



Called to CARE

A guide for family and friends



JOHNS HOPKINS
M E D I C I N E

JOHNS HOPKINS BAYVIEW MEDICAL CENTER

Called to Care

Called to Care is an innovative program developed by Johns Hopkins Bayview Medical Center that prepares and supports individuals caring for loved ones with health-related needs or limitations. Called to Care offers a wide range of resources, including educational programs on important topics and support groups for patients and those who care for them. These classes and support groups are offered at the Medical Center and at various community sites, and many can be accessed by telephone or the Internet.

In addition, Johns Hopkins Bayview has partnered with a number of community organizations and agencies in Maryland that already provide valuable services to caregivers and their loved ones. With the assistance of these key organizations, Johns Hopkins Bayview is strengthening connections to and across resources, programs and providers who serve family caregivers, and improving the coordination of care and communication between health care providers and family caregivers.

Called to Care is funded in part by a generous grant from the Weinberg Foundation and is part of *Together We Care*, the Foundation's statewide initiative to make Maryland the best place to grow old.

The Harry and Jeanette Weinberg Foundation

The Harry and Jeanette Weinberg Foundation, one of the largest private charitable foundations in the United States, provides approximately \$100 million in annual grants to nonprofits that provide direct services to low-income and vulnerable individuals and families, primarily in the U.S. and Israel. Grants are focused on meeting basic needs and enhancing an individual's ability to meet those needs, with emphasis on older adults, the Jewish community and the Foundation's hometown communities of Hawaii, Maryland, Northeastern Pennsylvania and Israel.

Together We Care

Demonstrating its commitment to preserving the dignity and independence of the poorest and frailest older adults, the Weinberg Foundation has set a course to identify and implement the best practices in supporting both informal and paid caregivers. By 2020, the Weinberg Foundation dreams of *Making Maryland the Best Place to Grow Old*. This comprehensive initiative, known as *Together We Care*, is intended to develop the infrastructure to provide support and services to all caregivers who serve older adults, as well as adults with disabilities in Maryland. The plan will initially focus on Baltimore City, with a goal of statewide implementation. The Foundation—with numerous partners—will identify, coordinate, and employ the best practices in providing a network of care, training and support for older adults.

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“There are only four kinds of people in the world: those who have been caregivers, those who are currently caregivers, those who will be caregivers and those who will need caregivers.”

—Former First Lady Rosalynn Carter

Welcome to Called to Care: A Guide for Family and Friends

A sincere “thank you” ... and more

This booklet is for individuals who provide care for a family member or friend. Even if the assistance you provide seems limited—perhaps mostly helping your mother purchase and organize her medications, or taking your friend to his medical appointments—you play a critical role in health care today. The care that doctors, nurses and other health professionals provide is essential, but so is the care that family and friends give at home. Because of that, we want to begin by recognizing your valuable contributions and saying, “Thank you.” We sincerely appreciate all that you do.

But, we want to do more than just say, “Thank you.” We know that most people who are called to care—whether it is because of a loved one’s injury, a short-term illness or a long-term medical condition—have had little preparation for many of the tasks they take on. And providing this care can be physically and emotionally demanding. It often means sacrificing

You Are Not Alone

According to a 2015 survey, 39.8 million Americans are providing unpaid care for an adult family member or friend, with the majority—approximately 34.2 million—caring for someone age 50 or older.

some of your own interests and not paying enough attention to your own health. However, with the right resources and support, you can be an effective caregiver, and maintain your own physical and emotional health.

As you navigate the world of caregiving, this booklet will provide you with valuable information and resources to make your journey as easy as possible. More importantly, it will remind you that you are not alone. Just as you are there to care for your loved one, there are many individuals and organizations available to help you.

In this booklet you will find:

- Personal stories about the caregiving journey
- The basics of family caregiving
- Caregiving tips
- How to care for yourself
- How to plan for the future
- Where to turn for help

How To Use This Booklet

This booklet is designed to give you an overview of some of the issues and challenges you might face as you help care for and support a family member or friend. You may want to read this booklet all the way through, or you may find it more helpful to use the table of contents to guide you to sections that match your needs or concerns.

