

# CAREGIVER'S HUB CROSS

ROAD

CONNECTION FOR CAREGIVERS

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### **Definition**

This CrossRoad is where you begin your caregiving journey. In this section we will define what a caregiver is and the stress and burdens that are associated with the role. Also described is a CareTeam, a group of people who will support you and the older adult as you navigate through the aging and caregiving networks. The Caregiver Hub will guide you through assessing the needs of both you and the older adult and identifying potential resources to meet those needs.

### **Glossary of Terms**

A list of terms you may come across while researching this CrossRoad.

### **Search Our Database**

On the Navigating the CrossRoads main page you will find a drop down menu of pre-populated search terms that will bring you to a list of Central Massachusetts agencies and programs that relate to this topic. You may also [CLICK HERE](#) to go to our Guide to Elder Services, an online searchable database, to do more extensive searches or for results in a specific zip code, city/town or Central Massachusetts geographic region. *\*\*If you are unable to find a keyword on the pre-populated list and it consists of two terms, transpose the order of the terms i.e. to search for Caregiver Support Groups use the keyword Support Groups, Caregiver.*

### **Helpful Links**

A list of outside websites to visit for further information.

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*This information was written with older adults in mind and is meant to provide a general overview of the options and challenges that can be encountered on a caregiver's journey. The information provided does not discuss every aspect of this topic. This information does not constitute legal nor medical advice. We encourage you to consult with competent professional and/or legal representatives for advice.*

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## **Introduction**

Welcome to the Caregiver's Hub! Here you will find general information about caregiving for an older adult. You may be one of the millions of individuals who provide care to an older adult but do not even recognize the fact that *you are a caregiver*. You may think, "I am just doing what anyone would do for their spouse" or "I am just being a good son/daughter." If you provide care and support for an older adult, regardless of the extent to which it is needed, then you are in fact a "caregiver". Having this realization and defining yourself as a caregiver is absolutely crucial as you go about providing the best possible care not only for the older adult, but for yourself as well. The information we provide here is intended for caregivers who have embraced the idea of helping an older adult remain living in the community as independently as possible. However, even if the older adult is eventually placed in a long-term care facility, your role as a caregiver does not come to an end. You may find yourself doing much less for the older adult in terms of daily tasks, but you will remain very valuable as his/her advocate. Once you are clear about your role, you can then begin to take control of your caregiving experience. Caregiving can be extremely rewarding yet difficult at the same time. In order to provide the care the older adult needs to remain independent, you will have to do a great deal of research. It is our hope that you will be able to find many answers here. Just simply by reading this right now, you are already on your way towards empowering yourself to become the best possible caregiver that you can be.

## **Caregiver Definition**

A caregiver of an older adult is anyone who provides physical, financial, and/or emotional support for an older adult whose daily activities are limited by diminished mental or physical function. Caregivers assist and support older adults so they can live as independently as possible. The support caregivers provide varies greatly depending on the physical and/or mental needs of the individual older adult. Caregivers may provide direct personal care and/or they may research and manage care provided by community professionals. They may organize an older adult's home health care services, transportation to medical appointments, grocery shopping or other chores, or help manage finances. Caregivers are the backbone to our aging network and long-term care system.

There are many different types of caregivers of older adults. The two main types of caregivers are "informal caregivers" and "formal caregivers." Informal caregivers, also called family caregivers, can be anyone not in a professional position who provides assistance to an older adult. This could include family members, friends, or neighbors of the older adult. Formal caregivers are professionals who are paid to help care for an older adult. This could include home health aides, physicians, social workers, etc. Another distinction made of caregivers is a "primary caregiver" versus a "secondary caregiver." An older adult's primary caregiver is generally the person the older adult turns to first for help, the person who steps in first to handle a situation or help, and/or the person with the most responsibilities with regards to caregiving. Secondary caregivers play a smaller, but still important, role in caring for older adults. An older adult's secondary caregiver is a person who provides additional assistance to the older adult and the primary caregiver. Finally, caregivers may or may not reside with the older adult. They may live nearby or provide care from a different city/town, state, or even country other than where the older adult lives. Someone who provides care for an older adult from some distance away is known as a "long distance caregiver." Long distance caregiving poses its own additional challenges. No matter the extent of the caregiving, it can be a challenging role. Identifying yourself as a caregiver is the first step in the process to improve your caregiving experience by allowing you to understand why you feel burdened and stressed.

Everyone's individual caregiving experience is unique. Your culture, spiritual beliefs, and financial situation may all greatly impact every one of your caregiving decisions and how you meet the older adult's needs. To provide the best possible care for the older adult, it is very important that you assess your own abilities, skills, willingness and challenges with regards to your caregiving role. By

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examining your effectiveness as a caregiver, you can see which needs of the older adult you are fulfilling and which needs you are not. You might be willing to address every need and perform every caregiving duty, but there may also be some that place too great of a burden on your life and/or you do not have the realistic physical or mental ability to handle. There very well may be some tasks that you are not comfortable doing for the older adult, such as helping them bathe or use the bathroom. These feelings are understandable and very common among caregivers. It is important to identify this early and find other resources to meet the older adult's needs that you personally cannot. Throughout your caregiving journey, you will likely find it very beneficial to educate yourself, learn new skills, and/or research outside programs and services in order to make sure all the older adult's needs are met. Caregiving can be a very rewarding, but also challenging, experience. Understanding your role as a caregiver is essential to providing the best possible care for the older adult and for yourself.

