

# A GUIDE FOR FAMILY CAREGIVERS

Creating Caregiver Provider Partnerships



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# THANK YOU

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## **WE COULDN'T HAVE COMPLETED THIS GUIDE WITHOUT THE TREMENDOUS SUPPORT OF THE FOLLOWING PEOPLE:**

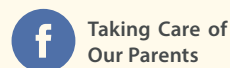
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## **THIS GUIDE**

is intended to help increase your confidence as a caregiver, and to help you recognize and prioritize your own needs as well as those of your loved one, at home, in your community, and especially when interacting with health care providers.

# A GUIDE FOR FAMILY CAREGIVERS

## Introduction

Our caregiving journey began with helping parents and loved ones through their struggles with **Chronic Disease** and aging. The experience has been positive and rewarding, but we continually face a variety of worries and frustrations rooted in the complex and uncertain nature of caregiving. We wanted to identify and address these challenges in order to support and motivate caregivers in their valuable work.

We worked with an advisory board of family caregivers, health care professionals, and other **Community Stakeholders** for more than five years to identify strategies and resources to aid and support family caregivers and their loved ones.

This Guide shares the project's key lessons which we wish we'd known earlier. Throughout the Guide, we **highlight** terms that might be unfamiliar. You can find these terms in the Glossary. We also include **Exercises** to encourage you to reflect how you are doing and **Templates** to keep track of important aspects of your loved one's health. Take notes as you read and share your thoughts with your loved one, other family members, and your loved one's care team.

We encourage you to use the parts of the guide that are most helpful for your situation. Find the sections that meet your needs. For example, if you are considering becoming a caregiver, **Creating a Confident Caregiver** provides an overview of what to expect and how to prepare yourself. If you are attending medical visits with your loved one, **Getting to Know the Care Team** would be a good one to review first. If you and other members of your family are caring for a parent, **Purposeful Communication** should be very useful.

We hope you find tips to help you in your important work as a family caregiver. This guide is intended to increase your confidence and to help you recognize and prioritize your needs and those of your loved ones.

# Creating a Confident Caregiver

The responsibility of looking after a loved one can be unexpected but also deeply rewarding. It will likely be one of the most challenging but also fulfilling experiences of your life. Providing at-home care for family members preserves their autonomy and social support networks, ensures they remain safe in their home, and delays or prevents expensive moves to assisted living facilities.

Caregiving can begin with picking up a prescription or making dinner, and often progresses to include helping your loved one with [Activities of Daily Living](#) (ADL) like eating, bathing, and dressing. Eventually, most caregivers are required to manage medications, injections, and the operation of medical equipment.

The evolving nature of caregiving requires family caregivers to grow and adapt, too. On average, family caregivers spend 20 hour per week caring for their loved one and 13% spend 40 or more hours per week. Things are always changing, and it can't be assumed that the family caregiver will be able to implement or carry out the recommended plan of care.

Understanding your individual needs and strengths is a critical first step in better meeting the needs of your loved one. The relationship between you and your loved one is at the heart of your caregiving. It is important to:

1. Assess your capabilities to provide care
2. Take care of yourself
3. Identify a network of support

## **CONDUCT A SELF-ASSESSMENT**

As a family caregiver, you are helping a loved one retain a familiar, safe and secure environment in which their health needs are met. You want to do everything you can to assist them. But you can't do it all, at least not by yourself. For you to be most effective in your role as family caregiver, it is important that you realistically assess your capabilities to provide care.

Be honest about your own capability, availability, and willingness to perform care tasks.

A number of variables may affect your ability to assist with aspects of your loved one's care. Physical health, employment obligations, and financial resources are just a few. Consider each of the following:

### **Your Physical Health**

Older adults lose mobility and strength as they age, or as their health deteriorates. You may be expected to help them move from chair to bed, into and out of the shower, or to and from the toilet. You might not be able to safely assist your loved one with transfers like these. However, equipment like walkers, booster chairs, and lifts can help. Ultimately, you may need assistance from a nurse's aide or home health aide.

## Your Emotional Readiness

Caring for another person takes a lot of emotional energy. If you don't have the skills, or are dealing with your own challenges, it may be very difficult to assume caregiving responsibilities. It's important to take your personality out of the care. Compassion is important but not pity, as that may be embarrassing for her. Let her know that you are sorry for the pain, or the frustration that she is experiencing, but also that you think she can cope, and you are there to help.

Don't be inflexible but do ask what's needed. Use your intuition. Creating some personal space each day is important; remaining as independent as possible is good for both of you. Seek the help of a mental health care provider if you feel unable to cope with the caregiving responsibilities.

## Your Skill Set

If you have never been a caregiver, you may not be trained in basic patient care or know how to move frail, older adults without hurting one or both of you. You're likely unfamiliar with the prescription drugs your loved one is taking. Some support and training in these and other areas may be required for you to be confident in your ability to help your loved one.

## Your Time Challenges

Having a job outside the home may make caregiving more difficult for many family caregivers. If your loved one needs transportation to a medical appointment when you can't take time away from work, maybe a friend or neighbor could drive them. Senior transportation services also may be available in your community. Check with the [Area Agencies on Aging \(AAA\)](https://www.n4a.org/caregivers) in your town (<https://www.n4a.org/caregivers>).

If you are a [Long Distance Caregiver](#), you may be able to correspond with your loved one's medical provider, participate in appointments by phone or computer, and/or schedule time to talk about health status, prognosis, and what to expect down the road. Plan ahead and schedule visits to your loved one so you can accompany them to medical appointments and meet with their providers.

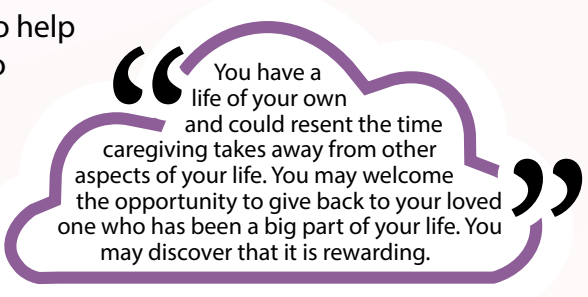
Many caregivers stop working to provide full-time help to their loved one. Carefully consider whether this is the right choice for you. The negatives may outweigh the positives. If the loss of income will be a hardship for you and your family, it may not be the best decision. Talk it over with other members of the family and informal care team.

If structure is critical to you, identify areas where a strict schedule is useful, like taking medications or meal times and emphasize them, but remember to provide your loved one with flexibility in other areas. Structure and consistency are helpful, rigidity is not. Mom's medications and physical therapy exercises are vital, having her hair done each day, maybe not.



## Your Willingness

Not everyone can or should be a caregiver. Willingness and ability to provide care may change over time. You should be honest with yourself and with your family about your commitment to caregiving. Sometimes you feel you must care for a family member. You might think there is no one else to help or that you'd feel guilty if you didn't step in. It is helpful to honestly consider what motivates you to care for your loved one. You have a life of your own and could resent the time caregiving takes away from other aspects of your life. You may welcome the opportunity to give back to your loved one who has been a big part of your life. You may discover that it is rewarding and that it allows you to become closer to your family member. If you are not sure you can do it, perhaps you should discuss with the family and see if there are others, including friends, who can step in. Maybe there are other ways to provide support for your loved one, including the possibility of paid caregivers.



“ You have a life of your own and could resent the time caregiving takes away from other aspects of your life. You may welcome the opportunity to give back to your loved one who has been a big part of your life. You may discover that it is rewarding. ”

## Your Financial Resources

The financial commitment you make as a family caregiver may take resources away from other priorities, such as saving for children's education, buying food, or paying for medical care for other family members. Think carefully about what you can afford to contribute to your loved one's care. Leaving your career to care for your loved one may seriously diminish your finances. Unless your employer supports paid leave you may lose income. Unless your employer supports the [Family Medical Leave Act](#), you may not be able to return to your former role. You don't want to deplete your financial resources and end up unable to respond to emergent needs. Financial assistance may be available in some circumstances. In some states, [Medicaid](#) pays family caregivers for the time they spend with loved ones providing caregiving tasks.

It is not uncommon for older adults to have unexpected bills and expenses. You may have to discuss these unplanned financial stresses with other family members or friends in order to successfully resolve them.



## Are You Ready to be a Caregiver?

Now that you have considered your readiness to be a caregiver, reflect upon how you feel. Make a note of any concerns you have and share them with other family members.

FACTOR AFFECTING YOUR ABILITY	SELF-ASSESSMENT OF YOUR ABILITY 1=not at all able 5= completely able	WHAT ARE YOUR CONCERNS?
Your physical health		
Your emotional readiness		
Your skill set		
Your time challenges		
Your willingness		
Your financial resources		

## TAKE CARE OF YOURSELF

### Consider Your Own Needs and Make Time to Meet Them

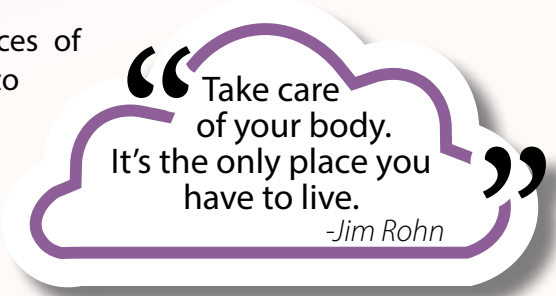
You cannot be an effective caregiver if you are not healthy and attentive to your own stress level. Balancing the competing demands of caregiving, work, family, and other commitments can be difficult. You can't effectively care for others without first taking care of yourself.

### Make Time for the Activities That Give You Energy and Strength

Keep doing what is important to you. Activities like walking, bike riding, hugging your pet, or reading may be added to your list of favorite things.

### Maintain Your Own Health

Stress, anxiety, and exhaustion — all regular consequences of caregiving — can cause illness and diminish your ability to provide effective care. Make sure you get enough sleep, exercise, and eat healthy meals. Learn about relaxation techniques such as meditation and other comforting practices such as walks in nature. Lean on friends for chats focusing on what is good in life.



“Take care of your body. It's the only place you have to live.”

*-Jim Rohn*

### Know When to Ask for Help

When much of your time and energy is devoted to meeting your loved one's needs, it can be difficult to recognize and acknowledge your own needs. It may be hard to admit to yourself and others that you can't do everything yourself, but it is important to move beyond the impulse to say, "I'm fine," and allow yourself to ask for help. It may be hard for others to know what you need. They will appreciate having you tell them, specifically, what they can do to help. **Compassion Fatigue** is real and can be prevented if you put some realistic boundaries around what you commit to doing.

### Know When to Take a Break

Caregivers say taking some time away is one of their most important supports, yet it's something many caregivers don't ask about or know how to arrange. Another family member or friend may be able to help for a few hours or a day, giving you some time to rest and take care of your own needs. Don't hesitate to ask for help. It will make you a better and more effective caregiver.

All states have **Area Agencies on Aging (AAA)**. They provide a variety of services and support for adults and their family caregivers, one of which is **Respite** care. You may be eligible to receive respite services. The National Agency on Aging can be reached at <https://www.n4a.org/> and Utah's agency at <https://daas.utah.gov/seniors/>.