In addition to this booklet, you may want to start a file, bookmark websites or designate a



special place in your home for caregiving resources. Even if you do not expect your current responsibilities to be long-term, this information can be helpful. There may come a time when you will be called to care for someone else, or people you know may be providing care for their loved ones. Sharing information and resources can strengthen the support system for those in similar situations.

It's OK to ask for help. It's the smart thing to do!

The important role of caregivers is rapidly gaining attention throughout the country. With the encouragement and generous support of The Harry and Jeanette Weinberg Foundation, a number of government agencies, non-profit groups and faith-based organizations in Maryland have partnered together to offer caregivers valuable information, training opportunities and supportive services. Offerings include, but are not limited to: help with meals, home modification, transportation, housing, legal matters and accessing benefits.

We encourage you to learn about resources that are available to you and hope you will take advantage of them as needed. Caregiving can present considerable challenges—physical, emotional and financial—many of which you may never have faced before. There is no reason for you to try to handle everything by yourself, especially when there are individuals and organizations eager to help. Educating and preparing yourself can make you a better caregiver and help you protect your own health and financial future.

A comprehensive list with additional information about our partner organizations and services is available on the Called to Care website: hopkinsmedicine.org/jhbmc/calledtocare.



The Voice of the Caregiver

Caring For a Spouse: Mary Sue's Story

When Mary Sue learned that her husband, Bill, would need surgery for cancer, she understood that she would be called to care for him once he came home from the hospital. She knew Bill would require assistance getting around the house and taking care of some basic needs. What she did not expect was that she would have to care for her husband in ways that she thought only doctors and nurses could.

Because Bill was not allowed to eat food for a couple of weeks, he had to rely on intravenous feeding for his nutrition. This meant that Mary had to learn how to prepare and administer the solution, plus carefully clean the syringe and tubing each day. She also discovered that because the solution was rich in sugar and carbohydrates, his blood sugar could rise

to dangerous levels. As a result, she had to regularly monitor his blood sugar and give him insulin injections when his sugar was too high. On top of that, Mary also had to tend to Bill's surgical wounds, which required careful attention each day.

Although Mary found her caregiving responsibilities exhausting—and even frightening at times—she was relieved to have Bill home under her watchful eye. Once she saw the important role she played in his recovery, she felt a sense of pride and accomplishment.



The Voice of the Caregiver



Caring For a Parent: Jaye's Story

Jaye's caregiving responsibilities started small but expanded dramatically over 13 years. At first, her mother just needed assistance with medications and a few household matters. Jaye was

able to handle those responsibilities without too much trouble and continued to work full time. However, after several years, her mother's memory problems and confusion became so serious that Jaye felt she had to retire in order to give her mother the attention and care she needed.

Caring for her mother proved to be intense and exhausting. In fact, there were many days when she didn't know where she was going to find the strength

to handle the stress of caregiving—until she found a caregiver support group. It was through this group that Jaye received the love and support that carried her through some of her toughest times. For example, when she needed help dealing with her mother's behavioral and communication problems, group members generously shared strategies that had worked for them.

The most important advice Jaye received from the support group was that in order to be the best caregiver and daughter she could be, she also needed to take care of herself. As a result, she asked friends if they could stay with her mother occasionally so she could take care of her own responsibilities at home. It also was through this support group that Jaye learned about grants that helped pay for someone to care for her mother when she needed to be away for an extended period.

The Voice of the Caregiver



Caring for a Spouse: Mary's Story

Mary's life didn't change too much after her husband, Emilio, was diagnosed with multiple sclerosis. He was able to continue working as a civil engineer, and the couple was still able to enjoy many activities together.