## **Caregiver Burden And Stress**

Although caregiving can be a very fulfilling experience, it can also prove to be quite exhausting and overwhelming. Being a caregiver for an older adult adds many more responsibilities to your life and these responsibilities can prove to be a significant burden. It is important to recognize any burdens that come with your caregiving role. Caregiver burden refers to the emotional, physical, financial or any other type of toll that caregiving can take when you overextend yourself in an effort to provide for the older adult. This burden could include an amount of money spent, a feeling of social isolation, or any other sacrifice that may have a negative effect on you and your daily life. The burdens that every caregiver faces and the way that he/she handles them are different for every individual. It is normal for caregiver burden to lead to caregiver stress.

Caregiver stress refers to the point at which the amount of pressure, strain, or tension caused by any aspect of your caregiving relationship becomes unhealthy for your mental and/or physical well-being. When stress caused by caregiving negatively affects your personal well-being, this can harm you, the caregiver, as well as the older adult that you are caring for. Identifying caregiver burden and stress and finding ways to reduce them can be very hard, but it can improve your life and the life of the older adult. This stress can take a serious toll on the physical and mental health of caregivers and is sometimes referred to by medical professionals as "caregiver syndrome." The pressure, tension, and anxiety associated with caregiver syndrome can lead to many negative physical and mental health effects. It is widely known by medical experts that caregivers often become physically ill or injured as a result of caregiving, and are likely to suffer from depression. Caregiver syndrome has also been linked to higher risks of serious medical conditions such as heart attack, stroke, and cancer due to a weakening of the immune system caused by stress. Research has shown that caregivers tend to have a high level of stress hormones. When compared to their non-caregiving peers, caregivers also tend to have a shorter life expectancy. Furthermore, many caregivers who neglect to look after their own well-being have even been found to die earlier than the older adult they are taking care of. As a caregiver, you may be stressed and overwhelmed by many aspects of caregiving. This may include the amount of time you spend providing direct care, traveling back and forth to the older adult's home, coordinating services and constantly worrying about their well-being. The level of stress that you feel can depend on many different factors such as your personality, your cultural background, demographic characteristics, and the relationship you share with the older adult. Also, everyone experiences, interprets, and is able to tolerate stress differently.

In order to maintain your own physical and mental well-being, you have to be aware of the burdens you face and the stress you feel. Only you can truly understand the burdens you are facing and the stress that these burdens may cause you. The extent to which these burdens lead to stress is different for everyone and no one handles this stress in the same way. This means that you should always advocate for yourself and ask for help when you need it. Be honest with yourself about any difficulties you are having. Do not act as though your role as a caregiver is easy for you if in fact it is not. Sometimes it can be hard to recognize and consider your own burden and stress levels.

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Learning about your own individual caregiver burden and stress is an ongoing process to be engaged in at regular intervals throughout your caregiving journey. You can then use this knowledge to reduce your caregiver burden or begin to handle it in a way that reduces your stress level. This can vastly improve your caregiving relationship.

There are many ways you can choose to support your mental and physical well-being. One concept that mixes meditation and yoga that is being used more often by the general public to manage stress is mindfulness. The practice of mindfulness can be greatly beneficial to caregivers in helping them create a healthy balance between expectations from their caregiving role and their daily life obligations. The key component of being mindful is to be present and aware of your physical and mental state in any given moment. It is important to be accepting and nonjudgmental of any thoughts or feelings you have regarding your caregiving role. Mindfulness can be done at any time, day or night, for any length of time and in any place. All that is needed to practice mindfulness is a willingness to set aside a few minutes to an hour. You must recognize that the time you take to practice mindfulness is beneficial to both you and the older adult. Both you and the older could even practice mindfulness together. This practice can result in a caregiver or older adult experiencing a higher level of self esteem, feeling more relaxed and having more energy. There are numerous online resources and books written on this topic. You may look online, check your local library or purchase materials to learn more about mindfulness. It is up to you to determine the balance and control that you so desire in your life and what steps you are willing to take to achieve it.

## **Caregiving 101**

As you embark on your caregiving journey, it is important for you to understand the process that lies in front of you. To be successful in fulfilling your role as a caregiver, you are continuously going to need to assess your caregiving situation, determine what resources are available, build and manage a CareTeam, look into programs and services, and most importantly, support your own well-being.