## Taking Care of Yourself: How Are You Doing?

TAKING CARE OF YOURSELF	YES, I DO THIS	NO, I DON'T DO THIS. I NEED TO WORK ON:
Know your own needs and make time to meet them		
Make time for the activities that give you energy and strength		
Maintain your own health		
Know when to ask for help		
Know when to take a break		

## IDENTIFY A NETWORK OF SUPPORT

Meeting the emotional, social, health, and transportation needs of your loved one can be overwhelming. Caregiving is too big a job for one person, and no one should expect to be able to do it alone. While caregiving can be isolating, support can spring from obvious but also unexpected sources. There may be family, work, church, or community supporters. Remember that health aides, nurses, medical assistants and doctors are also part of your support community.

Identifying the helpful people who surround you and your loved one can help solidify a new sense of community with a common purpose. Taking time to think about all those who help care for a loved one with you can reveal shared goals and complementary strengths that lead to better care and increased confidence.

A visual representation, or care map, illustrating the network of people who care for your loved one can be helpful. Sketching out relationships and roles, how far away they are, and how often they help with caregiving tasks can help you see what assistance is available.

Try to answer these questions and look at the map drawn below. This map was drawn by Mike who, with his wife Christine, cares for his mother (Mom).

### Think about all those who help with caregiving:

- Who provides support to whom in your circle?
- What are the different types of support provided?
- Who is deeply involved and who is not and why?

### The nearby circle of the care map (within 20 minutes):

- Who lives in the same house with Mom? Spouses, children, pets?
- Who lives close by and can visit Mom or help?
- What outside helpers come to the home to assist Mom?
- What professional care providers does Mom see regularly?

### The middle-distance circle (less than 2 hours away):

- Where do family members or friends live and how much do they help?
- Who could come to help occasionally?

### The faraway circle (more than 2 hours, out of state or country)

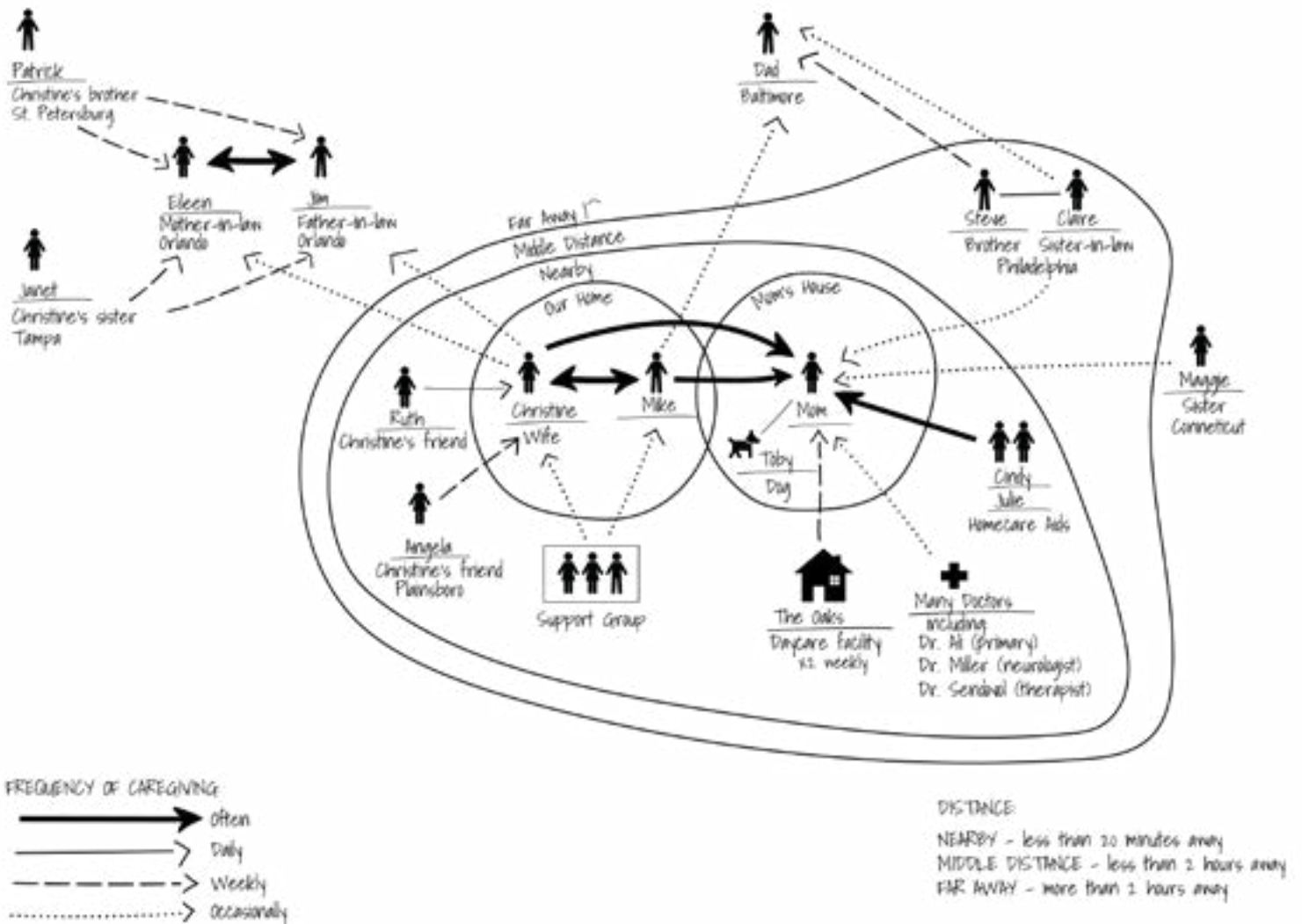
- Who can be called for advice or assistance?

Caregiving happens within a web of relationships of relatives, friends, professionals, and organizations. People are often simultaneously caring for themselves, caring for others, and being cared for by others. What each person does varies by ability and context, and over time.

[AtlasofCaregiving.com](https://AtlasofCaregiving.com)

# Care Map - Mike Stephens

November 2015



ADAPTED FROM [WWW.ATLASOFCAREGIVING.COM/CAREMAP/](http://WWW.ATLASOFCAREGIVING.COM/CAREMAP/)

Researchers found care maps help families:

- plan for potential difficulties
- manage the many people involved
- identify missing people and services
- communicate with everyone
- appreciate what is working well

The Atlas of Caregiving Map can be sketched with paper and pencil and/or using an app to create one electronically ([www.atlasofcaregiving.com/caremap/](http://www.atlasofcaregiving.com/caremap/)).

Identifying a network of support and creating a care map can help you recognize areas where you have enough support. It also can reveal gaps in care and even areas of overload for one or more individuals in your caring community. Finding problems in care patterns allows you to implement back-up plans, reshuffle team members, or seek additional support. A more comprehensive understanding of your network and resources can help you feel more supported, more confident, and better able to meet the needs of your loved one.

Many support groups are available if you would like to talk with others who are going through similar challenges. Local state AARP organizations have been sponsoring “CAREversations” in communities around the country (<https://states.aarp.org/tag/careversations>). These are typically facilitator-led roundtable discussions designed to help you:

- Discover steps to aid you in your caregiving journey
- Help you connect and exchange tips and ideas with fellow caregivers
- Learn about local caregiving resources available in your community

Support groups often have educational sessions as well as time to share stories with others. These groups may be found through disease-specific organizations (Diabetes, Alzheimer’s, etc.) or as part of aging services in your area.

## Getting to Know the Care Team

Among the many challenges of being a family caregiver is the expectation that you will navigate and manage the often-complex web of specialists, providers, appointments, and medications involved in your loved one's care.

You may feel like a small part in a large, intimidating system. Being empowered will help you navigate these challenges and provide effective care. Empowerment in this case means having a voice in caregiving and working to make sure you are heard by other members of the caregiving team.

Researchers have found, "family caregivers are more likely to be effective and less likely to be overwhelmed if both they and their ill loved one are empowered as full members of a care team working toward a common goal." (Berry, Dalwadi, and Jacobson, *Journal of Clinical Oncology*, 2018).

In this chapter, we review the potential members of the **Primary Care Team** and their roles. We suggest effective ways to speak up for yourself and your loved one when engaging with members of your team.

"Patients need to understand the different roles on a team so that they know who to go to for what, and so they have the right expectations."

- [patientnavigatortraining.org](http://patientnavigatortraining.org)

### **GETTING TO KNOW THE PROFESSIONAL CARE TEAM**

The professionals who care for your loved one are part of a broad network, including the clinic team that your loved one sees during primary care visits, as well as specialists who provide care for specific medical or emotional issues. The number and type of specialists may change over time. It makes sense to know everyone involved and what his or her role is in your loved one's care.

#### **Knowing Your Care Team Members**

Not every patient will have interactions with the full set of team members, but it is helpful to know the roles and the specific individuals involved in your loved one's care. Ask if your clinic has a "bio" sheet with picture, profile, and contact information for each care team member.

#### **The Primary Care Team**

Care teams are structured to include professionals with the specific expertise to meet patient needs. The care team may be a physician and a medical assistant supported by clerical staff. Or, it may be a comprehensive care team including all the members needed to treat issues and health problems common among older adults.

At their best, care teams work as a unit to meet patients' health needs and help them achieve their health goals. This requires team members to communicate effectively and understand one another's roles. As a family caregiver, you will want to know who makes up your loved one's care team.

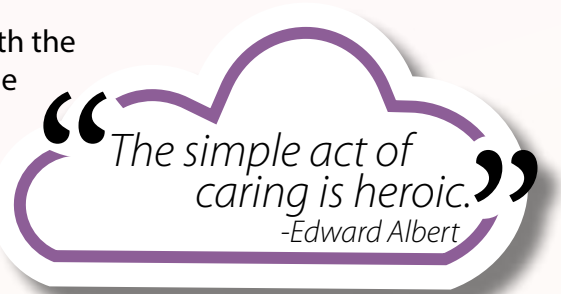


### **Primary Care Provider (PCP): Physician, Physician Assistant, and Advanced Practice RN**

The leader of a care team in a primary care or **Geriatrics** clinic is usually a physician or physician assistant. They focus on the whole patient, addressing acute medical issues as well as preventive health care. They provide regular check-ups, disease-screening tests, immunizations, and health counseling. Primary care doctors may be family medicine or internal medicine physicians (Medical Doctor, MD), or (**Osteopathic Doctor, DO**). Physician Assistants and Advanced Practice Nurses may be independently licensed or supervised by an MD. Different states have different laws for independent practice.

### **Medical Assistant (MA)**

The medical assistant has the important role of supporting both the physician and the patient. They typically escort the patient to the exam room, review the patient's medical history (including medications, health care issues since the last regular visit, diagnostic tests, preventive care that may be due). They alert the provider to any special concerns they notice or hear from the patient. They may stay in the exam room during the visit and ensure that recommended services are scheduled or done during the visit. They may help patients get an after-visit summary and/or schedule follow up appointments as needed.



