore-LIJ Health System senior services include geriatric medical services, support groups and other helpful resources. Information about Staten Island University Hospital geriatric services can be found at www.siuh.edu

North Shore-LIJ HouseCalls
northshorelij.com/homecare
Nassau & Suffolk (516) 876-4100
Queens (718) 830-4327
Staten Island residents can call (718) 226-4374 for a similar program.

The North Shore-LIJ HouseCalls program is perfect for individuals who are homebound or who have difficulty getting to and from doctor appointments. Experienced doctors and nurse practitioners can provide quality medical care right in the privacy and comfort of your home.

Circle of Care
(866) 651-4200
northshorelij.com/homecare

The North Shore-LIJ Circle of Care geriatric care managers can serve as someone to turn to when you are overwhelmed and don’t know who to call or where to start. Your geriatric care manager will conduct a thorough evaluation, lay out a clear plan and coordinate the care and services you or your loved one really needs.
North Shore-LIJ Health System Resources Continued

Nursing Homes
Our Stern and Orzac Centers for Extended Care and Rehabilitation are ranked among the top nursing homes in the country by *U.S. News & World Report*.

Manhasset  Valley Stream
(516) 562-8065  (516) 256-6710

Hospice & Palliative Care
(800) 2-HOSPICE
hospicecarenetwork.org

Make every day count for a loved one with advanced illness. Contact the Hospice Care Network. You can also contact one of our palliative care programs:

North Shore University Hospital
(516) 562-8884

Long Island Jewish Medical Center
(718) 470-8660

Franklin Hospital
(516) 256-6611

Huntington Hospital
(631) 351-2007

Vivo Health
vivohealth.com

Vivo Health offers a full line of medical, home safety, nutrition and self care products on-line or at the Vivo Health pharmacies.

Hospital Elder Life Program
(718) 470-7145

The program strives to improve the older patient’s hospital experience, maintain the patient’s cognitive orientation and communication skills, while simultaneously offering a sense of comfort and companionship. Specially-trained volunteers work directly with patients to address non-clinical needs, providing support to families and the clinical care team. Volunteers are always welcome. Contact Kirby Veevers, Coordinator, kveevers@nshs.edu for more information.
How to Find Reliable Health Information on the Web

There is so much information available on the internet on almost any subject. With all of the websites on health care and caregiving, it can be hard to know which sites to trust. If you do not have a computer, local public libraries offer free computers and internet service. If you are not familiar with how to use the computer or internet, ask a friend, family member or librarian to help you. Your health care team can tell you about websites, articles and books that would contain helpful and credible information.

Community Caregiver Resource Links

**Manhattan**

**NYC Department for the Aging**  
www.nyc.gov  
Search: Department for the Aging

**Health Information Tool for Empowerment (HITE)**  
www.hitesite.org  
The first online directory of health and social services specifically for uninsured and under-insured New Yorkers.

**Senator Liz Krueger Resource Guide for Seniors**  
www.nysenate.gov  
Search: Senior Resource Guide

**Nassau**

**Nassau County**  
www.nassaucountyny.gov  
Search: Senior Caregivers

**Health Information Tool for Empowerment (HITE)**  
www.hitesite.org  
The first online directory of health and social services specifically for uninsured and under-insured New Yorkers.

**Town of North Hempstead**  
Dial 311
**United Way of Long Island**
Dial 211

**Queens**

**NYC Department for the Aging**
www.nyc.gov
Search: Department for the Aging

**Health Information Tool for Empowerment (HITE)**
www.hitesite.org
The first online directory of health and social services specifically for uninsured and under-insured New Yorkers.

**Staten Island**

**NYC Department for the Aging**
www.nyc.gov
Search: Department for the Aging

**Health Information Tool for Empowerment (HITE)**
www.hitesite.org
The first online directory of health and social services specifically for uninsured and under-insured New Yorkers.

**Suffolk**

**Suffolk County**
www.suffolkcounty.gov
Search: Office for the Aging

**Caring for Seniors in Suffolk: A Resource Guide for Caregivers**
www.naswnys.org

**United Way of Long Island**
Dial 211

**Health Information Tool for Empowerment (HITE)**
www.hitesite.org
The first online directory of health and social services specifically for uninsured and under-insured New Yorkers.

**Staten Island Inter-Agency Council for the Aging**
www.seniorcitizenhelp.org

**National**

**The United Hospital Fund: Next Step in Care**
Family caregivers and health care professionals working together
www.nextstepincare.org

**The National Family Caregivers Association**
(800) 896-3650
www.nfcacares.org
AARP  
Caregivers, parent guardianship and caring senior and eldercare  
www.aarp.org  

National Alliance for Caregiving  
www.caregiving.org  

Eldercare Locator  
National guide for finding community assistance  
(800) 677-1116  
www.eldercare.gov  

Dorot  
Telephone support group for caregivers  
(212) 769-2850  
www.dorotusa.org  

National Association of Professional Geriatric Care Managers  
(520) 881-8008  
www.caremanager.org  

FEGS Health and Human Services System  
F·E·G·S is one of the largest and most diversified not-for-profit health and human services organizations in the United States.  
(212) 524-1780 or (516) 496-7550  
www.fegs.org  

Centers for Disease Control and Prevention (CDC): National Center for Injury Prevention and Control  
www.cdc.gov  

Family Caregiver Alliance  
www.caregiver.org  

Well Spouse Association  
www.wellspouse.org  

Compassion and Support at the End of Life  
www.compassionandsupport.org  

Get Palliative Care  
www.getpalliativecare.org  

National Hospice and Palliative Care Organization  
www.nhpco.org  

Ask Medicare  
www.medicare.gov  
Search: Caregiver
A Network of Care in Your Community

North Shore-LIJ is an award-winning network of hospitals and other health services right in your backyard. We provide access to top doctors and a depth of resources to meet all your health care needs.

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