Throughout this entire process, you must keep in mind that honesty is the key to effective caregiving. A lack of honesty does a major disservice to both you, as the caregiver, and the older adult. If you are honest about your own skills, abilities, and challenges, as well as those of the older adult, you and anyone else involved can make a proper assessment of the caregiving situation. It is also a good idea to be upfront and honest with others about traits of the older adult such as his/her personality, spirituality, and culture, so that everyone who gets involved with the older adult's care knows exactly what to expect. If you are a caregiver who is also employed, honesty when dealing with your employer is essential in order for them to possibly support you through the caregiving process. Finally, being honest with others about your own personal situation will ensure that you get the help you need as a caregiver. You should always be honest about your finances, time and abilities so you do not feel any pressure to overextend yourself. Also, make your feelings known if you are getting stressed or overwhelmed and always ask for help when you need it before your burden becomes too great. An honest approach to the caregiving process will allow for a much smoother experience as you care for the older adult.

### **The Process**

- Assessment  
First and foremost, you, as the caregiver, need to assess the older adult's current abilities and what he/she can still do independently. Activities of Daily Living (ADLs) are the simple self-care and functional tasks that determine whether or not someone can successfully maintain their independence. Basic ADLs include tasks such as personal hygiene, dressing, self-feeding, bowel and bladder management, and basic mobility around the home. Instrumental Activities of Daily Living (IADLs) are less fundamental for functioning but are still very important for independence and include tasks like housework, medication management, money management, shopping, telephone use, and transportation around the community.

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Knowing which ADLs and IADLs are manageable for the older adult and which ones present a challenge is a great way to determine the level of care the older adult is going to require. Assessing the limitations and challenges the older adult faces everyday will highlight the various needs that must be addressed.

Next, you must assess your own abilities, skills, and challenges as a caregiver. Looking at your own personal talents and expertise, you can determine the areas of care in which you will be able to directly provide for the older adult. You may feel that you have the ability and skills to help the older adult address each and every one of his/her needs. However, as the caregiving journey progresses you need to be honest with yourself regarding what you are realistically capable of handling on your own. Rare is the primary caregiver who can do it all alone. As the older adult's needs increase it is important for you to focus on the challenges that you face as a caregiver. When you know the specific aspects of caregiving that prove difficult for you it is then time to make a plan for obtaining and utilizing outside help and resources. The initial assessment process is a crucial step towards providing the best possible care for you and the older adult. As needs continue to change however, you will find that this process of assessment is ongoing.

- Knowing Both Of Your Resources

Now that you have assessed your caregiving situation and the need(s) that must be addressed, you can start to determine what resources are available for you and the older adult.

- *Older Adult's Resources*

First you should look into what the older adult has to offer with regards to resources. You need to understand to what extent the older adult can independently research and coordinate services to come into their own home. It will be important to assess the older adult's ability to pay for services they currently need or may need in the future. Remember many services are offered on a sliding scale or at no cost to those who qualify. It also may be helpful to look into their circle of family and friends to see if they will take on specific tasks or provide financial assistance to help the older adult.

If both you and the older adult do not have the financial resources or health care coverage to provide for the older adult's medical care, you may want to look into free or reduced-cost health care. In order to receive free or reduced cost health care services the older adult's eligibility for MassHealth (Medicaid), Medicare, and Commonwealth Care must be denied or limited. If the older adult seeks services that are not covered by their private or public health insurance plans or are too costly they may also qualify. There are many programs that offer free or discounted services, so you should thoroughly research what options are available in the older adult's area and whether or not he/she is eligible. Places like community health centers and walk-in clinics may be able to provide the older adult care and services at zero to little cost. There may be hospitals, nursing homes, and other facilities that are federally-obligated to provide a certain amount of free or reduced-cost health care to those who are unable to pay. [CLICK HERE](#) to visit the Health Research and Service Administration website for more information about these facilities and to locate one in your area. In Massachusetts specifically, there is a program in place called the Health Safety Net which allows residents of the state to receive free health care at hospitals and community health centers when they are unable to pay for it. Formerly known as Free Care, the Health Safety Net has certain eligibility requirements. The services that are provided for free are different at every health center and hospital. [CLICK HERE](#) to visit the Massachusetts Health and Human Services website for more information on the Health Safety Net and to locate facilities that are Health Safety Net Providers. While these are

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some of the current resources available, be aware that the Affordable Care Act may produce changes to these provisions.

- *Caregiver's Resources*

Now you should look into the resources that you bring to the table. Your time, money, and ability are all very valuable assets that you must consistently reexamine as they are drawn upon. For your own betterment as a caregiver, there are many educational programs and online resources out there so you can learn new skills and ensure that you are providing the best possible care. For example, various caregiver training and certification courses can provide you with the basics of what you should know about being a successful caregiver. As a caregiver you may find information provided by disease-specific organizations helpful if the older adult has a certain medical condition such as Alzheimer's disease. If the older adult has cultural beliefs and values that you are unfamiliar with, it is a very good idea for you to utilize community resources to help you become more culturally competent.

