
You & Your Aging Parents

A Family Approach to Lifelong Health, Wellness & Care



Hebrew
SeniorLife



HARVARD MEDICAL SCHOOL
AFFILIATE

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Recognizing the Change

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HOW CAN I BETTER
UNDERSTAND THE
CHALLENGES MY
PARENTS FACE
AS THEY AGE?



To understand the challenges your parents face as they age, you must begin by walking in their shoes and realizing that the walk is a marathon—not a sprint. This means being present when you're with them and talking with them about the journey they are on.

You can better understand the changes that your parents have been going through by asking them to describe what is important to them as they age and understanding their values and goals. Based on their answers, it is important to acknowledge what they are still able to do, what they can do with assistance from others, and what these changes mean to them related to their values and goals.

It is important to recognize that the changes they face often mean losing the ability to function in certain areas. There is a lot of information to be learned from the physical, psychological, and adaptive changes your parents may make to cope. How your parents deal with the loss of certain abilities will be determined, in part, by their resiliency—whether they have the physical and mental reserves, emotional fortitude, and spiritual health to respond to and withstand tough times. Having their own coping mechanisms, as well as support from others, can help them move through significant changes.

If you find that your parents' medical situation is changing and impacting their ability to maintain independence, use that as an opening to talk about how they are dealing with these changes. Ask them how that makes them feel. This requires listening skills, active engagement, and carving out time to have this type of conversation. It is important to reflect on what they tell you and then talk about it.

You can start by asking them for their parental wisdom in a personal situation you are facing. As the dialogue continues, you can get the conversation to shift and begin talking about their dreams and goals and what's really important to them to still try to accomplish in their life. If you can determine with them the barriers that are preventing them from achieving those goals, you can talk with them about putting together a plan to help them attain those goals in their remaining years. Understand those goals will change over time based on what they're capable of doing.

Remember, this is an ongoing process of learning and sharing. By sharing your own challenges with your parents, you begin to open up productive communication. This allows for a better understanding of what your parents want as they age, and helps you appreciate the changes you will encounter as you navigate the road ahead.

HOW CAN I OBJECTIVELY
ASSESS MY PARENTS' PHYSICAL
AND MENTAL HEALTH TO
GET AN ACCURATE HEALTH
AND WELLNESS PROFILE?

If you are observant, involved in your parents' lives, and know their patterns of behavior, you will know when things are changing. If you observe changes that are of concern to you, ask your parents about the changes, and whether they have seen their doctor about these changes and sought the doctor's advice. If you feel it is significant, help them to schedule a doctor's visit promptly. The changes may be side effects of medication they are taking, and the doctor can make immediate adjustments if that is the case. If they're reluctant to go to the doctor because they're avoiding hearing information or taking an action they are reluctant to accept, let them know that there are probably alternatives the doctor can recommend that can still improve their quality of life.

If your parents have multiple medical issues, it would be great for you to visit the doctor's office together. If you can't go to the visit, write down your questions for your parents to take with them to help them frame a productive conversation with the doctor. The Medicare benefit now allows for an annual wellness exam with a zero premium and no out-of-pocket costs for your parents. If they haven't been to the doctor, this is an annual opportunity for them to get a wellness assessment and create a wellness program with a doctor. This exam can identify any issues, and at the very least, confirm that you're on the right preventive path.



WHAT IS PART OF THE
NATURAL AGING PROCESS
AND WHEN SHOULD I BE
MORE CONCERNED?

While aging is a natural process, circumstances along the way will change. It is important to focus throughout the process more on whether your parents are enjoying a good quality of life and have a sense of purpose and meaning. If your parents lose focus, or become despondent and withdrawn, you should address this change with them. Early identification is very important in addressing changes that may not be self-evident to others. Talk to your parents about how these changes are impacting their lives and how they are dealing with them. Ask if this is preventing them from having a meaningful life and, if it is, ask them if you can help them solve the problem.

Remember, there are steps that can be taken to prevent decline, but often it can't be fully stopped. You can change the slope of the aging process, but aging is, by definition, a gradual process of slowing down. There's only so much energy and resiliency we all have as we get older, and your parents will have to deal with the daily challenges and tasks of life based on that.



WHAT ARE THE TRIGGER POINTS
ASSOCIATED WITH AGING
CHALLENGES FOR WHICH I
SHOULD BE ON THE LOOKOUT?

Think of your role as that of a coach who wants to get your parents activated and engaged on the playing field...

The trigger points associated with aging challenges that should be of immediate concern, and what we as doctors focus on, are functional changes in the ability to manage the activities of daily living alone. For example, if your parent is having trouble taking care of his personal needs like shaving, or remembering to eat, these may be warning signs. These changes impact your parent's ability to remain independent.

When these changes occur, there is an opportunity to revisit what is important to your parents and how these changes affect their goals. At these points in time when there will likely be a need for more care and services, it will be very helpful for your parents to have plans of care in place, as well as to know their goals of care, which may need to be revisited and modified. Your role at these “decision points” is to help your parents understand and accept the outcome they desire. It is important not to be paternalistic and stress your views in an overbearing and intrusive manner. Think of your role as that of a coach who wants to get your parents activated and engaged on the playing field, while realizing they're making the decision about where the ball ultimately goes.

There will also be trigger points in chronic conditions, which will become decision points, as well. As chronic conditions progress and it is clear that the disease is impacting your parents' health and function, it will be important to discuss your parents' values and wishes, particularly when they cannot maintain their independence. It is important to understand their advance directive and priorities, including whether they want to live as long as possible or to function as well as possible—decisions that weigh both quantity and quality of life. Their priorities can also change as their health and life status changes over time.

Remember, this is an ongoing process of learning and sharing. By sharing your own challenges with your parents, you begin to open up productive communication. This allows for better understanding of what your parents want as they age and helps you appreciate the changes you will encounter as you navigate the road ahead.

DID YOU KNOW?

TALKING TO YOUR PARENTS' DOCTOR

Parents need to give their doctor written permission that allows the doctor to speak with you directly about their medical conditions, diagnosis, and prognosis, as well as their care plan. Without that written permission, health care privacy law will prevent their doctor from talking with you regarding any aspect of your parents' medical records or conditions. If you have this approval, you are in a better position to help facilitate, navigate, and support them when they need it.