### **Nurses**

Nurses work closely with patients. Their job duties depend on education, area of specialty and work setting. Types of nurses include: Licensed Practical Nurses (LPN) have one year of community college or vocational school; Registered Nurses (RN) have completed a diploma program, an associate's (2-year) degree, or a bachelor's (4-year) degree; and Advanced Practice Nurses have more education and experience than RN's. Examples of advanced practice nurses are clinical nurse specialists, nurse anesthetist, nurse midwife, and nurse practitioner. All nurses are licensed by their state. Care teams may include nurses in a variety of roles.

### **Care Manager**

A care manager helps coordinate patient care between team members. They often check on patients between scheduled appointments, and sometimes conduct home visits. They can provide patient education including the likely progression of their health condition, self-care processes, and effective operation of medical equipment they use. Care managers are most frequently nurses or social workers. Your loved one may have more than one care manager. Insurance companies often assign care managers, sometimes called case managers, to work with patients with chronic conditions or severe illnesses. If your loved one has had a hospital admission, the hospital also may have a care manager. You may interact with all of them and get to know them well.

### **PharmD**

Doctors of Pharmacy (PharmD) are clinical pharmacists rather than dispensing pharmacists. They can help patients understand how to use medicines, answer questions about potential side effects, and alert them about adverse reactions. Sometimes the PharmD may help doctors

choose which medicines to give patients and let doctors know if combinations of medicines could be harmful. You may meet with the PharmD to help you manage the medicines.

The pharmacy where you fill prescriptions will have a dispensing pharmacist who can answer questions and help avoid medication errors. Be sure to ask them about changes or additions to medications included in your loved one’s care plan or anything you don’t understand about the medicines.

**Social Workers**

In a clinical setting, social workers are an integral part of the team. They can help patients and families cope with emotional, physical, and financial issues related to an illness. A social worker may also help coordinate services such as housing, transportation, financial assistance, meals, and long-term or hospice care. Social workers also may refer patients to additional mental health professionals for emotional or substance abuse support. Social workers have experience dealing with the stress and strain among family members and can offer suggestions.

**Administrative and Clerical Staff**

Administrative and clerical staff coordinate and facilitate patient care. They schedule appointments, answer phones, greet patients, keep medical records, handle medical billing, fill out insurance forms, arrange for laboratory or other diagnostic services, and handle financial records. You may interact with these staff members often, and they will get to know you well.

**Who is on your care team?**

Now you’re familiar with the many professionals who may be involved to ensure your loved one gets the best possible care. You might now take time to identify the individuals, their roles, and their contact information. Keep this list current as the professionals caring for your loved one may change over time. Remember that not all of the professionals on this list may be part of your loved one’s care team.

PROFESSIONAL ROLE	CARE TEAM MEMBER’S NAME	CARE TEAM MEMBER’S CONTACT INFORMATION
Primary care provider		
Medical assistant		
Nurse		
Care manager		
Pharmacist		
Social worker		
Clinic manager		
Patient experience specialist		
Receptionist		

## The Extended Professional Care Team

In addition to the primary care doctor, your loved one may see a number of specialists. Specialists diagnose and treat conditions that require a special area of knowledge. Clear communication between providers is important so that each knows who else is working with your loved one and why.

Patients may see a specialist to diagnose or treat a specific short-term condition or, if they have a chronic disease, they may visit one or more on a long-term basis. Examples of specialties include **Endocrinology**, **Oncology**, **Cardiology**, and **Neuropsychiatry**.

It can be helpful to make a list of all of the providers your loved one sees and the focus of the care each provides. Your list should include contact information (phone, email, address). It is

The CARE Act requires staff to identify the **Caregiver**, **Advise** the caregiver about the need to ask for their contact information, **Record** that contact information in the patient record, and **Empower** the caregiver by having the information needed to take their patient home.

a good practice to keep track of appointments, recommendations for care, and communications you have with personnel in those providers' offices. It may be helpful to include all of the providers in the care map of family members, friends, and neighbors who assist with care.

If your loved one's health worsens, they may have an emergency department (ED) visit and/or hospital admission. The staff in these facilities are also an important part of the extended professional care team.

The CARE Act, enacted in 40+ states, requires hospitals to keep the family caregiver informed about the care plan and help

prepare you for discharge from the hospital and for any care required once the patient gets back home. As the caregiver, you should be asked for contact information. If you are not asked, you can take the lead and offer your information, letting staff know that you want to be included in discharge planning.

The time following hospital discharge is particularly critical, as medications, diets, physical therapy, and other care may have changed. Although your loved one's primary care provider may get reports of what happened in the hospital, you will also want to be sure you understand the discharge plan. Ask for a hard copy of the plan or access to an electronic version. Share it with your loved one's primary care provider. Many patients will see providers who are affiliated with different health systems and may not have access to other systems' electronic reports.

## WAYS YOU CAN ENGAGE WITH THE PROFESSIONAL CARE TEAM

With a clear understanding of the members of the care team and their roles, you are in a better position to speak up for yourself and your loved one. Below are several guidelines that may help you feel empowered to participate and engage effectively with the team.

## **Identification and Access**

### **Introduce yourself and your role**

Let the provider team know you are the primary caregiver and that you are there to support the patient and the team. Tell them what you plan to do during the visit, such as take notes and ask questions.

### **Make sure you are identified in medical records**

Most clinics use an [Electronic Health Record \(EHR\)](#). It is helpful if you are listed in the EHR as the family caregiver. When you are identified in the medical record, all members of the professional care team will know who to contact if needed.

Medical staff need to be aware of who will be providing what care at home in order to support and to provide proper training. Check to see that your relationship to the patient and up-to-date contact information are noted in the medical record.

### **Arrange for health care information access**

With your loved one's permission, you can receive information about their status and care plan. This can include access to the [Electronic Patient Portal](#), allowing you to see test results, provider's notes, and recommendations for follow-up care. Because your loved one's record contains their private medical information, you will need to complete the paperwork together. Ask the provider for more information.

## **Before the Clinic Visit**

### **Prepare for medical appointments**

Preparing for clinic visits in advance will allow you to be most helpful. Intentional preparation gives you an opportunity to strengthen your relationship with your loved one. Prepare a list of questions before each appointment and prioritize the top 3-4 issues you want to discuss. Bring them up first thing so that time during the visit can be used efficiently. Know that the provider team may also have specific plans for the visit. Be sure to bring records you have been keeping including, a medication list, weight and blood pressure results, any lab tests, and/or other physical assessments.

### **Participate in patient care planning early and often**

Early participation in your loved one's care will improve your outlook and experience. It helps ensure that the care plan is feasible for your loved one and your informal care team. It is also a clear sign to the care team that you are there to support them and will do all that you can to be sure the plan is implemented as recommended.

## **During the Clinic Visit**

### **Accompany the patient to medical appointments**

Being with your loved one during medical appointments and participating in the visit is important in a variety of ways. Not only can you provide emotional support, you also can make the visit easier by helping with transportation and mobility issues. You may also fulfill specific tasks during the visit such as taking notes about the provider's recommendations and asking questions to be sure you and your loved one understand them.

### Take notes

Health care appointments go by quickly and remembering technical or unfamiliar information can be difficult, especially when you are anxious about the medical issue being discussed. Taking good notes will help you remember important instructions. Pay particular attention to the provider's recommendations about:

- changes in medications
- referrals to specialists
- recommended diagnostic tests or scans, and
- next steps.

Bring a recording device or notebook and pen so you can keep notes on the information provided by the doctor for review or to share with family members after the appointment. A convenient form for taking notes is included in Appendix I.

### Ask questions

Your loved one may be overwhelmed or nervous during the appointment. Be prepared to ask questions on her or his behalf.

WHAT IF:	YOU CAN:
The provider suggests new diagnostic tests	Ask the provider to explain the importance or benefits of additional tests and what may be learned from the results.
A visit is scheduled to discuss a loved one's new symptom	Ask what might have caused the symptom.
The provider suggests a new treatment	Ask about it and other options and the risks and benefits of each.
Your loved one has a chronic condition	Ask what to expect in the future.

Your provider may be able to direct you to additional information sources, support, and community services. Don't be afraid to ask.

### Be Your Loved One's Advocate

#### Encourage and prompt patient

There may be an opportunity to help your loved one talk to the provider about their health goals and priorities. You can encourage them to share stories about why those things matter.

#### Offer additional information and context

Your loved one may dislike a new medication prescribed at the last visit. You can add context about difficulties they have incorporating new recommendations or medications into their

existing routine. Directions may be flexible, so it's important to ask the provider if they can work new medications into your loved one's routine more effectively.

### **Provide details the patient doesn't mention**

You may notice your loved one is spending more time napping during the day. This could indicate worsening of an underlying health issue. Knowing this, the provider may have suggestions for treatment.

Perhaps your loved one is feeling dizzy. You could share that they have not been eating regularly or drinking enough water. You are concerned that they might be light-headed and possibly dehydrated.

### **Explain circumstances at home that impact patient's ability to follow through on care plan**

The situation at home will impact the feasibility of the care plan. For example, a loved one living alone could find it difficult to always prepare nutritious meals. It might be unrealistic for you to provide daily meals. Together with the provider, you may explore other meal delivery options such as [Meals On Wheels \(sometimes called Community Meals Programs\)](#).

Maybe your loved one recently had a fall at home and was hospitalized with several cracked ribs. Since returning home, she has been sleeping in her lounge chair in the living room. Ask for suggestions to assist her to be more comfortable for restful sleeping.

## **After the Clinic Visit**

### **Be sure you understand the care plan**

Be aware of changes to therapies or medications, as well as future appointments and referrals to other professionals. Understand not just what the care plan is, but also why the suggested actions are recommended.

### **Clarify provider recommendations**

Review main points of the visit with the provider before you leave the office to make sure you both agree on what was discussed. It may be helpful to repeat back what you heard the provider say. Speak up if there's something you don't understand, or if you have concerns about the health of your loved one that have not been raised.

Communicate with the care team as needed to clarify and or ask questions. If the situation seems urgent, don't wait for the next appointment, too much can happen before then. Be sure you have access to your loved one's patient portal so that you can review the provider's notes and be reminded of next steps and follow-up appointments. Record the clinic's phone number in case you have questions once you are back home.

### **How are you doing?**

Now that you have thought about some ways you can engage with your loved one's professional care team, use the checklist below to be sure you are doing all that you can. Which of these steps have you already taken? Make a plan for when and how you will take each of those steps you haven't yet taken.



## Engagement Plan

ACTION TO ENGAGE WITH PROFESSIONAL CARE TEAM	YES, I'VE DONE THIS	MY PLAN FOR DOING THIS
<b>Identification and Access</b>		
Introduce yourself and your relationship		
You are identified in your loved one's medical record		
Arrange proxy access to your loved one's medical record		
<b>Preparing for the Medical Visit</b>		
Prepare for medical appointments		
Participate in patient care planning early and often		
<b>During the Visit</b>		
Accompany your loved one to medical appointments		
Take notes during the visit		
Ask questions		
<b>Be Your Loved One's Advocate</b>		
Encourage and prompt patient		
Offer additional information and context		
Provide details the patient doesn't mention		
Explain circumstances at home		
<b>After the Visit</b>		
Be sure you understand the care plan		
Clarify provider recommendations		



## **GET THE EDUCATION YOU NEED**

Increasing knowledge and skills related to your loved one's care will also empower your participation in the care team. Family caregivers are routinely required to provide assistance that was previously performed by trained medical professionals. These tasks often require additional training to be carried out safely. Whenever a provider mentions something to be done at home, ask how to do it properly and where and how you can learn more about it.