Perhaps the most significant resources available to you as a caregiver are the other people that help you along your caregiving journey. Because you have assessed the challenges you face and determined the areas in which you need assistance, you can now turn to family, friends, and professionals as resources to provide this assistance. Let your family and friends know about the aspects of caregiving that you are struggling with and find out if they are willing to help you. There may be many people in your life who are willing to help you but do not realize that you need help, especially if you are good at disguising your stress and making your caregiving role look easier than it is. This could mean getting someone you trust to help or even take over some of your caregiving responsibilities at certain times to relieve you of some of your caregiving burden. Additionally, certain areas of your caregiving may require the help of a hired professional such as a nurse, physician, or home health aide. All of the different professional and non-professional individuals who take part in caring for the older adult or supporting you as the caregiver become members of the CareTeam. If you are going to bring in outside services to help meet the needs of the older adult you need to consider the financial cost. This may mean that the older adult, you or another member of the CareTeam may have to pay out of pocket for services. If no one has the financial resources to pay for services you may need to think creatively on how to meet these needs. If you are a good cook then you could cook for neighbors of the older adult twice a week; in return they could mow the older adult's lawn when necessary.

Another way to help ensure that you are able to afford the services the older adult needs is to look into programs that may pay you, the caregiver, to provide care to the older adult. Two of these programs are the Personal Care Attendant (PCA) program or Adult Foster/Family Care program. [CLICK HERE](#) to visit our Services CrossRoad for more information on the PCA program. [CLICK HERE](#) to visit our Housing CrossRoad for more information on the Adult Foster/Family Care program. Finding new and creative ways to meet the needs of the older adult will be important throughout your caregiving journey.

In the United States, millions of working individuals are also caregivers for ill family members. If you are a caregiver who is also employed, there may be resources in place that allow you to balance your caregiving duties with your career goals. The Family and Medical Leave Act entitles eligible employees of covered employers to take unpaid, job-protected leave for specified family and medical reasons with continuation of group health insurance coverage under the same terms and conditions as if the

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employee had not taken leave. This law allows you to take leave for twelve work weeks out of a year to provide care for the older adult. Also, many employers offer Employee Assistance Programs (EAPs). EAPs are employee benefit programs that are intended to help employees deal with personal problems that might negatively affect their work performance, health, and well-being. Most EAPs offer counseling and referral services to employees and their household members. EAP counselors provide assessment and support as well as referrals to additional resources that can help employees. If your employer does not have an Employee Assistance Program, your Human Resources Department may offer similar support options.

Balancing employment and a caregiving role can prove to be challenging. Throughout the caregiving journey caregivers are faced with having to make some very personally challenging decisions. You will constantly assess the older adult's needs with those of your own and figure out what will be the best plan for both. This may result in you assessing your present employment situation. You may consider a change in your existing work schedule (moving from day shift to night shift, flexible schedule) or, lowering your hours (moving from full time to part-time). If these cannot be accommodated you may consider seeking other employment or leaving the workforce entirely. The answers to each of these questions will be extremely personal and usually have wide ranging ripple effects.

You may choose to turn to online tools and resources for guidance. There are many websites that offer tips, advice, support groups, chats, and facts about medical diagnoses. As you progress in your caregiving role you may want to utilize web based tools that assist you in organizing and sharing information with other CareTeam members. This can include professionally or peer-facilitated support groups, online schedules, calendars of appointments, prescription information, photos, medical information, etc. Many of them allow you to create an account with a password, but each site is different. Some may be designed for you to keep track of information for yourself while others are set up to facilitate sharing information with other people. This can be helpful if there are multiple caregivers who need access to information about the older adult. If you use a website like this, make sure that if you are sharing sensitive information it is in a secure place where only those people you have designated can access it. Also, most of these sites are free, so do not pay for a service unless you understand what it is and really think that it will be useful to you.

If you are struggling, you need to seek out and utilize the resources available to you. But most importantly *YOU NEED TO ASK FOR HELP* from family, friends, neighbors, employment resources and aging and caregiving network professionals. There is absolutely no need to feel guilty about reaching out for support.

***You don't have to go it alone!***

## **The CareTeam**

An extremely important step in your caregiving journey is establishing and working with other members of the older adult's CareTeam. The CareTeam for the older adult includes everyone who is providing any sort of support to the older adult or you, as the caregiver. It is critical that the older adult be at the center of the CareTeam. The core of this team will include the older adult and the caregiver(s) (primary, secondary, and long distance). Commonly you will find that CareTeams will also include medical professionals, allied health professionals, lawyers, homemakers, home health aides, EAPs, support group facilitators and anyone else who contributes to supporting the health and well-being of the older adult and you, as the caregiver. For the team to function successfully, the

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members have to communicate and cooperate effectively with each other. A successful CareTeam is a valuable resource to the older adult and can support you by helping to relieve some of the burdens of caregiving.

In order to create a successful CareTeam you will need to think about the older adult's needs and who will best assist in meeting those needs. When adding individuals to the CareTeam you need to always consider how they will support you in your role as the caregiver. Qualities of a successful CareTeam include members who communicate effectively and work well with each other. Building a CareTeam that is willing to cooperate with each other will help both you and the older adult achieve the goal of better physical and mental well-being. You may be in a situation where you are the older adult's primary caregiver and the only member of his/her CareTeam. In this case, you and the older adult would need to build the rest of the CareTeam from scratch, choosing members that you both trust to provide quality care for the older adult. If you are in a position where the older adult's CareTeam has already been established, you should try to become familiar with that CareTeam early so that if a problem or an emergency arises, you will be better prepared to handle any situation. Keep in mind that a CareTeam is never set in stone, and you both always have the right to bring in new members or ask existing members to leave.