Having this access is particularly necessary if you are your parents' health care proxy. As their proxy, you will need to have accurate information and know their current situation to make decisions and respect your parents' wishes with respect to those decisions.

Acknowledging the Change

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DOES EVERYONE GET
FORGETFUL AS THEY AGE?

It is not uncommon to experience some memory loss as we get older. Although your loved one may complain of memory problems, that does not mean they have dementia. Mild forgetfulness is part of normal aging and should not interfere with one's ability to participate in everyday activities.

Common memory issues include difficulty remembering names and details of events. If this does not interfere with any daily functioning, then it can be considered normal and likely related to natural aging.

In contrast, significant memory loss is not a part of normal aging. A list of the 10 early warning signs of dementia is included on page 20. These symptoms, which are progressive over time, interfere with one's everyday functional abilities. If there is any concern that memory symptoms may not be normal, it is a good idea to consult a clinician who can conduct an assessment. Sometimes patients can receive clear information after one assessment, but oftentimes

additional testing is indicated, as well as possible referral to a memory care specialist. After thorough evaluation, sometimes the diagnosis is "dementia." There are many illnesses that cause dementia. Alzheimer's disease is the most common, and other conditions include vascular disease of the brain, Parkinson's disease, and many more. If dementia is diagnosed, current approaches focus on helping people maintain mental function, manage distress if it occurs, and slow or delay the symptoms of disease. There are several prescription medications that can be used to treat people who have been diagnosed with dementia. Most medications work best for people in the early or middle stages, and can slow down the rate of memory loss over time. It is important to understand that none of these medications stop the disease itself.



WHAT SHOULD I DO IF I BELIEVE DEMENTIA EXISTS?



**...there's a lot of information,
services, and research trials
to support family caregivers.**

First, find out more about dementia and its symptoms. Talk with your extended family to get their impressions, and see if they share your concerns. If your loved one is displaying symptoms, accompany them to their next appointment with their primary care clinician. You can request a consultation with someone who specializes in cognitive disorders. Early diagnosis and intervention methods are improving, and treatment options and sources of support can improve quality of life for persons with dementia and their family members. Around Boston and elsewhere, there are many opportunities to participate in clinical research trials of new treatments for Alzheimer's disease and other conditions. It's also important to think about the role of family caregiver; if you identify yourself or others in your family as one of the primary supports to a person with a memory condition, then you should consider resources for "family caregivers"; there's a lot of information, services, and research trials to support family caregivers.

HOW DO I HAVE THE
DIFFICULT CONVERSATION
ACKNOWLEDGING THESE
CHANGES WITH MY PARENTS?

Consider having other family members present for the conversation. Be mindful not to have more than a few people present because a large group may frighten your loved one. Start the conversation by addressing why you are concerned, and stress that your loved one is still the remarkable person he or she always was, independent of any cognitive impairment. It may help to explain that the medical community knows much more about dementia today and that treatment options do exist. Also, discuss some of the positive interventions available, such as physical exercise, a healthy diet, avoiding social isolation, and participating in mentally stimulating activities.

It is helpful, if possible, to have a conversation with your loved one early on, before the symptoms progress or even before they are visible, so you know their wishes. The conversation about medical advance directives is not an easy one, especially if someone is already experiencing cognitive impairment. It is best to have these conversations as far in advance of any medical issues as possible. The Conversation Project and National Healthcare Decisions Day are excellent resources to help guide this important conversation.



HOW DO I WORK THROUGH
MY PARENTS' DECREASING
INDEPENDENCE AS A
RESULT OF DEMENTIA?

Begin with identifying one or more clinicians that you and your loved one trust to be available over time if dementia symptoms progress. Ask to have a meeting to discuss goals of care, and then work with this clinician to put supports and systems in place to meet those goals.

If you have not yet identified one lead clinician, then focus on the basics: safety and self-care. Regarding safety, make sure to address driving concerns and any home issues, such as mistakes with prescribed medications, and misuse of a stove or other potentially dangerous equipment. If any potentially dangerous situation exists, then seek help from a primary care clinician or social service agency immediately. Regarding self-care, consider family caregiving supports, including help from other family members, one's own clinicians, employee assistance work programs, religious organizations, and social services.



DID YOU KNOW?

10 EARLY SIGNS AND SYMPTOMS OF ALZHEIMER'S

This checklist from the Alzheimer's Association outlines the signs to look for and when to consult a physician.

- 1 Memory loss that disrupts daily life
- 2 Challenges in planning or solving problems
- 3 Difficulty completing familiar tasks at home, at work, or at leisure
- 4 Confusion with time or place
- 5 Trouble understanding visual images and spatial relationships
- 6 New problems with words in speaking or writing
- 7 Misplacing things and losing the ability to retrace steps
- 8 Decreased or poor judgment
- 9 Withdrawal from work or social activities
- 10 Changes in mood and personality

Managing the Change in the Family

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WHAT IS AN AGING LIFE
CARE PROFESSIONAL™ AND
HOW CAN THEY HELP ME
AND MY AGING LOVED ONE?



An Aging Life Care Professional (ALCP), also known as a Geriatric Care Manager (GCM), is a health care professional who provides a thorough assessment of an elder's needs and assists families in developing a comprehensive and manageable plan of care. ALCPs have extensive knowledge of the medical, psychological, cognitive, social, and physical challenges of aging. They possess specialized expertise to implement an appropriate care plan, balancing the elder's needs, values, and wishes with what is both realistic and possible. Families can rely on an ALCP to help navigate complex systems and gain access to public and private resources, while providing support and advocacy. The need to talk with an ALCP often arises when there is a change in circumstances, such as a change in location, a change in medical or cognitive status, or the loss of a spouse.

HOW DO I BECOME AN
ACTIVE PARTNER IN MY
PARENTS' DECISION MAKING?

Having conversations with your parents sooner rather than later about planning for their future is the best possible approach. This allows you to share thoughts, concerns, and wishes, and make plans before you find yourselves in crisis mode. Parents are accustomed to being the primary decision makers, and may initially be reluctant to involve their children in decisions about health and care. Adult children should be sensitive to this change in family dynamics. Let your parents know you are here as a loyal partner to help them make their own decisions, not to usurp their responsibilities.