Demonstrations can be especially helpful. It's a good idea to repeat back the instructions you are given to be sure that you understand what to do. The provider will appreciate your attention and effort.

## **Understand Your Loved One's Condition**

Learn all that you can about your loved one's condition. Many organizations exist to help people with specific illnesses, such as the American Cancer Society for cancers of all kinds, American Heart Association for all types of heart disease, or the American Diabetes Association. Many helpful resources are available, and your health care team may be able to direct you to relevant websites or local events.

For example, if you are caring for a loved one with Alzheimer's disease, you should learn about the various stages of Alzheimer's and what to expect as the disease progresses. Many resources are available at [www.alz.org/help-support/caregiving](http://www.alz.org/help-support/caregiving). People who are living with chronic disease often have two or more conditions, and the second one is often dementia. If your loved one is dealing with dementia, you might look into educational materials developed by the Utah **Geriatrics** Education Program which include an Overview of Dementia (<https://utahgwep.org/trainings/dementia-training>).

## **Ask for the Type of Assistance You Need**

Depending upon your loved one's condition, a variety of medical and nursing tasks may be required. Don't let the care team assume you can do what is needed without any training. Be sure to ask how to do things. There are good online instructional materials including video demonstrations. Some of these are noted in the following section.

Here are examples of some of the most common tasks caregivers may be required to perform:

### **Assisting with injections, IVs, and oxygen**

Seriously ill or post-surgery patients may be prescribed medications to be administered by **Intravenous Injection** and/or **Intramuscular Injection**. Many patients will require **Supplemental Oxygen**. You will need to know how to give these medications and operate the medical equipment. Care team members can be a great resource for teaching correct procedures. Ask them to show you how to do things and be sure to carefully observe when they're caring for your loved one.

### **Helping with exercises and therapies**

You may function as a personal trainer for your loved one, supervising and supporting their assigned regimen. If a provider suggests exercises to help build leg strength and

improve mobility, you might need to show your loved one the correct way to do them. A demonstration from a care team member may give you ideas about the best way to show the correct technique to your loved one.

### **Managing medications and supplements**

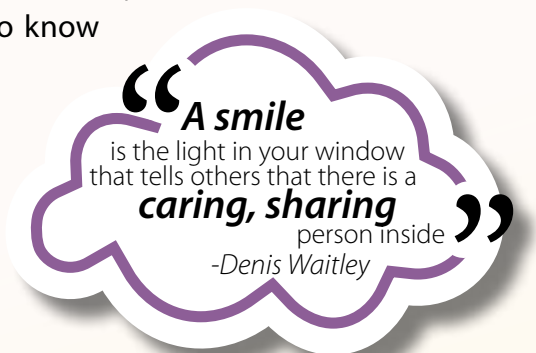
Most seniors are taking multiple medications. Your loved one may be taking medications simultaneously to treat different conditions and symptoms. Family caregivers are regularly asked to ensure their loved one takes medicines appropriately. They often describe this responsibility as one of the most worrisome because they're afraid of making mistakes. Drug interactions and over-medication are real risks. There are a few things that you can do to help manage your loved one's medications accurately.

Follow instructions; use the right amount; give medicines on time; report problems. Organizing your loved one's medications is very helpful. Pill organizers that group daily medications are available from pharmacies and grocery stores. Putting pills into an organizer is also a great reminder about what medications are to be taken daily. If different medications are to be taken on different schedules, organizers also can help in keeping track of the timetable of administration. You also should ask questions of your provider and/or pharmacist if you are not sure. It is especially important to know whether the medications are safe for older adults.

Create and maintain an up-to-date medication list. This list should include the generic and brand names, dosages, dosing frequency, and reason for taking the drug. Make sure the pharmacy label says why your loved one is taking a particular prescription.

Medications can have side effects. Be sure to read the information included with the medication or ask your dispensing pharmacist. If you notice any side effects, your provider may be able to prescribe a different medication. Be sure to take the medication list with you to your loved one's medical appointments. Discuss your loved one's experiences with their medications.

Use the fewest number of providers and pharmacists to prevent or minimize problems. Your loved one's primary care provider can help coordinate with specialists regarding the best medications to treat your loved one. Using only one pharmacy for all medications can help ensure appropriate dosage and reduce the risk of adverse drug effects and interactions (A Place for Mom, 8/14/2017).



### Worksheet: Record of Medications

The [National Institute on Aging](https://www.nia.nih.gov/health/tracking-your-medications-worksheet) created a worksheet that may help you identify and track the medications your loved one takes. Many medications have similar color and size, and it is very important to know which one each is. Describe each medication in as much detail as possible so someone helping you will not be confused. <https://www.nia.nih.gov/health/tracking-your-medications-worksheet>

NAME OF MEDICINE	WHAT IT IS FOR	DATE STARTED	DOCTOR	COLOR/ SHAPE	DOSE AND INSTRUCTIONS

### Preparing and maintaining medical equipment

Maybe your loved one has been prescribed breathing therapy. You are expected to see that the therapy is done on a regular schedule and in an appropriate manner. If you are unsure how to set up and operate the equipment, ask a member of the clinic care team or the equipment provider to come to your home and demonstrate the right way to use the equipment.

Your loved one's provider may recommend oxygen at home. The care team arranges with a medical supply company to deliver the oxygen to your loved one's home. The delivery person can demonstrate how to use the equipment and train you so that you know how to turn on the oxygen and adjust the oxygen level.

### Preparing special meals

Special diets often are recommended for specific health conditions. Some medications can interact with foods. It is important to understand whether certain foods should be avoided with the medications your loved one is taking. Your loved one may have [Diabetes](#) and [Hypertension](#). It is important to follow a strict diet in order to keep their [Blood Sugar](#) and blood pressure in control. [Insulin](#) injections must be timed around meals, and mealtimes should be consistent throughout the day.

Additionally, your loved one's diet may need to include foods that are high in fiber and/ or potassium and low in sodium. Be sure you understand as much about your loved one's conditions as possible.

In preparing meals, it can be helpful to have menu suggestions to follow that include recommended serving sizes as well as combinations of main course and side dishes that will have the needed nutrients.

### **Tracking symptoms and body measurements (weight, blood pressure)**

There are a number of processes that are so routine to your provider that they will think nothing of saying, “oh, remember to get her blood pressure every day,” and you don’t have any idea how to do that. Be sure to ask for instructions and a demonstration. There are several measurements that are together referred to as “Vital Signs” and you may need to learn about some or all of these (Body Temperature, Oxygen Level, Pulse Rate, Respiration Rate, Blood Pressure, Pain Level).

A form to record these measurements is included in the Appendix for you to use to monitor your loved one’s vital signs over time. Make sure you know what changes are normal and which require more attention. Take these records with you to your loved one’s next appointment.

Family caregivers should discuss vital signs with their loved one’s provider for guidance in interpreting vital signs as they apply to individual patients. The provider may offer some tips for specific actions to take.

### **Wound Management**

Your loved one may have had a surgical procedure, and you will make sure that the incision is kept clean and dry and take care of changing the dressing. Watching the care team member or asking them to demonstrate wrapping the incision should help you feel confident that you can change the dressing. You may get instructions about signs that could indicate potential problems with the healing. Ask for pictures of those signs, and also what normal healing should look like.

### **Pressure Injuries**

If your loved one is relatively immobile there is a possibility that they may get “pressure sores.” A pressure sore is any discoloration or break in the skin caused by too much pressure in one

## **ASK HOW TO DO THINGS**

### **Blood Pressure:**

- Have a blood pressure cuff at home in order to get measures on a regular schedule.
- Take the blood pressure cuff to an appointment with your loved one’s primary care provider and ask the MA to demonstrate the correct placement and operation of the cuff.
- Ask the provider about the best time of day to take the measurement and whether to take it before or after your loved one takes any medications for blood pressure and whether to take the reading while she is lying down or sitting up.

### **Weight and Body Temperature:**

- Weigh your loved one every morning. If they gain weight from one day to the next, this may indicate that they are retaining fluid, and their doctor may prescribe medication to help reduce fluid retention.
- Take your loved one’s body temperature at the same time every morning. Temperatures out of range may indicate dehydration or fever and may need action.

place, for example, when one sits or lies in one position too long. The skin may not be broken but is red or discolored. This type of skin damage can develop quickly in anyone with reduced mobility, such as older people or those confined to a bed or chair. Try to make sure your loved one moves or at least turns from one side to the other as often as possible. If your loved one develops a pressure sore, keep pressure off the injury and maintain good hygiene; wash with mild soap and water, rinse well, pat dry carefully (but gently). Do not rub vigorously directly over the wound. Be sure to tell the provider as soon as possible and ask for help. <https://npuap.org/page/resources>

**What tasks will you be required to perform for your loved one? Get the education you need.**

MEDICAL/NURSING TASK	I'VE RECEIVED TRAINING	STEPS I CAN TAKE TO GET THE EDUCATION I NEED
Assisting with injections, IVs, oxygen		
Helping with exercises and therapies		
Managing medications and supplements		
Preparing and maintaining medical equipment		
Preparing special meals		
Tracking symptoms and body measurements		
Wound management		
Pressure injury		

### Helpful Internet Resources

In addition to in-clinic training for specific tasks, there are many online resources that can provide you with broadly applicable information.

Many community colleges and community education programs have courses aimed at training family caregivers to perform common nursing and medical tasks.

Websites maintained by health care institutions, including the Mayo Clinic (<https://www.mayoclinic.org/healthy-lifestyle/caregivers/in-depth/Mayo-Clinic/hl-20049441>) and Harvard Medical School ([www.health.harvard.edu/staying-healthy/attention-caregivers-making-use-of-helpful-services](http://www.health.harvard.edu/staying-healthy/attention-caregivers-making-use-of-helpful-services)), offer content about caregiving tasks.

The Family Caregiver Alliance (<https://www.caregiver.org/resources-health-issue-or-condition>) has a variety of webinars and videos under categories including Daily Care, Planning for Care, and Self-Care. Topics range from dementia-proofing your home to caregiving through the holidays.

The National Association of Area Agencies on Aging (AAA) (<https://www.n4a.org/caregivers>) website provides information for caregivers and links to local agencies for information and assistance. Caregivers and seniors can find AAA offices throughout the state of Utah at <https://www.caregiver.org/utah-area-agencies-aging-utah-division-aging-and-adult-services-3> and AAA resources in their area <https://www.agingcare.com/local/utah-department-of-human-services-division-of-aging-adult-services-salt-lake-city-area-agency-on-agi>

AARP's Prepare to Care program is a valuable resource with helpful tips on how to have vital conversations with older family members, organize important documents, assess your loved one's needs and locate important resources. A guide to AARP's Prepare to Care can be downloaded from: <https://www.aarp.org/caregiving/prepare-to-care-planning-guide/>.