Good communication among the members of the older adult's CareTeam is crucial to the success of the team. There are a wide variety of people on the CareTeam and it can be hard to coordinate communication with all of them. Here are some general tips for establishing effective communication with the CareTeam:

- Ensure that the older adult is at the center of the CareTeam and remains informed about all details affecting their own care.
- Be organized with all important information and keep the members of the CareTeam up to date.
- Be honest with yourself and the other CareTeam members.
- Be clear and specific and clarify any confusion or misunderstandings.
- Discuss any concerns you have with the appropriate members of the CareTeam.
- Listen carefully to what the other members of the CareTeam are telling you. Speaking and listening are both equally important to good communication.
- Keep in mind differences in religion, culture, age, and gender when communicating with different individuals.

Communication between you and the older adult will depend on your relationship and each person's own skills and abilities. If there is already a good relationship in place, communication might be easier, but if the relationship is strained or distant, both parties will have to work harder to communicate well. There are many reasons why it can be difficult to communicate effectively with the older adult. The older adult may have trouble understanding everything that is happening because of physical or cognitive decline. Also, certain topics like personal hygiene or the dying process may seem uncomfortable or embarrassing for both of you to discuss. It is important to talk to the older adult, even if it is hard, to become familiar with his/her opinions, values, attitudes, concerns, etc. If the older adult is unable to speak due to a medical condition, it may be a good idea to contact a professional who can help with developing other methods of communication. Remember that the older adult is the main member of the CareTeam and should be included in all important discussions. Some of these tips apply to communicating well with anybody and might be self-explanatory. However in stressful situations it is valuable to keep in mind these suggestions for communicating well with the older adult:

- Communicate early about what the older adult's wishes are such as medical interventions and/or care. These conversations should start when the older adult is still well. Having done this will make you more prepared for when a crucial situation arises.

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- Take your time in any conversation.
- Use the older adult's name and maintain eye contact throughout the conversation.
- Offer some visual help, like hand motions or drawings, if the older adult has memory and/or understanding problems.
- Gently remind the older adult of words, names, and facts if they are having trouble remembering.
- Speak clearly and slowly. If the older adult has trouble hearing, speak loudly.
- Give the older adult enough time to understand and ask questions.
- Do not interrupt the older adult.
- Talk about one topic at a time to avoid confusion.
- Avoid distractions such as TV, radio, or a crowded area.
- Be encouraging, especially if the older adult seems nervous or confused.
- If the older adult has aids for hearing or seeing, make sure they are utilized.
- Do not give up or get frustrated if you have to repeat things.
- If the older adult does not seem to understand, try another tactic-reword it, write it down, draw a picture, etc.
- Do not talk down to or treat the older adult like a child. Even if the older adult has memory or understanding problems you should make every effort to engage them in conversations about their own care.
- Take a break from the conversation if you or the older adult needs to.
- Choose a time of day to talk when the older adult functions best. With many older adults, this may be in the morning or early afternoon. Also make sure both you and the older adult are in a good, calm state of mind before engaging in any major conversation.

Family members and friends can be important allies on the CareTeam. They can help you when you need it, but only if they know that you need the help. Do not assume that because they are family or friends that they will somehow realize that you need support without you point blank telling them. If you are struggling or need some assistance, you need to ask for help. There is nothing wrong with admitting that the burdens of caregiving are too much for you alone or that you need a break. Relationships and histories between families and friends can be complicated and difficult. In these situations it might be a good idea to bring in the help of a mediator because the dynamics between family members and friends and any past issues will not simply disappear when you begin caring for an older adult. Any problems that you had in the past with each other will most likely pose similar problems on the CareTeam. The past roles and relationships among members of the CareTeam can make working together difficult and possibly even strain those relationships further. This can affect your communication with these individuals and make it more challenging for you all to work together on the CareTeam. In times of much stress or crises even strong relationships can become severely strained. Here are some suggestions for communicating effectively with family members and friends:

- Make your feelings and opinions known. If your caregiving role is hard on you, do not hide it.
- Always ask for help when you need it.
- Do not let any personal issues with family or friends prevent you from communicating and working with the rest of the CareTeam to help the older adult.
- Have the older adult clearly state or write down any wishes and make them known to all family and friends to avoid later confusion and contradiction.
- Set boundaries about each of your responsibilities and limits.
- Choose a time to talk when you have enough time to discuss everything you need to.
- At all times try to fully engage the older adult in any planning discussions. Make sure that you do not talk to the older adult like a child or act like they are not there.