It may take time to gain their confidence when it comes to raising difficult issues. Shift the focus to one of sharing these challenges, rather than fostering a feeling that your parents are now moving from independence to dependence.

Many parents express a clear and resounding preference to remain in their own homes. They may exact a promise from their children to “never put me in a nursing home.” Rather than making a promise that may be impossible to keep, use this statement as a springboard for a more productive conversation on what is realistic and most beneficial for your parents in the event they become physically or cognitively compromised in the future.



WHEN DOES
DECISION MAKING
TRANSITION FROM MY
LOVED ONE TO ME?

Observe how your parents are functioning cognitively and emotionally in their current situation. Some simple questions to ask include:

- Are they becoming increasingly isolated and no longer enjoying or participating in their favorite activities?
- Are they forgetting to pay bills or paying them multiple times?
- Are they not able to manage the various medications that have been prescribed?
- Are you worried about your parents' ability to drive and/or have they been involved in accidents recently?
- Have you traveled in a car with your parents and witnessed that they are not as aware as they should be when driving?
- Was your mother a meticulous housekeeper, but now her apartment looks cluttered and dusty?
- Has either of your parents lost weight recently?

If your answers to the above questions suggest there is cognitive decline or depression, then seek out a cognitive assessment from a physician or neurologist. This assessment is used to determine if there is a progressive cognitive decline and what the cause of that decline might be. If the assessment determines they lack the capacity to fully understand the decisions they are making and the consequences of those decisions, the ALCP can help craft a proactive approach to helping your parents.



HOW WILL THESE
CHANGES AFFECT
FAMILY DYNAMICS AND
SIBLING RELATIONSHIPS?

It may be helpful to have a family meeting...to discuss what roles different family members can play in providing support to Mom or Dad.

Recognize that if your family had difficulties co-existing in the past, those dynamics are probably not going to change for the better. Even good family relationships can deteriorate from the stress involved in caregiving decisions. If all family members try to focus on your parents and their well-being, it can help prevent any actions to their detriment.

It may be helpful to have a family meeting, including all the siblings, to discuss what roles different family members can play in providing support to Mom or Dad. If you find it difficult to get your siblings to agree to sit down and talk, consider engaging a professional to facilitate the discussion. ALCPS are experts at assisting families in negotiating the push and pull of difficult dynamics. Recognize that family members can contribute in different ways, be they financial or otherwise, to form a cohesive plan of support.

HOW CAN I DEAL
WITH THE CHALLENGES
OF FAMILY CAREGIVING?



The challenges of family caregiving are very strenuous and difficult to balance with the demands of your own family, career, and life. These challenges can best be met by having family conversations early on and seeking professional help to augment the family's capabilities and negotiate a sometimes difficult, fragmented system of support services.

Good family caregiving "takes a village," so it's important to allow family members who want to help to play a role, as well as to identify the additional support you need from a professional network. Local support groups are an excellent way to connect with other caregivers who are facing similar challenges.

There is a special burden that comes with being an only child of aging parents. On the one hand, it may be a relief to be the only one in control without any conflicting opinions from siblings. On the other hand, it can be stressful and isolating to handle the challenges of parent care alone. For adult children without siblings, it is especially important to find additional professional support to share the burdens and challenges of caregiving.

DID YOU KNOW?

WHEN SHOULD I ENLIST THE HELP OF AN AGING LIFE CARE PROFESSIONAL (ALCP)?

The best time to call an ALCP is before a crisis occurs. However, if you do find yourself in a crisis situation, it's not too late to contact an ALCP. The ALCP will act quickly to evaluate the immediate problem and come up with an effective and timely solution geared to your particular situation.



Assessing Medical Options

Jennifer Rhodes-Kropf, MD

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There are numerous important elements to consider when selecting a physician for your aging loved one. Evaluating the following criteria will help determine which doctor is best suited to caring for your parent.

EXPERIENCE—Review the physician’s education and training and ensure that his or her board certifications are still current. You can find this information online or by asking the physician or their office’s receptionist directly.

PERSONALITY AND EMPATHY—Before committing to a physician, schedule a brief 15-minute interview to help determine if his or her disposition and medical philosophy are the right fit with your parent’s.

HOSPITAL AFFILIATION—Confirm that the doctor is affiliated with your parent’s preferred hospital and that the hospital is conveniently located.

OFFICE—Look for a doctor whose office staff is friendly and organized. Offices that use electronic outpatient records and electronic prescribing are also preferable.

AVAILABILITY—Find out the average wait time to see the doctor, if the practice offers same-day urgent appointments, and if the doctor or his or her colleagues are available for calls after hours. In addition, determine who the doctor of record will be if your parent is admitted to the hospital and what the system of communication will be with the hospital physician on admission, during hospitalization, and then on discharge from the hospital.

INSURANCE—Check to ensure that the practice accepts your parent’s medical insurance and, if not, find out if it is possible for your loved one to change medical plans.

Geriatricians specialize in health conditions that commonly affect older adults, such as osteoporosis, falls, dementia, and frailty. In addition to being board-certified and completing a residency in internal medicine or family medicine, geriatricians also complete a separate geriatrics fellowship (one to two years of additional training). A very small percentage of physicians actually specialize in geriatrics; currently there are only 5,000 geriatricians in the U.S.

Geriatricians discuss the balance of quality of life and longevity with each patient to determine what is important to them. They use this knowledge to guide the patient's medical care. Decisions are based on how tests and interventions will impact the patient's quality of life, as well as the results from research data to support whether an intervention will impact a patient's longevity.

Though geriatricians care for the gamut of seniors from the healthiest to the frailest, they are particularly skilled at handling complex multisystem conditions that are common in older patients.



Learning More About Housing Options

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HOW DO I ASSESS
MY LOVED ONE'S
LEVEL OF NEED?

Assessing a loved one's level of need can require input from numerous sources. To best understand the degree of support your loved one needs, it is helpful to consult the following professionals:

AGING LIFE CARE PROFESSIONAL (ALCP)—An Aging Life Care Professional (ALCP), also known as a Geriatric Care Manager (GCM), can be an invaluable resource in helping to determine the care that is needed and in helping you navigate the elder care system. ALCPs have a variety of skills and backgrounds (i.e., nursing, social work, therapy, etc.) and have lots of experience with the support network available to elders and their families within their geographic area.