The Home Alone Alliance has produced videos that can be found on AARP's website at Family Caregiving Video Series (<https://www.aarp.org/ppi/initiatives/home-alone-alliance/>). The videos are a joint project developed by the AARP Public Policy Institute and the Betty Irene Moore School of Nursing at the University of California — Davis. The videos currently available include Medication Management, Mobility, and Wound Care. Specific topics of interest include:

- Giving Insulin Injections
- Organizing and Administering Pills
- What to Do When Someone Falls
- Using a Walker or Cane and Navigating Stairs
- Moving from a Walker to Shower or Bed
- Treatment of Skin Tears
- Pressure Ulcers: Prevention and Skin Care



## Purposeful Communication

Trust is the hardest of all elements to build; it can also make the most powerful impact

Douglas Gerber, Team Quotient  
[www.douglasgerber.com](http://www.douglasgerber.com)

As a family caregiver, you probably communicate with a wide range of people who have important roles in your loved one's life, including a support network of family, friends, and neighbors. You also communicate with a wide range of health professionals, including members of the **Primary Care Team**, specialists who provide care, and community-based organizations that provide services. Most importantly, you communicate with your loved one about their needs and wishes. Effective communication about hard choices, in difficult situations, is essential to

building and maintaining trust amongst team members and especially between you and your loved one.

Effective communication is central to many tasks that often fall to the primary caregiver. You may be called upon to:

- Keep family and friends informed about your loved one's health status and any changes or important events
- Coordinate family members, friends, neighbors, and paid home care aides who can help with transportation, errands, and companionship. Allow them to step in to give you time away from your responsibilities (respite)
- Manage community-based services that your loved one relies upon such as paratransit, meals on wheels, etc.

In this chapter, we outline some of the actions that can be helpful in improving communication with your loved one, the broader network of family and friends, and their professional care team.

...evidence reveals the upside for the patient if the focus of care expands to the patient-caregiver dyad. Making the family caregiver an afterthought or a peripheral concern is a missed opportunity ... It is time to move beyond the concept of merely patient-centered care and place both the patient and the family caregiver at the center of care that benefits all stakeholders in the complex task of serving patients with cancer.

Berry, Dalwadi and Jacobson  
*J Clinical Oncology*, 2018



## EFFECTIVE COMMUNICATION

You are part of something bigger than yourself. Your role as a caregiver creates a unique opportunity for both intimacy and understanding. In striving to provide the best care for your loved one you are not alone; you are part of several teams:

- The team of you and your loved one, sometimes called the patient/family caregiver dyad
- The team of other family members and friends who assist in aspects of your loved one's life
- The clinical team at the primary care clinic where your loved one goes for on-going care
- The team of specialists your loved one sees for specific health issues.

These teams function differently. Learning how each one works and contributes to the wellbeing of your loved one is important. Recognizing that they all want to provide the best care may help you cope with the ups and downs of caregiving. Mutual purpose is at the core of every high-performing team. Each team and team member should be focused on the shared goal of quality care for your loved one.

Quality care is different for every individual. It depends upon the preferences of your loved one, you, your family members, and the medical needs identified by the health care team. Sharing information about all of these, and listening carefully to each member's input, can help ensure that goals and values are aligned.

Investing in teamwork empowers caregivers by fostering transparency, responsiveness to team members' needs, open discussion and problem solving, mutual learning and appreciation, and of course, trust

California Health Care Foundation  
[www.chcf.org/](http://www.chcf.org/)

In a high-performing team, members know each other well and trust one another. Trust is earned, fostered through building relationships and communicating openly. Ongoing, honest communication enables team members to work together as allies, fulfilling their shared purpose.

You and your loved one may have different ideas about what "the best care" means. Health care professionals may have different perspectives about what care is needed. Care teams function best when members learn to accept ideas that are different from their own, agree on a mutual plan, and work together.

## COMMUNICATING WITH THE PATIENT

Efforts are underway to create a more "age friendly" health care system. The engagement of family caregivers, the opportunity for patients and their caregivers to choose the sort of care they want, and the value of excellent communication -- between providers and caregivers and between caregivers and patients -- are at the heart of such a system. (Fulmer et al, Journal of the American Geriatrics Society, 2017).

## What Matters Most

In order to support your loved one and decide upon a plan of care, you need to know what matters most to them. It is also helpful to consider what matters to you and other family members. Your loved one's preferences and values should be at the center of decisions about medical care. Families often delay conversations about what matters most until a time of crisis. Having these conversations early, and on an ongoing basis, leads to a better understanding of your loved one's motivations.

These broad conversations should explore what's important to your loved one beyond their health (e.g., children, family, pets, hobbies). Priorities may change as your loved one ages and as their health status changes. It may be helpful to have such conversations when there is a new diagnosis or change in health status.

New treatments could facilitate or impede your loved one's ability to do the things they enjoy (e.g., walking, cooking, everyday activities) or attain certain life goals (e.g., attending a meaningful event).

Knowing what matters most to your loved one is also helpful when doing advanced care planning. As your loved one moves into the final years of life, conversations about needs and desires should include a discussion about the care your loved one wants during the final phase of their life as well as how and where they want to die. Many older adults prefer to remain at home surrounded by friends and family. All too often, no one asks these questions.

## How You Can Help in the Medical Visit

There is another conversation that you may want to have as you prepare for an upcoming medical visit. Explore how comfortable your loved one feels with you participating in a visit and the role they would like you to assume.

You and your loved one can decide on the role(s) that you will each have in the upcoming visit. This conversation should include both what your loved one is comfortable with you doing, as well as what you are comfortable contributing. You can discuss what should be covered at the visit and prioritize those issues. If you disagree, you can negotiate which issues will have priority. You only have a short time with the provider, so limit the list to three issues or less that can be discussed. This purposeful communication can help ensure that

## WHAT MATTERS MOST

Asking loved ones what matters most to them can reveal goals that otherwise might not be taken into consideration in care planning.

What matters most to care recipients may change over time with changing circumstances and their changing health status. Thus, these conversations should be ongoing.

Nine out of 10 Americans think that it is important to discuss their own and their loved ones' wishes for end-of-life care, but only 32% have discussed what they want with their loved ones. Even fewer have discussed their wishes with their health care professional.

you and your loved one are on the same page. It can help set a constructive agenda for the medical visit.

Try preparing for the next medical visit using the questionnaire below.

**Making the Most of Your Doctor Visit**

This conversation guide is for patients who attend doctor visits with a family member or friend. Together, use this guide to prepare for today’s visit.

**STEP ONE:** How can your family member or friend be most helpful today?

Together, decide what types of help you would like. Mark (✓) all that apply.

<input type="checkbox"/>	Listen to what the doctor says and take notes
<input type="checkbox"/>	Help you to understand what the doctor says or means
<input type="checkbox"/>	Remind you to ask questions or tell the doctor concerns
<input type="checkbox"/>	Ask questions or give the doctor information
<input type="checkbox"/>	Allow you time alone with the doctor for some or all of the visit

**STEP TWO:** What do you want to discuss with your doctor today?

Together, decide which concerns are most important

Issues affecting the patient:	Mark (✓) if a concern to:	
	Patient	Family
Hearing or vision		
Fear of falls, dizziness, or balance		
Bladder or bowel problems		
Safety at home or when driving		
Difficulty bathing, dressing, or walking		
Financial matters that affect patient health		
Planning for serious illness or progression of current illness		
Changes in personality or behavior		
Stress, worry, or feeling sad or blue		
Trouble concentrating or making decisions		
Memory problems		
Managing or taking medications		
Other:		

## Other Crucial Conversations

### Safety First

Patient safety may require additional precautions in order to prevent new or worsening health problems. Maintaining independence and staying at home are two common goals of older adults. Achieving them while keeping your loved one safe, may require compromise.

For example, your loved one lives alone, and above all, values her independence. She wants to avoid moving into an assisted living facility and prefer to stay in her own home. She values privacy and strongly objects to the idea of home health aides around the clock or having someone move in to help her. However, because of mobility issues, she needs help with transfers. Home care would reduce the probability of a fall. If her mobility decreases further, an assisted living facility may be necessary to ensure her safety.

These competing values require compromise. A crucial conversation may be needed to work through the trade-offs. Frame the discussion around what your loved one wants, not what she doesn't want. You might begin this crucial conversation by asking what she needs to feel safe and comfortable at home.

The immediate choices are: move into a care facility (at least temporarily), thereby giving up on the desire to stay at home, or hire home health aides and give up on the desire for privacy and independence. As a family caregiver, you and your loved one need to discuss the advantages and disadvantages to each course of action. Once an option is agreed upon, a plan for making it happen is needed.



Behavior change strategies could be helpful. Key steps include:

- Recognizing the issue: your loved one needs help with her mobility
- Identifying options: move to assisted living facility or arrange for home health care
- Committing to a solution: realization that home health care will keep your loved one at home but alter her privacy and sense of independence.
- Creating an action plan: implementation requires identification of the specific tasks home health aides will perform, and creation of a schedule that balances their time in the home with your loved one's need for private time and space.

You and your loved one should discuss everything [Home Health Aides](#) might help with. Write a list of specific tasks they will be required to perform. Identify and interview potential candidates, and hire aides to help carry out the plan. Agree on a schedule of hourly coverage

and create a back-up plan in case shift changes are needed. When the plan is in place, it is important that everyone involved have complete contact information (home phone, cell phone, email), not just for you and your loved one, but for everyone involved in carrying out the plan. Home health can be expensive and insurance may not pay for it, so look into this option carefully.

### **Need to Know, Not Prying**

Once you accept the role of family caregiver, it is important that you recognize there are certain responsibilities. There are things that may have previously been private that you now need to know. Don't think of it as being nosy or prying. Ask your loved one if they are willing to help you help them.

You may find yourself in the role of go-between, needing to take or send messages and help keep household operations working smoothly. For example, your loved one's primary care team and/or friends and family may leave messages or send emails. You can't retrieve those messages unless you have the password to access their voicemail. You can't check or respond to email unless you have the login information and password to their computer and email software. You can't make sure regular monthly payments are made for things such as utilities and credit card bills without access to your loved one's checking account. You may need to ask your loved one if they are willing to share this personal information with you.

### **Legal and Other Important Documents**

In order to be the most helpful to your loved one and ensure critical aspects of their lives continue smoothly, there are things you need to know and understand. As health deteriorates, or in the case of a medical emergency, you should know the status and location of existing legal documents.

An **Advance Directive** identifies a proxy decision maker (who can make decisions for a person if they are not able to make decisions for themselves). A **Medical Power of Attorney (sometimes called Healthcare Power of Attorney)** is one form of **Advance Directive** that gives authority to a designated individual to make decisions about care and aspects of the care plan when the patient lacks capacity to make medical decisions. The medical POA is not in effect while the patient has capacity to make a medical decision, only when they cannot decide for themselves.

Every person should complete an **Advance Directive** (sometimes referred to as a Health Care Directive) to help family members understand their needs and wants. This document is especially important for older adults. Documenting discussions about preferences and values can help ensure they are respected. An **Advance Directive** can reduce uncertainty and minimize disagreements between family members. They should be shared with providers and hospitals to be sure they know your loved one's wishes. If your loved one becomes seriously ill and is approaching the end of life, additional conversations are necessary.