Professionals, such as doctors, social workers, and lawyers, are valuable resources for you on the CareTeam and can help you understand various aspects of the older adult's care and supportive

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services for yourself. However, talking to some professionals can often be confusing or intimidating. Here are some suggestions for communicating well with professionals on the CareTeam:

- Establish a relationship and rapport with all professionals so that if and when you need their help, the relationship is already formed.
- Write your questions down ahead of time.
- Try to be clear and not ramble.
- If you have more to discuss than can be done in the time of a regular appointment, make an appointment for a consultation. Be aware that many professionals will charge you for this additional use of their time.
- Recognize that not all questions have answers. Also remember that professionals do not know the answers to every question you may have and they may need to refer you to someone else for answers.
- Do not take your anger and frustrations about caregiving, especially stress related to the older adult's physical and cognitive challenges, out on the professionals. They are on the same team as you and the older adult and are not to blame for problems such as illnesses, health insurance limitations, or various restrictive program policies and procedures.
- Remember to be polite and thank the professionals that help you.
- Be persistent if you need to be, but do not be rude.
- Take detailed notes during every meeting or discussion with a professional.
- Ask questions about anything that is not clear.
- Mention any concerns you or anyone on the CareTeam has about the health, well-being and/or safety of the older adult.

Individuals who start off as the sole provider of care to an older adult may find the concept of seeking additional help as a sign of personal weakness or failure in their caregiving role. However, there is nothing further from the truth. As a caregiver establishing a solid CareTeam around you is essential in order to provide both of you with the appropriate level of care and support. You may be experiencing severe caregiver stress and undergoing confusion and frustration without even realizing that you need to have your caregiving responsibilities shared amongst more individuals. It is important to realize that expanding the CareTeam to include more family members, friends, neighbors, volunteers and professionals to help out with caregiving responsibilities shows that you care enough to organize the best possible care plan for both of you. It is not a sign of weakness and you should never hesitate to seek out more individuals who are willing to contribute to the CareTeam. A CareTeam that includes the right people who all work and communicate together effectively ensures that every need and concern of the older adult is addressed and can relieve you, the caregiver, from some of the burdens and stress associated with your role.

## **Programs And Services**

With the older adult's basic CareTeam established and working effectively, you may begin to look into utilizing various programs and services that can benefit the older adult's care and relieve you of some of your caregiver burden. Some of these may already be in place when you enter your caregiving role or you may look into them in order to plan ahead for the older adult's care. Certain programs and services may be needed immediately following a crisis. Because of this, it would be a good idea to in advance be familiar with available resources. There are a number of different programs and services available, so it is recommended that you look thoroughly into every option before deciding what works best for you and the older adult. As the older adult's needs change, different options may become relevant so examining programs and services will prove to be an ongoing process. When researching programs and services you will find that they can provide a wealth of support such as legal, financial, medical and domestic services. Programs like respite care and adult day care are great ways for you to get needed time away from the burdens and stress of caregiving, while knowing that the older adult

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is in safe, professional hands. Respite care may have the older adult attend a program in the community or a professional caregiver may come to the older adult's home. Either way the goal is to relieve you of your caregiving duties for some period of time. Through an adult day care service, a popular form of respite care, the older adult spends time at a non-residential facility in which supervision, activities, meals, and social outings are provided.

Before you commit to any program or service you should fully understand the policies and procedures as well as make sure that they have a good reputation and are trustworthy. You need to question how the program or service is paid for because it may be a crucial factor in determining whether or not it should be considered and is affordable. Some programs and services may be covered by Medicare, MassHealth (Medicaid), long-term care insurance, or Veterans Administration benefits. However, many others require you to pay out of pocket, which, depending on your financial situation, could rule them out. Another important thing to keep in mind when setting up services is to make sure that any individual or agency representative, who is assisting with the care of the older adult, is dependable, reliable and trustworthy. You have to use your judgment when it comes to the decision of hiring someone. You should not be overly trusting and should not hire an individual or agency without knowing anything about them. Whether or not they are properly licensed and have a good reputation are both very crucial factors. Recommendations from trusted individuals, references, and background checks are all good ways to decide whether a person or an agency is acceptable to be hired. These are especially important if the individual or agency representative hired will be alone in the home with the older adult.

One way of doing a background check on someone is to request a Criminal Offender Record Information (CORI). A CORI provides information about an individual's criminal history and record in Massachusetts. Many organizations pre-screen their personnel with CORI checks. If you bring anyone into the home that is not provided by a trusted agency, it is a good idea to conduct a background check to make sure the person does not have a criminal record. In Massachusetts you are able to obtain the personal criminal history for yourself or that of another individual by requesting a copy of the Criminal Offender Record Information (CORI). Be advised that it will only provide certain pieces of information and is not all inclusive, but can help eliminate people with a serious criminal history. The form you will fill out is the "Criminal Offender Record Information (CORI), On Behalf of-Home Health Aide Request form". This form has no fee associated with it but will need to be notarized. This form can be used for various types of in-home care providers such as home health aides, homemakers, companions and individuals who provide chore services. For more information, [CLICK HERE](#) to visit the Massachusetts Government website to view the form. You may call the Massachusetts CORI Unit of the Department of Criminal Justice Criminal Information Services at 617-660-4640 and request the form. If you do not have access to a computer printer you may choose to visit your local library to print the form. [CLICK HERE](#) to visit the Executive Office of Public Safety and Security website for more information.