GERIATRICIAN—Geriatricians can help medically assess what level of support is needed for seniors. Geriatricians have the expertise and the specialized experience with the medical and cognitive issues unique to seniors, and therefore can provide the most appropriate recommendations and referrals.

PRIVATE CAREGIVERS—Because hands-on caregivers are on the front line for extended periods of time, and often on a daily basis, caregivers can give feedback on the senior's physical and emotional state, including memory, safety, activities of daily living, and social or emotional issues. This critical feedback on even small details of activities of daily living can have great impact on larger decision making and planning.

SENIOR CARE DAY PROGRAM—The team within an adult day program is trained to care for and support the psychosocial and physical health of older adults. They can give you feedback on how the individual manages within a social setting as related to programming, peer interactions, activities of daily living, medication administration, and transitions throughout the day.

NEUROLOGIST/NEUROPSYCHOLOGIST—It is important to work with specialists who will provide a comprehensive diagnostic work-up if there are cognitive changes with a senior. These professionals will complete a battery of tests (lab work, neuropsychological testing, physical exam, MRI) to try to rule out anything treatable that might be causing dementia (such as medication interactions, infection, dehydration, malnutrition, etc.). Having a clear understanding of the type of dementia, and whether or not it is reversible, will then inform treatment and future planning.

WHAT OPTIONS ARE THERE
FOR SENIORS WHO WOULD
PREFER NOT TO OR CAN NO
LONGER LIVE INDEPENDENTLY
IN THEIR OWN HOME?

HOME HEALTH AIDE CARE AND/OR COMPANION

SUPPORT—For seniors who prefer to stay in their own homes, but need assistance with activities of daily living, private home health care can provide additional support with these activities, including bathing, dressing, grooming, toileting, medications, and walking. Aides may be Certified Nursing Assistants or Certified Home Health Aides. Companions can be hired to supplement and facilitate social connections. Companions do not necessarily have to have any medical background or training, and are less likely to provide hands-on care. Home care can also be supplemented with an adult day health program that offers socialization, nutritious food, and a team of senior care professionals.

CONGREGATE SENIOR HOUSING (ALSO CALLED SENIOR APARTMENTS)—This option offers independent market rate or subsidized housing in an apartment complex with the security and conveniences of community living. Congregate housing communities may offer housekeeping services, laundry facilities, linen service, meals or access to meals, local transportation, and planned social activities. Some may even offer amenities such as swimming pools, spas, exercise facilities, lounges, and reading rooms. Health care is generally not provided, but many communities allow a home health aide or nurse to come into an apartment to assist with medicines and personal care.

CONTINUING CARE RETIREMENT COMMUNITY—Also known as CCRCs, these communities provide a continuum of care, often including independent living, assisted living, and nursing care, all in one location. A CCRC is appealing because it offers a full range of housing, residential services, and health care options as seniors' needs change over time.

While the cost of living in a CCRC is often higher than in other types of senior living options, residents have a lifelong assurance of knowing that increased assistance and health care services are available if needed. CCRCs provide a wide range of services and amenities to residents. In general, this type of community requires both an entrance fee and a monthly fee.

ASSISTED LIVING COMMUNITY—Assisted living is a social model of care that provides a greater level of support than in-home care, day programs, or independent living. Assisted living residences typically provide all meals, housekeeping, programming, a predetermined number of hours of assistance with activities of daily living each day, nursing support, and assessment, as well as 24-hour staffing from certified nursing assistants. Assisted living residences can be standalone buildings or part of CCRCs. They can also provide specialized programs for people living with dementia. Assisted living is most often a private pay, rental model. There are some communities that do offer subsidized rent through state programs.

SKILLED NURSING FACILITY—Also commonly referred to as a nursing home, this residential option provides around-the-clock skilled medical care through onsite nurses, social workers, and rehabilitation professionals.

LONG-TERM CHRONIC CARE HOSPITAL—Long-term chronic care is a hospital level of care that delivers clinical services beyond those typically offered by skilled nursing facilities, employing an in-house staff including medical directors, physicians, social workers, and rehabilitation professionals, as well as nurses. Some long-term chronic care hospitals have units designed for seniors with specific illnesses, such as Alzheimer's disease or other dementia-related conditions.

HOW DOES INDEPENDENT LIVING DIFFER FROM ASSISTED LIVING?



Independent living and assisted living are wonderful options that have similarities and differences. One difference is cost. Independent living is often a buy-in. Seniors pay a large entrance fee to enter the community (usually 90 percent refundable upon leaving the community) and then pay an additional monthly fee that covers maintenance, housekeeping, security, some meals, and programming. Assisted living is more often a rental model. Monthly rental fees cover the same services listed above, in addition to one to two hours of personal care assistance per day, all meals, and 24/7 staffing.

Another difference is in how care is delivered. In independent living, seniors are responsible for contracting and paying for supportive care on their own: care is not included in their entrance fee or monthly rent. In assisted living, one to two hours of daily personal care often is included in the monthly rent (and if it is not, this is available for an additional fee). This may include assistance with bathing, dressing, grooming, toileting, and medication administration. These care needs are reflected on the resident's service plan, which is reviewed on a regular basis by the professional team of caregivers. Assisted living also provides some nursing observation from registered nurses or licensed practical nurses, as well as certified

nursing assistants and home health aides. Another key difference between independent and assisted living is environmental design. Independent living communities may be designed as multiple buildings spread out on large campuses, with a central gathering area for programming and meals. Spaces, including apartments, are often larger, and there is often greater distance to travel between buildings. Assisted living facilities are generally smaller and more intimate. The majority of the resident's needs are provided right in the assisted living building. Memory programs within assisted living are even more intentional in their design. There may be, for example, enhanced lighting, color coding, visual cues, memory boxes, easy-to-navigate walking paths, and secure outdoor and indoor spaces.

HOW CAN I PREPARE
FOR WHEN MY LOVED
ONES CAN NO LONGER
MANAGE FOR THEMSELVES?


Planning ahead for the time when your loved ones can no longer care for themselves is extremely important and will ultimately decrease the level of work and stress you will experience when, and if, this change occurs. Discussing the plan in advance with the senior leading the conversation is ideal.