The end of life conversation is not always easy but is crucial in order to understand your loved one's values and desires. A **POLST** (Provider Order for Life Sustaining Treatment) is a paper signed by the patient and the provider and carried by the patient everywhere they go to clearly state what measures the patient wants or specifically does not want at the end of their life. The **POLST** should be reviewed after any change in condition, such as an ED or

hospital visit. If a trip to the emergency room or a hospital admission is necessary, be sure that a copy of this important document is provided to the facility. Your loved one may not want **Cardio-Pulmonary Resuscitation (CPR)**, but antibiotics for infection may be acceptable. It is important you know what your loved one wants.

ADVANCE DIRECTIVES VS. POLST	
ADVANCE DIRECTIVES	POLST
For anyone 18 and older	For persons with serious illness and/or limited life expectancy at any age
Instructions for <b>FUTURE</b> treatment	Medical orders for <b>CURRENT</b> treatment
Does not guide Emergency Medical Personnel	Guides actions by Emergency Medical Personnel
Guides inpatient treatment decisions	Guides inpatient treatment decisions
	Only legal mechanism for a Utahn to have a Do Not Attempt Resuscitation- DNR order outside of a licensed health care facility

When discussing final planning, be cautious about putting your own desires ahead of your loved one’s. When their goals are captured in an **Advanced Care Plan**, they can make their wishes clear. You won’t have to guess their preferences. The plan will take a huge burden from you and other family members.

By making and sharing the plan, a provider team can act as your loved one would want, even when they can’t speak for themselves. Other legal documents that can help you be a more effective family caregiver include, a **General Power of Attorney (also called Durable Power of Attorney)**, which designates an individual to conduct business/financial actions and a **Will (Last Will and Testament)** and **Trust** that describe how an individual wishes their estate to be handled after their death.

### COMMUNICATING WITH FAMILY AND FRIENDS

Family caregivers can sometimes feel overwhelmed and alone. Figuring out who you can call on for assistance with day-to-day needs can be daunting. Identifying all of those around you who help your loved one, along with the type of support they provide, can help you feel more in control.



### **Plan ahead for the future**

Much like investment or retirement planning, it can be very helpful for patients and their family caregivers to plan ahead for the assistance the patient may need with various aspects of their lives beyond their health. Things like lawn mowing, snow shoveling, or even feeding pets may need to be done if your loved one becomes less able to do them. It can be a stress reliever for both of you to know that plans have been made.

### **Make a caregiving task list**

Breaking down tasks into bite-sized assignments will make it easier for others to pitch in. Once you identify your loved one's needs, reach out to form a network of friends, family, and neighbors. Engage with acquaintances from the faith community and/or organizations in which you or your loved one have been active. You may feel hesitant to ask others for help, but some people need only a little encouragement to take on a task. They may feel left out otherwise. When people offer to do whatever they can, show them the list of tasks and let them choose how they can best be helpful.

### **Identify willing experts**

Some family members may have special skills in technology, finance, or nutrition. A tech expert could set up a digital calendar to track medical appointments, or research fall alert systems that work in your loved one's area. Friends could have work schedules that allow them to run errands when you can't. Some neighbors may be more than happy to drop by to check on your loved one, pick up the mail, or reassure you that everything at home is OK. Let them know that whatever they would like to do will be a big help.

### **Decide what information to share with whom and how**

Decide what information to share with your loved one's network of caregivers. Finding the right balance between helpful health information and information that is too personal can be tricky. But, the more your network understands about your shared needs, the better prepared they will be to help meet them.

Maintain an up-to-date list of contact information including home phone, cell phone, and email. You also will want this information in case plans change and different needs emerge.

Although everyone in your network is well-intentioned, updates may feel like one more obligation. Let others step in to help. Someone else can regularly update the network about changes in care or health status.

Coordinate information updates with another family member who can then inform extended family. This not only reduces the communication responsibility, but may also help defuse any tension between other family members.

Regular family meetings can be helpful, especially if there is more than one family caregiver. Meetings create opportunities to share information about your loved one's health status, changes in their care plan, and evolving needs for caregiving. Set aside a specific day and time for these meetings and get them on everyone's calendar. Holidays can be a convenient time



to hold meetings if family members are together. In-person meetings are easy if everyone lives close by. They can also happen by telephone or computer.

Use a care map to identify the composition and size of your caregiving network. The map can help you communicate efficiently with your network. It can be a conversation starter about what motivates and fulfills each person. It can help you determine which tasks are best suited to specific individuals. Improved understanding can help you know what information should be communicated to which individuals.

## **COMMUNICATING WITH THE PROFESSIONAL CARE TEAM**

Communicating with your loved one's health care providers is one of your key roles. Together, you share a common goal of excellent treatment and care. The more clearly you communicate, the more likely you are to get the answers you want.

It's important to learn all you can about your loved one's condition. During medical visits, you can be a second set of ears listening to the provider's explanations and recommendations. Listen to:

- Gain information
- Get a better understanding of the care plan
- Learn about new treatment options

Your engagement has a big impact on relationships with your loved one's providers. Active listening can increase respect and understanding.

Communication will be most effective if you interact respectfully. Acknowledge the provider's recommendations and ask questions to demonstrate engagement with the proposed plan. Show respect for all the care team members and respond to their requests for information. Don't hesitate to ask about alternatives - their pros and cons, and their likely cost.

At the same time, demonstrate respect for your loved one. Don't ignore their input or speak over them. Assume a supportive role when possible, letting your loved one lead the discussion. Assist the care team in whatever way you can.

Your attitude during appointments is important. When advocating for your loved one's needs, you can be assertive while still being respectful. Ask questions without being argumentative. Be firm without being aggressive and inform team members about you and your loved one's needs for additional support.

Effective two way communication between you and your loved one's providers is facilitated by establishing expectations early.

You contribute a great deal to building the relationship by expressing the needs of your loved one, clearly and concisely, without adding your own biases. You can facilitate communication both in and outside of medical visits. Begin by determining, and following, your provider's preferred method of communication.

## Ways to Communicate with the Provider Team: Use the Best One

In communicating with your loved one's providers, there may be a trade-off between convenience and privacy. Providers must always ensure that their communications about patients are secure. Provider teams often have established routines for communicating with patients and family caregivers between visits. It's best to ask what the team prefers. Some alternatives include:

### Electronic Health Record and Patient Portal

Most providers' offices have electronic health record (EHR) systems with patient portals. All of the patient's records are kept in the EHR. With few exceptions, the patient portal is a preferred channel of communication where information is secure, complete, and available for all care team members to view. Clinic staff can tell you what information is available through the EHR and how to access it.

In many cases, proxy permission allows you to access your loved one's health record through the electronic patient portal. You and/or your loved one can send messages to the provider team through the patient portal. Register and obtain login credentials so the team will recognize your communication. Do not send personal or protected patient information through [Unsecured Electronic Communication \(Email\)](#).

Information in a patient's EHR follows them throughout an organization or health care system. However, not all providers are part of the same organization or system. Although notes about visits to other providers may find their way into your loved one's EHR, request hard copies of imaging studies, test results, diagnoses, care plans, and medications ordered from any outside providers and carry them with you to medical visits to ensure that this information is included in your loved one's EHR.

Some clinics are using the patient portal to send questionnaires to patients ahead of visits. Completing these questionnaires is a great way to ensure two-way communication between the professional care team and you and your loved one.

### Phone

The phone is also a common way in which you can reach your loved one's providers. Provider offices may take incoming calls through a call center or designate one team member to answer calls, forwarding messages and/or questions to the clinic nurse or provider as needed. Busy schedules within the clinic may lead to "phone tag," and it may be some time before you receive a response. Including a time that you will be available in any message you leave may increase the likelihood of you connecting with the provider. Your provider also may have an

... health care professionals are moving toward partnership with you to achieve optimal treatment and care ... As a caregiver and advocate for a loved one, you play a central role in this partnership.

[www.caregiver.org/pathways-effective-communication-health-care-providers-and-caregivers](http://www.caregiver.org/pathways-effective-communication-health-care-providers-and-caregivers)

emergency phone number to call if you need immediate assistance; be sure you make a note of this number.

Although you may be very comfortable using text messaging, your loved one's providers are less likely to use texting. There are many rules regarding [Unsecured Electronic Communication \(Email\)](#) that are designed to protect patients. Texting also may go beyond the boundaries of the patient/ provider relationship.

### **Email**

You may be tempted to use email so that you can leave a longer message. However, providers have legal restrictions on email communication, perhaps making it difficult for them to send messages. Be sure to check to see if the provider receives and responds to email.

# Glossary

## **AARP**

AARP is an advocacy organization in support of people over 50 years of age. AARP provides education and policy statements around issues impacting older adults. <https://www.aarp.org/>

## **Activities of Daily Living**

Activities of daily living is a term used in healthcare to refer to people's daily self-care activities. ADLs include the following:

- Personal hygiene: *Bathing, grooming, oral, nail, and hair care*
- Continence management: *A person's mental and physical ability to properly use the bathroom*
- Dressing: *A person's ability to select and wear the proper clothes for different occasions*
- Feeding: *Whether a person can feed themselves or needs assistance*
- Ambulating: *The extent of a person's ability to change from one position to another and to walk independently*

Needing help with one or more ADL is not unusual for older adults with chronic conditions, and they often rely on family caregivers to assist.

## **Acute Health Care Condition**

Minor injuries or illness that will be completed or cured over a relatively short period of time are referred to as acute, as compared to chronic conditions which are never fully cured and likely last the duration of one's life.

## **Advance Directive (sometimes referred to as a Health Care Directive)**

There are a few documents that are part of the Utah Advance Health Care Directive: the Medical Power of Attorney and the Living Will. Advance Directives are for everyone, not just someone who is seriously ill. An Advance Directive communicates one's wishes about decision makers if one cannot speak for oneself. Also, one's preference for life sustaining measures should one become seriously ill and not be able to communicate one's health care wishes. An advance directive can assign a proxy decision maker when one is not able to make one's own healthcare decisions, so it should be someone with whom you have discussed your preferences. POLST (provider orders for life sustaining treatment) is also an Advance Directive and is used in consultation with one's medical provider when someone has a terminal illness or is nearing the time when they might be likely to die.

### **Advanced Care Plan**

Advanced Care Planning is a process that allows one to make plans about **future** healthcare. This involves discussions with family members, caregivers, and professional providers and includes one's values, goals, and preferences that are important to them. Some people may not have written down their wishes, but if they want to have a say in their end of life decisions, those wishes should be well documented and communicated clearly to one's loved ones.

### **Advocate**

An advocate is a person who believes in another and acts in ways to support and encourage. A person can advocate for themselves by speaking up and showing self-confidence and advocates for others by helping them feel confident and encourage them to be assertive. Organizations are sometimes considered advocate organizations because they speak for groups who are not being treated appropriately.

### **Alzheimer's Association**

The Alzheimer's Association is the leading voluntary health organization in Alzheimer's care, support, and research. The mission is to eliminate Alzheimer's disease through the advancement of research; to provide and enhance care and support for all affected; and to reduce the risk of dementia through the promotion of brain health. <https://www.alz.org/>

### **Alzheimer's and Related Dementias**

Alzheimer's disease is a degenerative brain disease and the most common form of dementia. Dementia is not a specific disease. It's an overall term that describes a group of symptoms.