However, as Emilio's multiple sclerosis progressed, Mary found her life changing dramatically. One of the most far-reaching changes came when she and Emilio had to uproot themselves from their Colorado home, leaving behind many friends, and move to a warmer, more hospitable climate. Mary also had to

take on many additional responsibilities, including coordinating Emilio's increasingly complex medical care. And much of what she needed to do every day was physically demanding and emotionally draining, often leaving her little time or energy to attend to her own health.

There has been no escaping the physical and emotional strain of caregiving, but Mary has wisely recognized that to be a good caregiver, she also needs to take good care of herself. One way to do this has been to meet with other caregivers who understand what she is going through. But she also finds it important to take time to meet with friends and engage in activities that allow her to shift her attention away from caregiving. Caregiving remains a central part of her life, but is not all-consuming.

Quiz: Are You a Caregiver?

A family caregiver can be someone caring for a spouse, a parent, an extended family member, or even a friend or neighbor.

Read the examples to the right and check “yes” or “no” based on your experience.

If you checked “yes” to one or more, you are a caregiver and will want to learn more about the resources and support available to you and your loved one.

Do you help a family member or friend with:

- | <i>Yes</i> | <i>No</i> | |
|--------------------------|--------------------------|--|
| <input type="checkbox"/> | <input type="checkbox"/> | Transportation to medical appointments? |
| <input type="checkbox"/> | <input type="checkbox"/> | Purchasing or organizing medications? |
| <input type="checkbox"/> | <input type="checkbox"/> | Monitoring their medical condition? |
| <input type="checkbox"/> | <input type="checkbox"/> | Communicating with health care professionals? |
| <input type="checkbox"/> | <input type="checkbox"/> | Advocating on their behalf with providers or agencies? |
| <input type="checkbox"/> | <input type="checkbox"/> | Getting in and out of beds or chairs? |
| <input type="checkbox"/> | <input type="checkbox"/> | Getting dressed? |
| <input type="checkbox"/> | <input type="checkbox"/> | Bathing or showering? |
| <input type="checkbox"/> | <input type="checkbox"/> | Grocery or other shopping? |
| <input type="checkbox"/> | <input type="checkbox"/> | Housework? |
| <input type="checkbox"/> | <input type="checkbox"/> | Preparing meals? |
| <input type="checkbox"/> | <input type="checkbox"/> | Managing finances? |

The Context of Caregiving

The term “caregiver” has been used throughout this booklet; however, it may not be a term that you use to describe yourself and your role in a person’s life. You may just consider yourself a close relative or friend who is simply doing what needs to be done when someone needs help.

What is a caregiver?

In simple terms, a caregiver is a person who tends to the needs or concerns of a person with short- or long-term limitations due to illness, injury or disability. We use the term “family caregiver” to describe individuals who care for members of their family of origin, but also to refer to those who care for their family of choice. This could be members of their congregation, neighbors or close friends.

And, believe it or not, family caregivers play a significant role in health care today. They are



often the main source of valuable information about the patient.

To understand the importance of a caregiver, think of health care as a three-legged stool. Family caregivers serve as one leg of the stool; professional caregivers (doctors, nurses, etc.) act as another; and the care recipient is the third leg. Without all three legs, health care cannot be as effective as it needs to be.

The face of the family caregiver

Caregiving in the U.S. 2015, the national survey conducted for the National Alliance for Caregiving and the AARP Public Policy Institute, gives us a good picture of caregivers—who they are and what they do.



40 MILLION






Americans are providing care for an adult family member or friend.

Caregivers most commonly assist with:

-  SHOPPING
-  CLEANING
-  MEAL PREPARATION
-  FINANCES
-  MEDICATIONS
-  TRANSPORTATION

60 PERCENT

of caregivers assist with at least one Activity of Daily Living (ADL), such as:

-  Getting in and out of bed
-  Getting dressed
-  Tending to incontinence
-  Getting to and from the toilet
-  Showering/bathing
-  Eating/feeding



People may become caregivers at any time during their life.