To understand your options, start by collecting as much information as you can about everything from housing and financial issues to local senior agencies and geriatric care management services. Read books, attend lectures, consult online resources like the Massachusetts Executive Office of Elder Affairs' Age Info site, subscribe to senior care blogs, or join a support group to hear stories from peers who are in a similar process with their loved ones.

Meet with an attorney or financial advisor to look at your loved one's assets in relation to the trajectory of care needs, and discuss how their finances will or will not meet this trajectory.

Try to visit potential communities while your loved one is still able to participate in the process and before there is an immediate need for a change. Ultimately, it will be easier to go through this experience together, and it will help you to understand the type of community the senior prefers. Encourage your loved ones to add their names to wait lists, so that when and if a change is needed, they will have options and choices.

Also consider communities that provide a continuum of care, starting with independent living, then moving to assisted living, long-term care, and potentially a medical practice. These communities provide a greater level of intercommunication between all levels of care, and hopefully a more seamless transition between programs if the senior needs additional support as he or she ages.



Meet with an attorney or financial advisor to look at your loved one's assets in relation to the trajectory of care needs...

DID YOU KNOW?

KEEPING UP COGNITIVE FUNCTION

Exercising five basic aspects of well-being can help your loved ones maintain their vitality.

PHYSICAL—

exercising three to five times a week in a structured way

COGNITIVE—

playing computer games, doing puzzles, reading

EXPRESSION—

writing poetry, listening to music, painting, knitting

SPIRITUAL—

attending religious services, reading spiritual materials, participating in scripture study groups

SOCIAL—

attending parties, celebrating community events, having casual small group discussions between programming

Supporting Your Parents at Home

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HOW DO I DETERMINE
WHETHER MY LOVED
ONE SHOULD CONTINUE
TO LIVE AT HOME?

Determining whether a senior can continue to live at home must be decided on a case-by-case basis, factoring in the physical, mental, and emotional health of the individual and how safe it is for them to live independently. For seniors with more serious medical conditions, home health care provides clinical care during recovery from an acute illness or while coping with a chronic illness or disability that produces distressing symptoms or limits mobility. Clinical care specialists can also evaluate your loved one's home and recommend adaptive equipment or environmental changes that promote safety.

When support is required to feel safe at home managing daily tasks, private care services can offer a wide range of support from cleaning and laundry to bathing, dressing, errands, shopping, meal preparation, mobility assistance, medication management, and companionship. Private care can also be combined with home health care to provide a comprehensive combination of services that cover the complete spectrum of medical, personal care, and homemaking needs.

Continuing to care for a senior at home may no longer be safe when physical or mental challenges cannot be overcome or managed effectively with either home health care or private care services. Being observant of the home situation and maintaining constant communication with the home care provider will help determine if the situation is no longer an effective solution. Consulting your medical professional on what you observe and what home health care reports can also help you anticipate the need for a change before a more serious event occurs.



Clinical care specialists can also evaluate your loved one's home and recommend adaptive equipment or environmental changes that promote safety.

HOW DO I EVALUATE HOME CARE AND HOME HEALTH CARE SERVICES?



Critical to all evaluations is the safety and well-being of the individual who will be receiving the care. In Massachusetts, all home care providers are required to conduct a criminal background check on employees. For Medicare-certified home health care providers, quality and patient satisfaction measures are standardized and publicly reported on the Medicare website. At www.medicare.gov, you can get a Home Care Compare report that provides a snapshot of how an agency compares to other providers in your area.

- Obtaining evaluation data in Massachusetts can be challenging because the state does not license or regulate private home health care agencies. Information on or complaints about providers may be available through the Attorney General's office or Better Business Bureau.
- Here are some questions you can ask to evaluate which services are best for your loved one. By asking these questions in advance, you will be able to identify a home health care agency that is the right fit and resource to ensure that your family member is comfortable, safe, and engaged.
- Outline your specific needs and expectations. Evaluating your options is easier when you're

clear about requirements. (For example, what type of tasks require assistance? What is the best personality fit for your loved one? What can you afford?)

- Ask family, friends, and coworkers for references—they are a valuable source for subjective information that you can use to evaluate home care services.
- Consider how quickly an agency responds to your inquiries and requests.
- Make unscheduled visits to observe the agency personnel in action and notice how they interact with your loved one.
- Trust your instincts based on your personal experience. Remember that the family member receiving care may be the least vocal and more inhibited in expressing their issues or concerns.
- Review the agency hiring practices and personnel policies. At Hebrew SeniorLife Home Care, for example, every person we hire is supervised, has undergone a CORI check, and is insured. Also check that policies are in place for illness and vacation to ensure that there will not be a lapse in coverage if an aide is unavailable.

WHAT ARE THE TYPICAL COSTS INVOLVED WITH HOME HEALTH CARE?

Home health care, when prescribed by a physician certifying medical necessity, is typically covered by Medicare or other private insurance. This is short-term care that generally follows an acute episode of some nature. For private pay services, home health care aides bill on an hourly basis, and some agencies have a minimum daily requirement for number of hours. The rates vary, but a private care aide will typically range from \$15 to \$20 an hour. If hiring an aide through an agency, rates are typically \$25 to \$27 an hour, but the rate can vary based on the time of day, weekdays or weekends, holidays, 24-hour care, or care provided in a shorter time shift. Payment can also be tiered based on the number of hours required per week.

Supportive care is costly, so it is important to be realistic about financial resources, know the extent of your resources, and clearly outline your care goals. If you are planning for long-term care insurance to cover home health care costs, carefully evaluate your policy and ask questions about the specifics of your policy if it is unclear. Long-term care insurance can be a great resource, but the policies often have very defined criteria that must be met to be eligible for coverage.



HOW DO I HELP MY
PARENTS STAY AS SAFE
AS POSSIBLE IF THEY CHOOSE
TO CONTINUE TO LIVE AT HOME?

Begin an open dialogue with your parents about your concerns. Start the conversation by discussing what you have noticed, and offer to help them plan how to get assistance with the difficulties they are having. Be respectful. It is not easy for people to admit that they might need some help. Start small if possible—introduce twice-a-month cleaning services, offer to assist with paying bills, set up a regularly scheduled trip to the grocery store, or assist with ordering home delivery. Introduce services over time after openly discussing perceived changes and concerns whenever possible.