People with dementia may experience behavioral and psychotic symptoms, including depression, hallucinations, delusions, aggression, agitation, and wandering. Being forgetful is not the same as dementia, but it may not be due just to old age, and you should see a professional for diagnosis.

### **Area Agencies on Aging (AAA)**

Agencies designated by the state with the responsibility for planning and coordinating services for older people or for older people and adults with disabilities within a specific geographical area. Both agencies provide information, resources, assistance and links to community services.

### **Assisted Living Facility**

Housing for those who may need help living independently, but do not need skilled nursing care (nursing home). The level of assistance varies among residences and may include help with bathing, dressing, meals and housekeeping.

### **Autonomy**

Personal autonomy is the ability to decide for oneself and pursue a course of action in one's life, often regardless of any particular moral content.

## **Blood Sugar**

Blood sugar, or glucose, is a sugar found in one's blood. It comes from the food one eats and is the body's main source of energy. One's blood carries glucose to all of the body's cells to use for energy. Diabetes is a disease in which one's blood sugar levels are too high.

## **Cardiology**

A branch of medicine that deals with the disorders of the heart as well as some parts of the circulatory system. The field includes medical diagnosis and treatment of coronary artery disease, heart failure, valvular heart disease and electrophysiology. Physicians who specialize in this field of medicine are called **cardiologists**, a specialty of internal medicine.

## **Cardio-Pulmonary Resuscitation (CPR)**

An emergency procedure for someone whose heart has stopped beating or who has stopped breathing. CPR combines chest compressions often with artificial ventilation in an effort to keep oxygen rich blood moving through one's body until further measures are taken to restore spontaneous blood circulation and breathing.

## **Care Plan**

A formal care plan is a written guide that organizes a patient's history and diagnostic examinations, and information about the patient's intended care. Care plans usually contain a standardized care plan, which will be similar for patients with the same needs as well as an individualized care plan, that is designed just for a specific patient. Care plans can change during a hospital stay, and the patient and family caregiver should be made aware of what is in the plan.

## **CAREversations**

CAREversations are events sponsored by AARP and held in a number of communities, to give family caregivers an opportunity to learn about caregiving and to meet other caregivers. The facilitator-led roundtable discussion are designed to help one:

- Discover key steps to aid in one's caregiving journey
- Connect and exchange tips and ideas with fellow caregivers
- Explore local caregiving resources available in one's community.

<https://states.aarp.org/tag/careversations>

## **Chronic Disease**

A disease that persists for a long time. A chronic disease is one lasting 3 months or more, usually for the duration of a person's life. Chronic diseases generally cannot be prevented by vaccines or cured by medication, nor do they just disappear.

### **Community Stakeholders**

People in a community who share an interest in certain types of health conditions or other areas on common interest. The community stakeholders for CCPP include providers, patients, caregivers, researchers, and service and advocacy organizations.

### **Compassion Fatigue**

A state experienced by those helping people in distress. It is an extreme state of tension and preoccupation with the suffering of those being helped. It can cause stress for the helper. Compassion fatigue occurs with doctors, nurses, and other health professionals. It can occur with family caregivers and may result in self-neglect and failure to take appropriate care of one's self.

**Dementia;** see Alzheimer's and related dementias

### **Diabetes**

A disease in which one's blood glucose, or blood sugar, levels are too high. Glucose comes from the foods one eat. Insulin is a hormone that helps the glucose get into one's cells to give them energy. With type 1 diabetes, one's body does not make insulin. With type 2 diabetes, the more common type, one's body does not make or use insulin well.

### **Diagnostic Tests and Scans**

Testing to determine the presence of diseases or health conditions. Laboratory tests help providers make diagnoses through the analysis of body tissues or fluids. Diagnostic imaging is a range of studies that include the use of radiation or other energy; x-rays, CT scans, MRI, nuclear medicine scans etc.

### **Discharge Planning**

Discharge planning takes place while a person is in the hospital to prepare the patient and their caregiver for the time when they will leave the hospital. The plan includes when and where the patient will go following discharge; home, to a care facility or rehabilitation center. This is a time the family caregiver is involved to be certain they know what care will be needed at home and to understand all of the instructions to be followed at home. Often a social worker will be involved to help with any decisions about potential facility care needed after discharge.

### **DNR: Do Not Resuscitate Order**

An order written by a doctor to fulfill an individual's expressed medical care wishes during a medical emergency. People who have a terminal disease may want to be clear that should their heart stop beating that they do not want to be resuscitated but rather be allowed to die naturally. In Utah, this is documented in a POLST form.



### **Durable Power of Attorney for Finances (also called General Power of Attorney)**

The durable power of attorney for finances is a legal document that allows one to give authority to another trusted person (one's proxy, or agent) to make financial decisions on their behalf. The designation "durable" means that it will stay in effect if one becomes unable to manage their own financial affairs. The Power of Attorney automatically terminates at one's death and one's proxy no longer has financial authority on their behalf. After one's death, the proxy will lose access to their funds and the ability to pay their bills, make funeral arrangements, or transfer property to those who will inherit. (See Last Will and Trust)

### **Electronic Health Record (EHR)**

An electronic health record (EHR) is a digital version of a patient's paper chart. EHRs are real-time, patient-centered records that make information available instantly and securely to authorized users. An EHR contains the medical and treatment histories of patients. EHRs can contain a patient's diagnoses, medications, treatment plans, immunization dates, allergies, radiology images, and laboratory and other test results.

### **Electronic Patient Portal**

A patient portal is a secure online website that gives patients convenient, 24-hour access to personal health information from anywhere with an Internet connection. Using a secure username and password, patients can view health information such as: recent doctor visits, discharge summaries, medications, immunizations, allergies, and lab results. Some patient portals also allow one to securely message their doctor, request prescription refills, schedule non-urgent appointments, check benefits and coverage, update contact information, make payments, download and complete forms, and view educational materials.

### **Endocrinology**

The branch of physiology and medicine concerned with endocrine glands and hormones. Endocrinologists are doctors who specialize in glands and the hormones they make. They deal with metabolism, or all the biochemical processes that make one's body work, including how one's body changes food into energy and how it grows.

### **Family Caregiver**

Anyone who provides unpaid assistance to another person who is ill, has a disability or needs help with daily activities. This includes family members, friends, and neighbors who provide assistance.

### **Family Medical Leave Act (FMLA)**

A law that requires some employers to let you take unpaid time off work (up to 12 weeks) for illness, having/adopting a baby, or caring for an ill family member. Your job or equivalent is guaranteed when you return. If you work for a small employer or are a new employee, you may not be able to get the leave. Some states have passed similar laws that require employers to provide paid time off.



### **General Power of Attorney (also called Durable Power of Attorney)**

The durable power of attorney for finances is a legal document that allows one to give authority to another trusted person to make financial decisions on their behalf. The designation “durable” means that it will stay in effect if one becomes unable to manage their own financial affairs. See Durable Power of Attorney above.

### **Geriatrics**

The branch of medicine or social science dealing with the health and care of older people. Geriatrics is the specialty focused on the high-quality, person-centered care we all need as we age. “High-quality care” aims to improve health, independence, and quality of life for older people. “Person-centered care” puts our personal values and preferences at the heart of our care decisions.

### **HbA1c**

Hemoglobin A1c is a term commonly related to diabetes. Also called glycosylated hemoglobin, this test measures the average blood sugar levels over the previous three months. In addition to any daily blood sugar testing, HbA1c should be monitored by your doctor.

### **Home Health Aides**

An individual who helps with bathing, dressing, grooming, assistance with meals, and light housekeeping. A home health aide may be paid privately by a patient or their family or in some cases by the patient’s insurance provider.

### **Hypertension**

Another name for high blood pressure. It can lead to severe complications and increases the risk of heart disease, stroke, and death. Blood pressure is the force exerted by the blood against the walls of the blood vessels.

### **Insulin**

A hormone made by the pancreas that allows one’s body to use sugar (glucose) from carbohydrates in the food that one eats for energy or to store glucose for future use. Insulin helps keep one’s blood sugar level from getting too high (hyperglycemia) or too low (hypoglycemia).

### **Intravenous Injection**

The giving of something such as medicine into a vein using a syringe. This allows the medication to be absorbed into the bloodstream quickly. Sometimes an IV (intravenous) catheter will be inserted into a vein and secured in place to give continuous (drip) medications or to keep the vein open for future injections without an additional needle stick.

### **Intramuscular Injection**

An intramuscular injection is a technique used to deliver a medication deep into the muscle. The medication is absorbed slowly into the system. One example is a vaccine, such as the flu shot.

## **Living Will**

A legal document, usually part of an Advance Directive, that spells out medical treatments one would want or would NOT want to be used to keep them alive, as well as one's preference for other medical decisions, such as CPR, DNR, antibiotics or pain medicine. There are different forms in each state, so make sure one completes the one for the state where they live.

## **Long Distance Caregiver**

When one lives an hour or more away from a person who needs care, they are considered a long-distance caregiver. This kind of care can take many forms — from helping with money management and arranging for in-home care to providing respite care for a primary caregiver and planning for emergencies.

## **Meals On Wheels (sometimes called Community Meals Programs)**

Balanced, nutritious meals for those age 60 and over and their spouses. May be served at community locations or delivered to the older adult's home.

## **Medical Power of Attorney (sometimes called Healthcare Power of Attorney)**

A Medical Power of Attorney or a Health Care Power of Attorney (HCPA Health Care Proxy) is a special kind of power of attorney in which one appoints another person to make health care decisions should they become unable to do so. Sometimes the term "durable" is added to power of attorney, which means it continues to be a legal document when one is not able to communicate themselves. The medical power of attorney ends when one dies and does not make their loved one responsible for their medical bills. Often times part of the Advance Directive in many states.

## **Medicaid**

A joint federal and state program that helps with medical costs for some people with limited income and resources. Medicaid programs vary from state to state, but most health care costs are covered if one qualifies financially.

## **Medicare**

Medicare is the federal health insurance program for:

- People who are 65 or older
- Certain younger people with disabilities
- People with End-Stage Renal Disease (permanent kidney failure requiring dialysis or a transplant, sometimes called ESRD)

## **National Institute on Aging**

The mission of the National Institute on Aging (NIA) is to improve the health and well-being of older Americans through biomedical, social, and behavioral research. The Institute conducts and supports research on aging through grant programs, focusing on aging processes, age-related diseases, and special problems and needs of the aged. The grant program funds research and training at universities, hospitals, medical centers, and other public and private organizations

nationwide. NIA also has a broad information program to communicate about research and health with older people, their families, health professionals, researchers, policymakers, and others.

### **Neuropsychiatry**

Neuropsychiatry is a branch of medicine that deals with mental disorders attributable to diseases of the nervous system. Common neuropsychiatric disorders include cognitive deficits, migraine headaches, addictions, eating disorders, depression, anxiety, and others.

### **Nursing Home (Skilled Nursing Facility)**

A care facility that provides intermediate care, such as assistance with personal care and activities of daily living and/or skilled nursing care; 24-hour medical, nursing and rehabilitation care; often a transition from hospital to home.