THE AVERAGE AGE IS 49.



Women are often caregivers, but the number of male caregivers in the U.S. has risen to

40 PERCENT.

“The real ‘saints’ in health care are the family and friends of an ill or injured individual. As I have witnessed as a physician, this caregiving is vitally important for healing and achieving quality care that provides comfort, confidence and dignity.”

**–John R. Burton, M.D.,
director, Johns Hopkins
Geriatric Education Center**

6 in 10 caregivers of someone older than 50 currently assist with medical/nursing tasks. Recent research has revealed that in addition to activities of daily living, family caregivers are increasingly performing tasks that nurses typically perform. Known as “medical/nursing tasks,” these skilled activities include, but are not limited to:

- Managing medications
- Preparing and administering intravenous feedings
- Giving injections
- Helping with assistive devices for mobility
- Preparing food for special diets
- Providing wound or ostomy care
- Using meters and monitors (glucometers, blood pressure monitors, oxygen saturation monitors)
- Using incontinence equipment and supplies
- Operating medical equipment (lifts, home dialysis equipment, suctioning equipment)

Who Are Care Recipients?

Almost any illness, injury or medical condition can result in a person needing a family caregiver. Some individuals may require only temporary, short-term assistance, while others may need long-term care.

Health conditions that often lead to the need for a caregiver include:

- Alzheimer's disease and other dementias
- Cancer
- Chronic obstructive pulmonary disease (COPD)
- Congestive heart failure (CHF)
- Diabetes
- HIV/AIDS
- Inflammatory bowel disease (IBD)
- Injuries resulting from falls
- Kidney disease
- Multiple sclerosis (MS)
- Parkinson's disease
- Psychiatric disorders
- Severe arthritis
- Stroke
- Traumatic brain or spinal cord injuries



Helpful Tips for Family Caregivers: A Place to Start

Create a safe environment at home.

Did you know that one out of three older adults falls each year? More than two million are treated in emergency departments for falls, and more than 700,000 are hospitalized.

Conduct a safety inspection of your loved one's home. In fact, it's a good idea for everyone to do this, especially if you have older adults who live with or visit you. For a home safety checklist, visit hopkinsmedicine.org/jhbmc/calledtocare.

Maintain medical records.

Most care recipients take at least one prescription drug. It's important to keep a list of all medications (including over-the-counter drugs), as well as the

dosage or strength, what condition the drug is treating and how often it is taken. A drug regimen may change often, so be sure to make regular updates to this list. If

needed, pharmacists can be a valuable resource for medication information.

It also may be helpful to keep a personal health record with symptoms, doctor visits, medications and other important health information.

Educate yourself.

Learn about each disease or condition your loved one has, its treatments and the likely course

of the disease. The more information you have, the more you will know what to expect and the better prepared you will be.

“The partnering of a patient and a loving caregiver with a health care team not only ensures the best patient care, but will be the foundation for transforming American health care.”

*—Richard G. Bennett, M.D.,
president, Johns Hopkins Bayview*

**“It is not how much you do,
but how much love you put into the doing.”
–Mother Teresa**

The Johns Hopkins Health Library is a valuable resource that provides information on the diagnosis, treatment and prevention of conditions. To access the library, visit hopkinsmedicine.org/healthlibrary.

Communicate with health care providers.

In order to be a good advocate for your loved one, you should understand the terminology used by health care providers. Don't be afraid to ask questions if you do not understand something that you hear or read.

If you feel like the health care team doesn't fully understand your loved one's needs and concerns, speak up. It's critical that there is good two-way communication between patients and providers. You can play a valuable role helping with this.

Keep extended family involved and informed.

Host a family meeting with all decision makers. Identify and discuss the issues of providing care for the family member in need. Come up with a plan to share responsibilities and to keep everyone updated regularly.

Ask for help.

Caregiving can be time-consuming and emotionally draining. Don't be afraid to ask for help! Finding ways to free yourself from some responsibilities can be helpful to both you and the care recipient.