If you do your homework and figure out which program or service will work best for you and the older adult, your caregiving experience can be greatly enhanced by the help you will find. Making your caregiving duties more manageable through outside help is a very good way to ensure that both you and the older adult are being taken care of in the best way possible.

## **Support**

Caring for an older adult can be an extremely rewarding endeavor but also one of the most challenging experiences in your life if you are not adequately prepared to handle the responsibilities, burdens, and stresses that come with it. You may find yourself in an overly stressful situation in which you are unsure of where to turn for help. You, as a caregiver may feel reluctant to ask for help with caring for the older adult. This is very common among caregivers. You may want to keep the needs of the older adult and yourself private because you may feel embarrassed about the situation. This

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may lead to you, as a caregiver, feeling isolated and alone in your journey. To combat the isolation you must find a secure place to vent about the stress and burden of caregiving and how it is affecting you. You may feel comfortable doing this with a close friend or family member or you it may be beneficial to turn to a support group to vent about your caregiving experience. Reaching out to others and addressing the stress and isolation you are feeling will lead to an improved caregiving situation. If your caregiving burden and stress are negatively affecting you and you continually ignore it, it may lead to you providing poor care to the older adult. In order to improve the physical and mental well being of the older adult and you, the caregiver, you must reach out for support and assistance with this caregiving journey. That is why it is very important to know that there are many supportive services to assist caregivers like you in fulfilling all the duties of your demanding role. Remember that the many informal and formal support systems available to you are tremendous resources that will help you throughout your caregiving journey.

One tool for increasing positive emotions and combating negative emotions related to your individual caregiving is to utilize social support. It can help you feel more connected to others. Social support comes in many forms and you need to decide what will work best for you. Social support can be as simple as having a friend over for tea to discuss your day (informal) or can be a structured support environment, like a caregiver support group (formal). You need to recognize your own need for social support and find the resources that will best help you. Healthy caregivers are often the ones who learn to utilize both kinds of social support, formal and informal. You are the only person who will truly understand when your caregiving tasks become burdensome and result in stress. Only you know how much and what kind of support you need. If you need support, *YOU NEED TO ASK FOR HELP!* Do not assume that people will know when and how to help you. It is up to you to seek out friends and family members to talk to, give you a break from everything, or to take over the responsibility of certain tasks. It is also up to you to seek out formal social support, such as a support group, if you think it might improve your life and caregiving experience.

### ***You don't have to go it alone!***

Informal social support is the comfort and assistance that can be offered to you by your social network, including family members, friends, neighbors, people in your spiritual community, and others. Everyone has a different social network and defines these relationships in different ways. Whatever form your social network takes, it can provide a support system for you during your time as a caregiver. This type of support may mean regularly scheduled get-togethers with others or spur of the moment visits. Your peers can often give you tips and advice on how to handle certain situations.

Formal social support, like support groups or facilitated chats, is more structured than informal social support. Support groups often meet at a specific time, with a certain number of people, at regular intervals. Each support group has its own goals and structure. Support groups may be disease-specific, online, or in-person. They may vary drastically in the way they are scheduled. Some support groups have leaders or facilitators with training in therapeutic or mental health disciplines while other support groups are peer run. Various support groups will bring in guest speakers. Many support groups run for a specific amount of time, say twice a week for six weeks, while others are continuous and on a drop-in basis. Be aware that there are specialized support groups available where both you, the caregiver, and the older adult attend together. The variety of support groups offers you many options to choose from. It is a good idea to research the available options to see what is out there and available. You may need to try more than a single support group before you find the one that best meets your needs. [CLICK HERE](#) to visit our website for upcoming support groups and chat sessions. Here are some things to keep in mind when choosing a support group:

- Whether it is online or in-person
- When the meetings are held, how often they are, and how long they last
- If it is in-person, where the meetings are held and how easy they are for you to get to

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- What the focus of the group is (for example, is it for caregivers in general or for caregivers of older adults with Alzheimer's disease)
- How large or small the group is
- The cost of the group and if it is covered by any insurance or Employee Assistance Program (EAP)
- The rules of the group and whether or not they are followed. For example, privacy and confidentiality rules, the format and etiquette of the meetings (does everyone take turns talking or do people talk at the same time), etc
- Who the facilitator/leader is and his/her background including education, experience, etc
- How comfortable you feel in the group. The personalities of the members are important. In some groups, members change on a regular basis, so you can try the same group at a later date if you do not feel comfortable with the current members

Many people turn to their religious faith when they are confronted with daily challenges, as well as when they face an unexpected adversity like a new diagnosis or death. Having the support of a religious community may be helpful for both the older adult and you, the caregiver. Research has shown that prayer increases overall well-being, specifically assisting in coping, increasing self-esteem, and providing relaxation. For example, researchers have shown that people who attend church more frequently have a lower mortality rate than those who do not attend regular church services. These findings show that maintaining a regular religious practice is important to positive well-being. Whatever your religious faith may be, having a religious community and a strong faith can provide you with a support system as well as comfort when dealing with the challenges that caregiving can bring. When you are feeling overwhelmed or in need of assistance, do not forget to call on your religious and spiritual 'family' to provide you with emotional and physical support.