### **Nurse Practitioner**

Nurse Practitioner (NP) or Advanced Practice Nurse is a career choice for nurses that includes deeper clinical training and greater independence in practice. Advanced Practice Nurses may certify in midwifery, women's care or neonatal care.

### **Nutrition**

Nutrition is how food affects the health of the body. Food supplies calories the body uses for energy and vitamins and minerals that serve a variety of critical functions to ensure the body operates at its best. Good nutrition is an important part of leading a healthy lifestyle. Combined with physical activity, one's diet can help one reach and maintain a healthy weight, reduce the risk of chronic diseases (like heart disease and cancer), and promote overall health.

### **Oncology**

The study and treatment of tumors. A branch of medicine that specializes in the diagnosis and treatment of cancer.

### **Osteopathic Doctor, DO**

Doctors of Osteopathic Medicine, or DOs, are fully licensed physicians who practice in all areas of medicine. Emphasizing a whole person approach to treatment and care, DOs look beyond your symptoms to understand how lifestyle and environmental factors impact your wellbeing.

### **PCORI**

Patient Centered Outcomes Research Institute is a United States-based non-governmental organization, created as part of a modification to the Social Security Act by clauses in the Patient Protection and Affordable Care Act. PCORI funds studies that can help patients and those who care for them make better-informed health care choices.

### **Physician Assistant**

Medical providers who are licensed to diagnose and treat illness and disease and to prescribe medication for patients. They work in physician offices, hospitals, and clinics in collaboration with a licensed physician, or they can work independently depending upon state laws.

**POLST (Provider Order for Life Sustaining Treatment)**

A POLST form is a document one signs and is then signed by their clinician to clearly say what they want to happen during the final phase of their life. One can indicate that they want all possible life-saving measures to be taken, or no life-saving measures, or anything in between. Having the conversation about their wishes and completing a POLST document will prevent one's loved ones from wondering what they would want when they can no longer communicate.

**Primary Care Provider (PCP)**

A health care professional who practices general medicine. PCPs are the first stop for medical care. Most PCPs are doctors, but advance practice registered nurses and physician assistants can sometimes also be PCPs.

**Primary Care Team**

A team of health professionals who work closely together to meet the needs of the people living in the community. They provide a single point of contact to the health system. PCPs are often MD or DO and advance practice nurses and physician assistants may also be PCPs.

**Proxy**

Proxy is the authority to represent someone else, usually with their permission. In the body of this guide, we refer to health care proxy, which allows someone to speak for an individual if they are not able. Proxy permission also is required for a family caregiver to access a patient's health care information.

**Respite Care**

A temporary break from providing care for a loved one. Respite care can be provided by family and/or friends through services such as attending an adult day services center. One also can have a paid home-care worker come to the home.

**Robert Wood Johnson Foundation**

The Robert Wood Johnson Foundation is the largest philanthropic organization in the U.S. dedicated solely to health care. RWJF funds a wide array of programs that are working to help build a national Culture of Health.

**Scans;** see diagnostic tests and scans

**Self-Determination**

Self-determination is believing that one can control one's own destiny. It is the ability to assess information and make decisions for oneself. Each person of adult age and intelligence has the ability to control their own life.

### **Supplemental Oxygen**

A physician-ordered therapy to provide one's body with extra oxygen to support vital bodily functions in the presence of heart or lung disease. By using an oxygen tank or a concentrator, one is able to obtain higher concentrations of oxygen than what's available in the air.

### **Support Groups**

Support groups for caregivers foster the setting for sharing information, insight, advice and encouragement. They provide an opportunity to learn from others who face the same challenges and allow one to talk about their experiences.

### **Trust**

A *trust* is a legal document that allows one to specify exactly how their estate will be distributed to their beneficiaries when they die. Trusts are traditionally used for minimizing estate taxes and can offer other benefits as part of a well-crafted estate plan. A trust can be especially important if one has beneficiaries who are special needs, on government needs based assistance, have spendthrift or dependency issues, or other issues that require responsible management of the inheritance be placed with another person (trustee). A trust is a fiduciary arrangement that allows a third party, or trustee, to hold assets on behalf of a beneficiary or beneficiaries.

### **Unsecured Electronic Communication (Email)**

Email is available to almost everyone, but it was not designed to be private. Additional encryption can be applied to provide some security, but email should not be considered private or secure from theft. If you wish to use email anyway, you can, but many providers and health care organizations have rules against using unsecured email.

### **Vital Signs**

Clinical measurements specifically pulse rate, temperature, respiration rate, and blood pressure, that indicate the state of a patient's essential body functions.

### **Will (Last Will and Testament)**

A legal document that communicates a person's final wishes pertaining to possessions and dependents. A person's Last Will and Testament outlines what to do with possessions, whether the deceased will leave them to another person, a group, or donate them to charity, and what happens to other things he or she is responsible for, such as management of accounts and interests. The Will only takes effect upon your death, not before, even if you are incapacitated.

### **Wound Management**

Contributes to the healing process by protecting the wound fluids, preventing/managing infection, controlling mechanical influences, and encouraging the collagen maturation process. The goal of wound management is to ensure proper healing of wounds, which includes cleaning and re-bandaging the wound and sometimes applying medicine directly to the wound area.

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# Appendix I: Helpful Templates

## ARE YOU READY TO BE A CAREGIVER?

<b>FACTOR AFFECTING YOUR ABILITY</b>	<b>SELF-ASSESSMENT OF YOUR ABILITY</b> 1=not at all able 5= completely able	<b>WHAT ARE YOUR CONCERNS?</b>
Your physical health		
Your emotional readiness		
Your skill set		
Your time challenges		
Your willingness		
Your financial resources		

**HOW ARE YOU DOING?**

TAKING CARE OF YOURSELF	YES, I DO THIS	NO, I DON'T DO THIS. I NEED TO WORK ON:
Know your own needs and make time to meet them		
Make time for the activities that give you energy and strength		
Maintain your own health		
Know when to ask for help		
Know when to take a break		

**WHO IS ON YOUR CARE TEAM?**

PROFESSIONAL ROLE	CARE TEAM MEMBER'S NAME	CARE TEAM MEMBER'S CONTACT INFORMATION
Primary care provider		
Medical assistant		
Nurse		
Care manager		
Pharmacist		
Social worker		
Clinic manager		
Patient experience specialist		
Receptionist		

## Engagement Plan

ACTION TO ENGAGE WITH PROFESSIONAL CARE TEAM	YES, I'VE DONE THIS	MY PLAN FOR DOING THIS
<b>Identification and Access</b>		
Introduce yourself and your relationship		
You are identified in your loved one's medical record		
Arrange proxy access to your loved one's medical record		
<b>Preparing for the Medical Visit</b>		
Prepare for medical appointments		
Participate in patient care planning early and often		
<b>During the Visit</b>		
Accompany your loved one to medical appointments		
Take notes during the visit		
Ask questions		
<b>Be Your Loved One's Advocate</b>		
Encourage and prompt patient		
Offer additional information and context		
Provide details the patient doesn't mention		
Explain circumstances at home		
<b>After the Visit</b>		
Be sure you understand the care plan		
Clarify provider recommendations		

## NOTES DURING YOUR MEDICAL VISIT

Date of Visit \_\_\_\_\_ Provider \_\_\_\_\_

Medication list; keep this current. Add anything the doctor adds during the visit

MEDICATION	PURPOSE	DATE STARTED	DOCTOR PRESCRIBING	DOSE AND INSTRUCTIONS

Current Symptoms, concerns and questions. Make notes prior to the visit so that you remember everything you want to talk about.

SYMPTOM/CONCERN/QUESTION	PROVIDER RESPONSE

Vital Signs; make note when the MA is checking the signs

WEIGHT	TEMPERATURE	BLOOD PRESSURE	PULSE RATE	PAIN (YES/NO)

Notes-anything you will need to remember- changes, additions, tests or imaging recommended, next steps

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## MEDICATION RECORD

NAME OF MEDICINE	WHAT IT IS FOR	DATE STARTED	DOCTOR	COLOR/ SHAPE	DOSE AND INSTRUCTIONS



## MEDICAL/NURSING TASKS

MEDICAL/NURSING TASK	I'VE RECEIVED TRAINING	STEPS I CAN TAKE TO GET THE EDUCATION I NEED
Assisting with injections, IVs, oxygen		
Helping with exercises and therapies		
Managing medications and supplements		
Preparing and maintaining medical equipment		
Preparing special meals		
Tracking symptoms and body measurements		
Wound management		
Pressure injury		

## MAKING THE MOST OF YOUR DOCTOR VISIT

This conversation guide is for patients who attend doctor visits with a family member or friend. Together, use this guide to prepare for today's visit.

### STEP ONE: How can your family member or friend be most helpful today?

Together, decide what types of help you would like. Mark (✓) all that apply.

<input type="checkbox"/>	Listen to what the doctor says and take notes
<input type="checkbox"/>	Help you to understand what the doctor says or means
<input type="checkbox"/>	Remind you to ask questions or tell the doctor concerns
<input type="checkbox"/>	Ask questions or give the doctor information
<input type="checkbox"/>	Allow you time alone with the doctor for some or all of the visit

### STEP TWO: What do you want to discuss with your doctor today?

Together, decide which concerns are most important

Issues affecting the patient:	Mark (✓) if a concern to:	
	Patient	Family
Hearing or vision		
Fear of falls, dizziness, or balance		
Bladder or bowel problems		
Safety at home or when driving		
Difficulty bathing, dressing, or walking		
Financial matters that affect patient health		
Planning for serious illness or progression of current illness		
Changes in personality or behavior		
Stress, worry, or feeling sad or blue		
Trouble concentrating or making decisions		
Memory problems		
Managing or taking medications		
Other:		

# Appendix II: Caregivers' Resources, Alzheimer's Association

Alzheimer's Association General Caregiver's Landing Page

<https://alz.org/help-support/caregiving>

Stages and Behaviors

<https://alz.org/help-support/caregiving/stages-behaviors>

Early-Stage Caregiving

<https://alz.org/help-support/caregiving/stages-behaviors/early-stage>

Middle-Stage Caregiving

<https://alz.org/help-support/caregiving/stages-behaviors/middle-stage>

Late-Stage Caregiving

<https://alz.org/help-support/caregiving/stages-behaviors/late-stage>

Care Training Resources

<https://alz.org/help-support/resources/care-training-resources>

Caregiver Health

<https://alz.org/help-support/caregiving/caregiver-health>

Support Groups

<https://alz.org/help-support/community/support-groups>

Activities

<https://alz.org/help-support/caregiving/daily-care/activities>

Communication and Alzheimer's

<https://alz.org/help-support/caregiving/daily-care/communications>

Daily Care Plan

<https://alz.org/help-support/caregiving/daily-care/daily-care-plan>

Safety

<https://alz.org/help-support/caregiving/safety>

In-Home Care

<https://alz.org/help-support/caregiving/care-options/in-home-care>

Planning Ahead for Legal Matters

<https://alz.org/help-support/caregiving/financial-legal-planning/planning-ahead-for-legal-matters>

Planning for Care Costs

<https://alz.org/help-support/caregiving/financial-legal-planning/planning-for-care-costs>

Residential Care

<https://alz.org/help-support/caregiving/care-options/residential-care>