Remember to be specific when asking for assistance. Instead of saying, “I need some help with Dad,” ask, “Can you stay with Dad for two hours on Friday so I can go to an important appointment?”

“It is one of the most beautiful compensations of life, that no man can sincerely try to help another without helping himself.”

–Ralph Waldo Emerson

Manage your time.

Keep an appointment book or calendar to schedule your daily activities, including visits to the doctor. Consider using an online calendar that can be shared with other family members.

Learn how to be an effective caregiver.

There are many resources available to help you become an effective caregiver. While some of your responsibilities may be common sense, others may need further education and training. For example, you may want to learn the safest way to transfer a loved one from a bed to a wheelchair. This can help prevent serious injury to yourself and the care recipient.

More information about training opportunities for caregivers can be found on the following pages.

Caregiver Training

You may not be fully skilled in all of the duties involved in caregiving. While bathing and feeding may seem like simple tasks, there are tips and tricks you can learn to make assisting in the activities of daily living easier.

Safety also is an important issue, especially since most care recipients are elderly or limited in some way by their medical condition.

You may find it helpful to locate books, videos, Internet resources or workshops in your community on topics that are relevant to your situation. Popular subject matters include:

- Caring for someone with a particular disease
- Working with medical professionals and navigating the health care system
- Managing activities of daily living, such as bathing, dressing and eating
- Preparing your home or the care recipient's home for safe caregiving
- Managing and organizing medications in the home, including recognizing and handling side effects
- Caring for someone who has difficulty following the advice of health care providers
- Operating and managing medical equipment, such as ventilators and oxygen
- Coping and stress reduction

We've been called to care for you.



Johns Hopkins Bayview Medical Center has developed a training program for family caregivers. This program, Caregiving 101, includes six modules:

- What It Means to be a Caregiver
- Taking Care of Yourself
- Building Cooperative Relationships
- Preventing and Solving Problems
- Accessing and Developing Resources
- Home Safety and Fall Prevention

The program brings caregivers and health care professionals together in a relaxed setting to discuss common issues, share ideas and gain a better understanding of each other's perspectives on caregiving.

Additional information about this program is available on the Called to Care website: hopkinsmedicine.org/jhbmc/calledtocare.

National Resources on Caregiving

AARP Caregiver Resource Center
[aarp.org/home-family/caregiving/
planning-and-resources](https://aarp.org/home-family/caregiving/planning-and-resources)

Caregiver Action Network
caregiveraction.org

Family Caregiving Alliance
caregiver.org

National Alliance for Caregiving
caregiving.org

Share the Care
sharethecare.org

Transitions in Care: Navigating the Health Care Maze

Caregivers of individuals with chronic illness experience increased stress during episodes of acute illness, which may require a transition from one care setting to another. Often, important health care decisions need to be made in a short period of time. This section will help guide you through that process.

Start your involvement from day one.

If you are the caregiver of someone who has been admitted to the hospital, start getting involved in your loved one's care from the time of admission. Introduce yourself to the health care team, and share your loved one's care plan that was in place prior to being hospitalized. Be clear about any aspects of care that you are worried about or those where additional help may be needed.

“The care and attention provided by family and friends often contribute the most to a patient’s recovery, dignity and comfort.”

**– David B. Hellmann, M.D.,
vice dean, Johns Hopkins Bayview**

Know your health care team.

If the hospital is an academic medical center, such as Johns Hopkins Bayview or The Johns Hopkins Hospital, your loved one will be cared for by a team of health professionals. Members of this team often include an attending physician, fellow, resident physician, nurse practitioner, physician assistant and medical student. Your loved one also may be cared for by a nurse, certified nursing assistant and—if necessary—physical, occupational or speech therapists.

It can be quite difficult and confusing to keep track of everyone who is caring for your loved one. We encourage you to speak up and let your team know if you are unclear about what the plan of care is, or

“If you want to go fast, go alone. If you want to go far, go together.”
–African Proverb

are uncertain about who will be involved in providing that care.