Consider what your family members can realistically do to support your parents in remaining in their home. These decisions will need to factor in flexibility, work schedules, and the financial resources to pay for care. In more medically complex situations, consider hiring a geriatric care manager to support your parents while they still live at home.



Evaluating Provider Structure and Financial Stability

Rachel Lerner, Esq.

General Counsel and Chief Compliance Officer, Hebrew SeniorLife

WHAT IS THE DIFFERENCE
BETWEEN A FOR-PROFIT
AND A NONPROFIT
HEALTH CARE ORGANIZATION?
DOES IT MATTER IF THE
PROVIDER IS PART OF
A LARGER COMPANY?



Organizations providing senior care services can come in all shapes and sizes—there are for-profits and nonprofits, and for-profits can be privately held or publicly traded. Regardless of whether nonprofit or for-profit, providers can be made up of just one local site, or part of a national chain, or everything in-between.

Particularly in health care, it's difficult to generalize about how the size or nonprofit/for-profit status of a company impacts the quality of services it provides. However, in this age of uncertainty in health care reimbursement, it is a good idea to learn as much as you can about a company's financial well-being—as that may have short-term or long-term impacts on the quality of care, staffing levels, and even the company's ability to stay in business. You can often learn a lot about a company's finances and operations by reviewing publicly available information online.

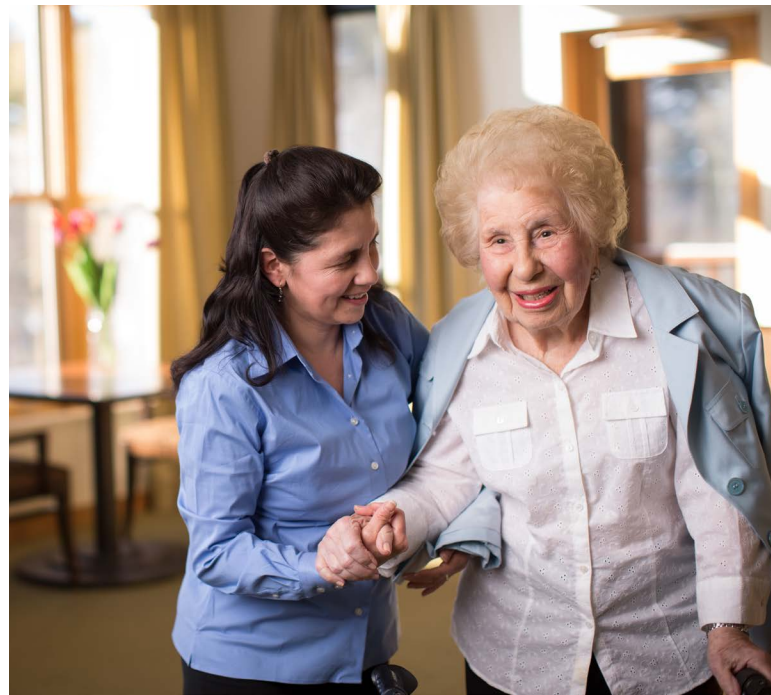
Here are a couple of examples:

- All nonprofits (including nonprofit health care providers) are required to file Form 990s annually, which are like informational tax returns. These filings provide helpful information about a provider's mission, management, donor contributions, and budget allocations. Nonprofits typically make 990s available on their websites. You can also visit www.guidestar.org to review many providers' 990s free of charge.
- Many providers post information about senior management on their websites. If publicly traded, a provider may also have copies of financials filed with the SEC, and detailed information about board composition and oversight.


WHAT SHOULD I KNOW
ABOUT A COMPANY'S
LICENSURE AND CERTIFICATION?

If a provider is licensed, that means: (1) it's obligated to abide by certain laws and regulations, and undergoes onsite government surveys; and (2) there will likely be more publicly available information about its performance track record through state and federal websites. Here are a few Massachusetts resources:


- If a provider is licensed as an Assisted Living Residence (ALR), you can locate the regulations governing their operations at the Massachusetts Executive Office of Elder Affairs (EOEA) website. The EOEA also has a free resource guide that outlines ALR services, typical costs, a summary of the applicable regulations, and more.
- The Massachusetts Senior Care Association (MSCA) website provides helpful information about how to choose a nursing facility, including an overview of payment eligibility, types of clinical services provided, and questions to ask.
- To understand how a licensed nursing facility has performed, search for Massachusetts results either by facility name or for all facilities in a given city or town at <http://webapps.ehs.state.ma.us/nursehome/>.
- On the Medicare website, you can learn how a single provider fares in a variety of quality of care and patient satisfaction categories, as well as how they compare against state and national averages.
- Examining Independent Living (IL) communities is more challenging, since they are not as regulated. Take a tour of the community and carefully review all lease-related documents.



HOW WILL I KNOW
WHAT SERVICES WILL
BE PROVIDED, AND
AT WHAT COST?



Look at what Medicare and/or Medicaid will or will not cover, and what types of services will result in additional fees or charges.



This is an important topic that should be discussed with your selected provider's fiscal or admissions office. Don't assume that Medicare will cover all the care your parent receives in an institutional setting. Understand what circumstances trigger Medicare to either fall short or stop coverage, and whether supplemental long-term care insurance and/or Medicaid coverage can help cover the gap.

Read through all admissions and financial documents carefully, and ask questions. Make sure you understand how the facility is using terms like "guarantor" or "financially responsible party," and identify any provisions that govern what the facility can and cannot do to a resident/patient who can no longer pay. Look at what Medicare and/or Medicaid will or will not cover, and what types of services will result in additional fees or charges.

It's advisable to have the financial admission documents reviewed by a knowledgeable elder law attorney. The National Academy of Elder Law Attorneys website is a good resource for finding an elder law attorney.

Make sure commitments made to you are in writing. Ask for the contact information of the marketing employee with whom you're speaking, and follow up with a confirmatory letter or email restating what was discussed. Having commitments in writing is helpful should the individual leave the company, or if there is a change in management or ownership.

WHAT CAN I DO
IF I'M DISSATISFIED
WITH MY LOVED
ONE'S CARE?