It is very important for you as the caregiver to focus on ways in which you can support yourself. You have probably heard it many times before, but you absolutely must take care of yourself if you are going to be of any use to the older adult. Your role as a caregiver can be very rewarding but simultaneously, it can be taxing on you emotionally, physically, spiritually and financially. To support yourself through this challenging experience, there are many things you should keep in mind that can benefit your well-being. Free time for some may be very limited, so understand that you do not necessarily need to dedicate hours towards your own well-being. Just using a couple of minutes wisely to do something you enjoy such as contacting a friend can go a long way towards reenergizing yourself. Taking care of yourself physically is essential, so you should try to maintain a healthy diet and do your best to always get enough sleep. Exercising regularly is another great way to relieve stress and maintain your physical health, but this does not mean you have to go to a gym. Doing simple everyday things like parking far away or opting to take the stairs are great ways to naturally work exercise into your routine. To support yourself emotionally and spiritually, stress reduction techniques, such as mindfulness, are a perfect way to put your mind at ease and find relief from the burdens and stress associated with caregiving. Whatever you choose to do, just making time for yourself and focusing on your own well-being can do wonders towards making your caregiving role much more enjoyable.

However you decide to go about getting support as a caregiver, it is important for you to be proactive in doing so. Make others aware of your feelings and any need for assistance. There are plenty of support options available to help you effectively fulfill your role as a caregiver, and seeking them out can ensure the best possible outcome for both you and the older adult.

## **[www.SeniorConnection.org](http://www.SeniorConnection.org) & The Connection For Caregivers**

As an Area Agency on Aging, Central Massachusetts Agency on Aging is here to *help you at the crossroads of eldercare*. Our agency plans, funds and monitors programs for older adults and caregivers throughout the 61 cities/towns in Central Massachusetts. We also provide Information &

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Referral to older adults, caregivers and professionals. Our website, [www.SeniorConnection.org](http://www.SeniorConnection.org) has a wealth of information and resources that are all free to you. It offers [The Guide to Elder Services](#), the region's most comprehensive online searchable database listing agencies and programs that serve older adults and their caregivers. This searchable database allows you to customize your query for the services you need. It is an indispensable resource for older adults, caregivers and professionals. We have also made "[The Caregivers' Guide](#)", an extensive resource guide for caregivers, available on our site. You may also click on [Connection for Caregivers](#) which is a home on the internet for people balancing the demands of work and home responsibilities that include caring for an older adult. On this site you will find a live monthly support group for caregivers that is facilitated by a licensed social worker and a peer support group that is available 24 hours a day 7 days a week for caregivers to receive informal support from other caregivers. Also you will find live monthly chats with community experts regarding reverse mortgage, health and prescription drug insurance, legal issues and prescription drugs. Connection for Caregivers also offers articles by experts in the "[Four Corners](#)" section. Here you will find four new articles each month on medical and legislative issues, ways to maintain well-being and a spotlight on resources available for older adults and caregivers. SeniorConnection and Connection for Caregivers offer a great deal of resources for older adults and caregivers. Remember, *You don't have to go it alone!* You can always turn to us for help when you need it. If you are still left with questions you can email, call us or stop by our office and we will do our best to answer all of your questions.

## **Conclusion**

While there are certain elements that any successful caregiving journey must include, this process is by no means a straight forward path. Assessing the abilities, skills, and challenges of both yourself and the older adult is a continuous, ongoing process because these factors can change at any given moment. As the caregiving journey goes on, you may be able to provide more for the older adult due to your increased level of experience or you may require even more outside assistance due to the older adult's diminishing abilities. Even if you stop providing direct care or pass on your responsibilities this does not mean that your caregiving role has stopped. Whether the older adult begins receiving formal care in the home or moves to a long-term care facility, you are still a caregiver. Your role may simply change and you will often have to still coordinate care and services as well as be a strong advocate for the older adult. Regardless of what changes occur, it is important that you always reassess your caregiving situation so that you can plan for the older adult's care in the most effective way possible. In the same way, the resources available to you as a caregiver can change regularly. Other individuals on the CareTeam may become too stressed or overwhelmed to continue caring for the older adult while at the same time, new help may emerge from people who are willing to assist you. This means that the older adult's CareTeam is never set in stone. You may constantly find new professionals and non-professionals alike that you wish to involve in the care of the older adult. Additionally, the older adult may become eligible for more programs and services along the way so those are areas you should continually look into. Flexibility is essential to the entire caregiving process. When you continuously try to explore every possible care option and resource, you are proactively taking every step to make your caregiving journey as happy, successful, and rewarding as possible.

## **Time To Get Started!**

No matter where you are in your caregiver journey the accompanying CrossRoads are full of information, tips and advice that will help you navigate the maze of aging and caregiving networks. Remember most importantly:

***You don't have to go it alone!***

**[CLICK HERE](#) TO RETURN TO NAVIGATING THE CROSSROADS TO BEGIN YOUR JOURNEY.**

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