Once your loved one is ready to transition from the hospital, a team of professionals will help coordinate additional care. The team, comprised of a social worker, nurse case manager and a case assistant, is trained to help families through difficult care decisions and to help them plan accordingly when there is a change in a patient’s functional abilities. They will refer you to community resources, such as nursing and rehabilitation centers, home care services, medical equipment providers and transportation services. The team also may be able to help with financial and legal concerns. It may be helpful to meet with this team early in the admission to start planning together.

Talk about the “tough stuff.”

Care transitions often happen when there is a change in your loved one’s condition. It is important to talk

about care plans and medical decisions in advance.

It’s especially helpful to discuss advance directives and a financial power of attorney so that if a crisis happens, the care recipient’s wishes are clear and you are able to uphold them.

Develop and maintain a good relationship with your loved one’s primary care physician. He or she can be instrumental in partnering with the hospital team if an admission is needed.

Identify and use all available resources.

–Take time to understand your insurance coverage. Many older Americans are not aware that Medicare does not cover the full cost of a hospital stay and other necessary care. Find out if your loved one qualifies for medical assistance and, if not, look into options for secondary insurance. Understand prescription coverage and co-pays for medications.



–Some insurance companies have case management programs to help navigate patients through chronic illness. Contact your loved one’s insurance company to determine if this option is available.

–Make connections in your community. If you belong to a faith community, find out what

resources are available to help you as a caregiver. It’s helpful to discuss options with people who have had similar caregiving experiences.

–Learn about community resources through your local Office on Aging, Department of Health, Department of Veterans Affairs or senior center.

Write it down.

Use a caregiving journal to keep a detailed record of all aspects of your loved one’s care.

–Include the names of all health care providers.

–Keep a list of current medications and side effects.

–When speaking with hospital staff and community agencies, write down names, phone numbers, dates and what was said. Make sure that you are receiving information from the treatment team in the language with which you are most comfortable.

Be firm, but flexible.

Be firm. Speak up if you feel that a plan is not meeting your needs. You have the right to say no to a hospital discharge if you feel it is premature or if you are not prepared to manage the necessary care at home. If someone tells you that a particular service is not covered or unavailable, take the time to see if the decision can be negotiated. Work together with your health care team to ensure the best possible care for your loved one.

Be flexible. You may not always find the perfect solution to a problem. Be willing to consider an alternate plan or a second choice. Understand that you almost certainly will incur out-of-pocket expenses for some care. If you are unable to afford necessary care for your loved one, ask your treatment team to link you with a hospital financial counselor.

“It all begins with you. If you do not take care of yourself, you will not be strong enough to take care of anything in life.”

**–Leon Brown,
baseball player**

Caregiver Health: Taking Care of Yourself

One of the challenges we face as we work with those who have been called to care is convincing them to take good care of themselves. We understand why this can be difficult.

You may feel that you do not have a right to tend to your own needs when your loved one is seriously ill or experiencing physical limitations. And then there are the other responsibilities that can place demands on your time—a spouse, children and work. But, to be an effective caregiver, you also need to take good care of yourself. If you neglect your own health, you run the risk of becoming ill and then not being able to care for your loved one.

Here are some suggestions that we hope you will take to heart.

Take breaks from caregiving.

Time away from your caregiving responsibilities—often referred to as “respite”—is essential to your health, which can impact the health of your loved one. Although it may seem difficult to arrange these periods of respite, there are several options that might be available to you.



In-home respite—Ask a family member or friend to stay with your loved one so you can take care of your own responsibilities or get together with friends. In some communities, religious congregations

have volunteers who are trained to provide in-home respite care for a few hours. For a fee, home health services can provide a personal care aide to stay with your loved one.

Adult day centers—These centers provide daily care in a group setting for individuals who need supervision. If you need a longer period of respite, check with local nursing homes or assisted living facilities to see if they are able to care for your loved one for several days.