If you have questions or concerns about how a provider is treating your loved one, and you are not satisfied with the answers you've received, there are a myriad of resources dedicated to advocating for your loved one and actions you can take, including:

- Call the provider's compliance officer or compliance hotline and discuss the problems in detail.
- Contact the local Long Term Care (LTC) Ombudsman, who is part of state government and dedicated to advocating on behalf of residents.
- Talk with the State Department of Public Health (DPH) or Executive Office of Elder Affairs (EOEA) to ask a question or file a complaint.
- Medicare or Medicaid allow you to ask a question or file a complaint directly, particularly if it's regarding a billing issue. (Quality of care issues are more appropriate for the DPH/EOEA.)
- Engage a geriatric care manager or elder law attorney to advocate for your loved one.



HEBREW SENIORLIFE RESOURCES

Continuing Care Retirement Communities

Orchard Cove, Canton • 781-821-1730

Situated on a serene 38-acre pondside campus in Canton, Massachusetts, Orchard Cove is a warm, inclusive, and award-winning senior living community. Home to a dynamic, resident-driven culture, Orchard Cove offers seniors an active lifestyle and the peace of mind that comes with our all-inclusive pricing model and living options that span the full continuum of care.

NewBridge on the Charles, Dedham • 781-234-9020

NewBridge on the Charles has set a new standard in independent living, and traditional and memory care assisted living, combining luxurious surroundings with exceptional amenities, first-class educational and cultural programming, and a complete continuum of care on a lush 162-acre multigenerational campus.

Supportive Living Communities

Center Communities of Brookline, Brookline • 617-363-8048

Located in the heart of one of the country's most senior-friendly cities, Center Communities of Brookline comprises three apartment buildings, offering a wide range of programs, amenities, and support services. This includes a Harvard Medical School-affiliated medical practice, fitness center, transportation, social workers, and much more.

Simon C. Fireman Community, Randolph • 781-986-8880

Featuring excellent amenities and plenty of activities, the Simon C. Fireman Community offers independent living apartments for low-income seniors. This stimulating environment promotes wellness, socialization, and personal fulfillment.

Jack Satter House, Revere • 781-289-4505

Located directly across the boulevard from historic Revere Beach, Jack Satter House offers affordable independent living apartments for seniors, with beautiful ocean views, convenient access to Boston, a state-of-the-art fitness center, and engaging social, cultural, and educational activities.

Community Health Services, Greater Boston Area

HSL Medical Group • 617-363-8041

Hebrew SeniorLife Medical Group is a primary care practice staffed by geriatric specialists, many with Harvard Medical School appointments. The practice is located on the NewBridge on the Charles Campus, at Orchard Cove, and at Center Communities of Brookline. The Brookline practice is open to residents as well as non-residents from surrounding communities.

HSL Home Care, Private Care, and Personal Assistance • 781-234-9900

Hebrew SeniorLife Home Care offers a comprehensive range of services to assist seniors in the Greater Boston area with their recovery following surgery, illness, or a hospital stay, or to manage chronic illness. Hebrew SeniorLife Home Care is staffed by seasoned professionals who specialize in the needs of older adults and are available 24 hours a day, seven days a week.

HSL Outpatient Rehabilitative Therapies, Boston • 617-363-8539

A team of physical, occupational, and speech therapists, as well as audiologists, who utilize the most up-to-date treatment techniques to maximize function and independence, treat patients at Orchard Cove and NewBridge on the Charles, and patients from surrounding communities at Hebrew Rehabilitation Center in Boston.

HEBREW SENIORLIFE RESOURCES

Adult Day Health, Boston • 617-363-8515

Located at Hebrew Rehabilitation Center in Boston and Jewish Community Housing for the Elderly in Brighton, Hebrew SeniorLife's adult day health programs serve seniors from the community in a safe, structured environment.

HSL Hospice Care • 781-234-9950

Hospice care is a special form of health and wellness care designed for patients at end of life. It takes a holistic view of patient needs, appreciating social and spiritual elements that contribute to a patient's sense of well-being. Hospice care neither hastens nor prolongs the dying process. Rather, it draws upon a multidisciplinary team to provide comfort and seek to optimize the quality of the experience for both patients and their families.

Long-Term Chronic Care and Post-Acute Care, Boston and Dedham • 617-363-8545

At Hebrew Rehabilitation Center, we provide extended medical and rehabilitative care for patients with long-term chronic or serious illnesses. Care is provided in a home-like setting and tailored to the individual needs of each patient. In addition to expert geriatric medical care provided by physicians and nurse practitioners from our onsite department of medicine, a multidisciplinary team offers a wide range of therapeutic programs that maximize function with the goal of helping our patients maintain independence for as long as possible. The Medical Acute Care Unit on the Boston campus serves patients requiring long-term acute care, and specializes in respiratory services. The Rehabilitative Services Unit, on the Boston Campus as well as on the NewBridge Campus in Dedham, cares for patients recovering from acute hospitalization due to surgery, injury, or illness, or patients referred directly by a physician.

Research

Institute for Aging Research (IFAR) • 617-971-5300

For more than 50 years, scientists in Hebrew SeniorLife's Institute for Aging Research have worked to discover mechanisms that cause age-related disease and disability; find ways to prevent, treat, and cure common age-related diseases; advance the standard of care for older people; inform public decision making; and develop the next generation of leaders in aging research. Areas of study include the aging brain, musculoskeletal conditions, mobility and balance, palliative care, and biostatistics and clinical trials.

CONTRIBUTORS



Maureen T. Bannan, R.N., M.A.,
Executive Director of Hebrew SeniorLife
Home and Community-Based Services

Maureen T. Bannan is executive director of Hebrew SeniorLife Home and Community-Based Services. Home and Community-Based Services provides senior patients with care and support in their homes and communities to help them recover after an illness, manage their chronic conditions, or adjust to new physical limitations. Bannan oversees programs and services addressing the national trend for increased service delivery. Prior to coming to HSL, Bannan served as executive director of a local visiting nurse association, where she successfully focused on improving quality of care and clinical outcomes. Her prior position was as vice president for clinical operations with a home care company.