Leisurely activities—Use your “down time” to care for yourself. Do things that you enjoy and that re-energize you. Read a book, listen to music or talk on

the phone with a good friend.

Safeguard your own health and well-being.

—Go to your family physician for regular check-ups. Let your doctor know that caregiving is an important part of your life. Make sure you mention any symptoms or concerns.

—Take your medications as prescribed and monitor your own health with the same attention you give your loved one.

—Get a flu shot. Supplies of the flu vaccine sometimes run short, so be sure to obtain one early in the flu season. You also may want to ask your doctor if you should receive the pneumonia vaccine.

—Find time to exercise regularly. You don’t need to join a gym or participate in exercise classes. Even short walks in your neighborhood can be beneficial to your physical and mental health.

—Take classes that focus on stress-reduction and coping techniques. You may find yoga, meditation and other relaxation techniques particularly helpful.

–Continue to participate in religious or spiritual activities, as well as recreational activities, sports or hobbies. You may not be as involved as you were previously, but it is important that you continue to engage in at least some of the activities that meet your social, emotional and spiritual needs.

Join a support group.

It is not unusual to feel isolated when you are devoting so much of your time to caring for a loved one. One valuable way to overcome these feelings is to join a support group where you will find others who understand the stresses and challenges you are facing. Members also may offer valuable advice, coping strategies and resources.

Some support groups are designed for all caregivers, while others are for individuals who care for people with a particular medical condition. Information about these and other support groups, including those where members can participate by telephone, can be found on the Called to Care website:

hopkinsmedicine.org/jhbmc/calledtocare.



Note: *The demands of caregiving can be overwhelming, often putting the caregiver's own health in jeopardy. It is not unusual for caregivers to experience stress-related disorders, including depression. If you are feeling down, depressed or hopeless; have little interest or pleasure in things you previously enjoyed; have trouble falling or staying asleep; have lost your appetite or have trouble concentrating, talk with your doctor or a mental health professional. There are effective strategies and treatments that can help restore your energy and lift your spirits.*

**“Planning is bringing the future into the present
so that you can do something about it now.”**
–Alan Lakein, author

Planning for the Future

Caregiving can be overwhelming, especially when you are faced with difficult financial, medical and legal decisions on behalf of your loved one. Planning for the future *before* a need arises helps avoid worry and stress when it's time to make a difficult decision. You can seek planning help from caregiving organizations, your local area agency on aging or an elder law attorney.

Work and Caregiving

If the demands of caregiving reach the point where they conflict with your work responsibilities, you may want to take advantage of the Family and Medical Leave Act (FMLA). This act allows eligible employees who work for an organization with 50 or more employees and who are caring for a spouse, parent or child with a serious health condition to take up to 12 weeks of unpaid, job-protected leave from work. Government agencies and elementary and secondary schools also are covered by FMLA, regardless of the number of employees. To learn more about FMLA, visit the Department of Labor's website: [dol.gov/whd/fmla/employeeguide.pdf](https://www.dol.gov/whd/fmla/employeeguide.pdf).

Many employers also offer additional benefits or services that can be of help to family caregivers. This could include telecommuting, flex-time, job sharing, or an information and referral program that can guide you to local resources. Check with your human resources department or employee assistance program to see what your company offers.

Important Legal Documents

Many people create a will to make sure their wishes will be followed after they die. However, many overlook creating important documents that spell out their medical and financial decisions while they are still living. Make sure your loved one has the following documentation in place.

- **Advance directive**—identifies a health care agent and outlines what medical care your loved one may want in the future
- **Power of attorney**—identifies the person who will make future financial decisions for your loved one
- **Living will**—spells out medical treatments your loved one would and would not want to be used to keep them alive, as well as other decisions such as pain management or organ donation

To learn more about designating a health care agent and completing a living will, visit the Called to Care website: hopkinsmedicine.org/jhbmc/calledtocare.

Other Important Documents

Find and organize birth and marriage certificates, divorce decrees, death certificates, insurance policies, citizenship papers, deeds, cemetery plots, funeral arrangements, income and bank statements, power of attorney documents and wills. You will most likely need some or all of these documents in the future.





Called to Care

Palliative Care

Palliative care is specialized medical care for people with serious illnesses. It focuses on providing patients with relief from the symptoms and stress of a serious illness. The goal is to improve quality of life for both the patient and the family.

Palliative care is provided by a specially trained team of doctors, nurses and other specialists who work together with a patient's other doctors to provide an extra layer of support. It is appropriate at any age and at any stage of a serious illness and can be provided along with curative treatment.

If you believe your loved one may benefit from palliative care, talk with a doctor or another member of the treatment team. To learn more about palliative care at Johns Hopkins Bayview, visit hopkinsmedicine.org/jhbmc/palliativecare.

Hospice Care

The word “hospice” means “a place of shelter.” Today, the “place of shelter” is not so much a physical location as it is a service that helps a patient who is terminally ill to die with dignity and peace. Hospice care can be provided at home or wherever the patient lives. Care usually involves relieving

troublesome symptoms, and providing psychological and social support for the patient and family. The goal of hospice care is to not only provide the terminally ill patient and the family with a comfortable death experience, but to also enable the person to live to the fullest—even with a terminal prognosis.

To qualify for hospice care, a patient usually has a life expectancy of less than six months.

Research has shown that hospice care at home helps the entire family. Family members are encouraged to take an active role in providing supportive care to the patient. In doing so, the family experiences fewer feelings of helplessness and the patient is not relying solely on strangers for all of his or her care.

If you think your loved one may benefit from hospice care, talk to a doctor or another member of the health care team. Ask if hospice care might be appropriate at some point, how that determination would be made, and what services would be part of that care.



Legal Issues of Caregiving

Caregiving often involves various legal and financial matters that can seem complicated and confusing. This is particularly true if the care recipient is impaired or facing end-of-life issues.

If you and your loved one encounter these types of issues, you may want to consult with an attorney or legal aid group that specializes in elder law.

**“Nobody cares
how much you
know, until they
know how much
you care.”**

**–Theodore
Roosevelt**

Final Thoughts

Your caregiving journey can be rewarding, but also difficult. Remember, you are not alone as a family caregiver. Help is out there. You just need to find it and take advantage of it.

Some things to take away from this booklet:

- Get connected to caregiving resources available in the hospital and out in the community.
- Accept the assistance of family and friends. Let them know how they can help. Be specific with your requests.
- Learn as much as you can about your loved one’s medical condition and treatments.
- Communicate any concerns to doctors, nurses and other members of the health care team. Don’t be afraid to ask questions.

Take good care of yourself physically, emotionally and spiritually.

- Pay attention to your own health needs. Keep your medical appointments and follow your doctor's recommendations.
- Stay connected with family and friends, even if your time with them may be briefer and less frequent.
- Find ways to take breaks from your caregiving responsibilities. Utilize respite care when possible, and don't feel guilty about the time away.
- Continue to engage in some of the activities that bring you pleasure and help energize you.
- Acknowledge your feelings about being called to care. Talk with family and friends who can offer understanding and support.
- Join a support group. Other members will understand what you may be going through and can offer problem-solving strategies.
- Watch out for signs of depression. Don't delay in getting professional help when you need it.
- Stay connected with your faith community and spiritual practices. If you are not part of a faith community but have some spiritual concerns, ask to talk with a hospital chaplain for support.

***Thank you,** once again, for accepting the Call to Care for a family member, partner or friend. No one is alone on this caregiving journey. It is a constantly unfolding experience, and we hope that you have now found a place to start and resources to support you along the way.*

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Sincerely,

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“When you are a caregiver, you know that every day you will touch a life or a life will touch yours.”

—Anonymous



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