Helen Chen, M.D.,
Chief Medical Officer at
Hebrew SeniorLife

Dr. Helen Chen is serving as senior clinical advisor and overseeing the organization's department of medicine. Chen brings more than 20 years of experience with evidence-based geriatric clinical care and training to her role, along with her longstanding interest in caring for our country's growing senior population through long-term care programs, post-acute rehabilitation, and community-based health care services, including home care and adult day health. Prior to joining HSL, Chen served as chief medical officer at the Center for Elders' Independence in Oakland, California, a nationally recognized, multi-site, nonprofit Program of All-Inclusive Care for the Elderly (PACE) designed for seniors whose health problems make it impossible for them to stay at home without the help of caregivers. A graduate of Brown University Medical School, she completed both her residency in internal medicine and a fellowship program in clinical geriatrics at the University of California, San Francisco. Chen holds board certifications in geriatric medicine as well as hospice and palliative care.

CONTRIBUTORS



Gary Epstein-Lubow, M.D.,
Medical Director, Hebrew SeniorLife
Center for Memory Health

Dr. Gary Epstein-Lubow brings nearly 20 years of academic and clinical achievements to his position at HSL. His current clinical appointment is as a staff psychiatrist in geriatrics at Butler Hospital in Providence, Rhode Island, where he previously served for nine years as the assistant unit chief for inpatient geriatric psychiatry. At Brown University, Lubow is an associate professor of psychiatry and human behavior; associate professor of health services, policy and practice; and associate professor of medical science in the teaching scholar track. Lubow is also a co-director of the Longitudinal Integrated Clerkship of Alpert Medical School's Primary Care-Population Medicine program and a fellow in the Health and Aging Policy Fellowship Program, where he is working to improve the care of frail elderly people nationwide.



Tara Fleming-Caruso, M.A.,
LMHC, Collaborative Care Advisor
at NewBridge on the Charles

Tara Fleming-Caruso serves as the collaborative care advisor for the NewBridge campus, making her an important resource for each of our residents and their families. Fleming-Caruso helps each senior moving to NewBridge both understand and access the variety of supports our continuum of care offers, so each can live their best life possible. Fleming-Caruso brings over 25 years of elder care experience to this role, including developing an expressive therapy program in a skilled nursing facility, serving as a program manager at a dementia-specific assisted living facility, and working at NewBridge on the Charles since 2009. She is a licensed mental health counselor and holds a master's degree in expressive arts therapies from Lesley University.

CONTRIBUTORS



Kate Granigan, MSW, LICSW, C-ASWCM,
CEO, LifeCare Advocates

Kate Granigan is a licensed independent clinical social worker and received her master's degree in social work from Boston College in 1994. She has worked as a clinician in the field of aging for over 20 years. Granigan founded C.A.R.E., a care management practice, in 1999, and in June of 2009, C.A.R.E. merged with Overlook Visiting Nurse Association & Hospice Services, part of the nonprofit Masonic Health System, where she acted as the vice president of care management until 2016. She is currently the chief executive officer for LifeCare Advocates, a care management practice with a team of professional care managers, both nurses and social workers, who provide assistance, advocacy, and guidance to elders and their families.



Rachel Lerner, Esq.,
General Counsel and Chief Compliance
Officer, Hebrew SeniorLife

Rachel Lerner is responsible for managing all legal and compliance affairs across Hebrew SeniorLife. She oversees HSL's compliance program and counsels the organization on a diverse array of legal issues that arise from HSL's health care, housing, research, and teaching operations. Lerner has spent her entire career working with health care and senior living organizations. After earning her law degree from New York University School of Law, she worked for a number of years as a health care transactional and regulatory attorney in a national law firm. She then served as associate general counsel and corporate compliance officer at Five Star Quality Care, a national long-term care and senior housing provider with approximately 250 sites in 33 states, prior to joining HSL in early 2012.

CONTRIBUTORS



Jennifer Rhodes-Kropf, M.D.,
Geriatrician

Dr. Rhodes-Kropf is a staff geriatrician at Hebrew Rehabilitation Center. She received her medical degree from the University of North Carolina, and completed her internal medicine internship at the Hospital of the University of Pennsylvania and her residency in internal medicine at Cornell University/New York Presbyterian Medical Center. Rhodes-Kropf, an instructor in medicine at Harvard Medical School, completed a geriatrics fellowship at Mount Sinai Hospital.



Emily B. Saltz, MSW, LICSW, CMC,
Founder, Life Care Advocates

Emily B. Saltz is the founder of Life Care Advocates (formerly Elder Resources), a private practice providing a full range of aging life care management services for elderly clients and their families since 1993. She received her master's in social work from Boston University and is a past president of the Aging Life Care Association. Prior to developing LifeCare Advocates, Saltz was a staff consultant to attorneys and clients at ElderLaw Services.

ABOUT HEBREW SENIORLIFE

Hebrew SeniorLife, an affiliate of Harvard Medical School, is a national senior services leader uniquely dedicated to rethinking, researching, and redefining the possibilities of aging. Based in Boston, the nonprofit, non-sectarian organization has provided communities and health care for seniors, research into aging, and education for geriatric care providers since 1903. For more information about Hebrew SeniorLife, visit www.hebrewseniorlife.org or connect on Twitter, Facebook or our blog.

HEALTH CARE

Hebrew Rehabilitation Center, Boston, and in the Gloria Adelson Field Health Center at NewBridge on the Charles, Dedham

Long-term chronic care

Post-acute care

Outpatient services

Hebrew SeniorLife Community Health Services

Primary and specialty medical care

In-home care

Hospice care

Adult day health

RESEARCH

Institute for Aging Research

TEACHING

Education and training programs for the next generation of geriatric professionals

SENIOR LIVING COMMUNITIES

Supportive Living Communities

Center Communities of Brookline

Julian and Carol Feinberg Cohen Residences

Marilyn and André Danesh Family Residences

Diane and Mark Goldman Family Residences

Sloane Family/Century Bank Primary & Specialty Care Center

Simon C. Fireman Community, Randolph

Jack Satter House, Revere

Continuing Care Retirement Communities

Orchard Cove, Canton

NewBridge on the Charles, Dedham on the Dr. Miriam and Sheldon Adelson Campus

Assisted Living Communities

NewBridge on the Charles, Dedham

Jack Satter Assisted Living Residences

The Gilda and Alfred A. Slifka Memory Support

Assisted Living Residences