

Featuring Special Section:
Dr. Ruth Westheimer
"The Spouse as Caregiver"



Understanding & Living with Dementia:

A Resource for Families

The Power to Redefine Aging.



Hebrew SeniorLife



HARVARD MEDICAL SCHOOL
AFFILIATE

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A Letter from Hebrew SeniorLife's Chief Medical Officer

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Dear Reader,

As we face the future needs of our aging population, Hebrew SeniorLife recognizes the current and rapidly growing demand for Alzheimer's and dementia patient care and services.

There are many ways Hebrew SeniorLife can help you face the challenges of diagnosing and caring for a loved one with memory challenges. This guide is a first step in helping you to do that. HSL's experts answer many important questions on Alzheimer's and dementia as well as provide direction on next steps for you to consider.

If you are unsure where to begin, [The Memory Disorders Clinic at the Hebrew Rehabilitation Center](#) in Boston can be a good place to start. Our clinicians can help determine if memory loss is part of the aging process, medications, or a sign of dementia.

When considering a memory care community, NewBridge on the Charles in Dedham offers the [Gilda and Alfred A. Slifka Memory Care Assisted Living Residences](#) to seniors with early-stage and mid-stage Alzheimer's and dementia. This community provides a personalized and meaningful assisted living experience for residents based on the history, preferences and goals of each resident. A wide range of life enhancing programs and services, as well as expressive therapies, offer innovative and enriching opportunities to engage residents. All residents also benefit from the specialized care provided by Harvard Medical School-affiliated physicians and geriatric care specialists.

As you face the challenges of diagnosing and caring for a loved one in need of memory care, we stand ready to lend a hand and help you determine the best path going forward.



Sincerely,
Helen Chen, M.D.
HSL Chief Medical Officer

A Letter from Hebrew SeniorLife's Chief Nursing Officer, Vice President of Patient Care Services

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Dear Reader,

At Hebrew SeniorLife, we are committed to providing the highest quality care with a dedicated staff that meets the needs of our Alzheimer's and dementia patients' in all stages of their disease and consistently supports the caregiver in the process.

We practice person-directed care that encourages a spirit of partnership between patients, residents, families and the care team throughout all the services HSL provides including assisted living, specialized long-term care and post-acute care.

Our staff receives specialized training in Alzheimer's and dementia that uniquely equips them to support the special needs associated with this diagnosis. Social workers, Life Enhancement staff and Expressive Therapy clinicians work collaboratively with nurses, providers and rehabilitation teams to create an engaging and supportive community for our residents.

Families play an important role in the care of their loved one. Our integrated staff of aging and geriatric specialists works in close consultation with our families to support individualized and personal care. Beyond this guide, Hebrew SeniorLife provides a variety of services and programs that offer more resources and greater support for the family caregiver. We've assembled a list of those resources in this publication to help you get started.

You are not alone in your questions nor will you be with a diagnosis. The resources and support of Hebrew SeniorLife are here to help your loved ones live their senior years to their fullest.



Tammy Retalic, MS, RN
HSL Chief Nursing Officer
Vice President of Patient Care Services

PART 1: UNDERSTANDING ALZHEIMER'S DISEASE & DEMENTIA

...

Acknowledging the Change

10 Early Warning Signs of Dementia

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

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 problems include difficulty remembering names and details of events. Also, there is a wide variability in rate and amount of decline so it is not helpful to compare your loved one with others.

In contrast, significant memory loss is not a part of normal aging. A list of the ten early warning signs of dementia is included in the sidebar. These symptoms, that progress over time, interfere with one's everyday functional abilities.

Sometimes it can be difficult to figure out if a loved one's memory problems are due to normal aging or dementia. If there is any concern, it is a good idea to consult a clinician who can often provide a diagnosis after a thorough evaluation. If dementia is diagnosed, there are now medications available for treatment of the cognitive impairment as well as behavioral symptoms.

What should I do if I believe dementia exists?

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 also request a consultation with someone who specializes in cognitive disorders.

How do I have the difficult conversation acknowledging these changes with my loved one?

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 they always were, 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.

MORE THAN
1/2
of adults
with dementia
go undiagnosed.



How do I work through my loved one's decreasing independence as a result of dementia?

- Do not do this alone. Seek assistance from family members, friends and religious organizations. If the burden of care is too difficult, there are services and agencies that can offer professional assistance. You can find out more through your loved one's primary care clinician, geriatric case manager or social worker. The book *"The 36 Hour Day,"* by Nancy L. Mace, is also a very helpful guide to caring for a loved one with memory loss.
- Watch out for safety issues such as managing medication, cooking and driving. Having a primary clinician who can work with you and your loved one is very helpful.
- Know the stages of the condition so you can anticipate what to expect and make plans for the future.
- 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.
- Take care of yourself. There is significant caregiver burnout when taking care of a loved one with dementia so it is especially important that you are mindful of your own mental and physical health.

Dispelling Dementia Myths

There are many myths surrounding dementia that can obscure our understanding of the issues facing our loved ones who suffer from dementia diseases, such as Alzheimer's disease.

Here are a few to ponder...

MYTH #1 Dementia is a normal occurrence in aging.

FACT: Dementia is a degenerative brain disease that mainly affects older adults, and is not a normal part of aging. If it were true, then everyone over the age of 65 would have it! Many adults advance into their 80s and 90s without much memory decline.

MYTH #2 Alzheimer's disease is an inherited type of dementia.

FACT: Alzheimer's disease is the most common cause of dementia. While genetics are cited in the development of Alzheimer's disease, it is likely that it is only one factor that plays a role. Lifestyle and environmental factors also contribute to development of the disease. There does seem to be a strong genetic link with younger onset Alzheimer's disease (those who develop the disease before age 60). Only about five percent of all adults with Alzheimer's disease have younger onset of the condition.

MYTH #3 There is nothing I can do to lower my risk of dementia.

FACT: While research is still looking at lifestyle and the risk of developing dementia, it seems that regular exercise and healthy nutrition lower the odds. Essentially what is good for the heart is good for the brain! In addition, staying socially active and engaging in brain fitness, such as completing crossword puzzles, tai chi, reading, and learning new skills, may be important in reducing the risk or at least delaying the onset of dementia.

MYTH #4 Once you have dementia there is nothing you can do.

FACT: Dementia is a progressive disease, meaning it continues to get worse the longer one has it. However, every person's experience with dementia is different and it is very important to be accurately assessed by a medical professional early in the course of the disease. There are treatments, if started early, that help with some of the more troubling symptoms of dementia.

MYTH #5 People with dementia don't know what they want, or cannot communicate what they want.

FACT: Adults living with dementia usually DO know what they want, however, the region of the brain that regulates communication, including language, can be affected by the disease. Therefore, patience becomes very important when helping adults living with dementia.

MYTH #6 I should correct someone with dementia when they say something that can't be true.

FACT: Research indicates that constant correction of an adults living with dementia can lead to depression, aggressiveness, or further confusion. Research has shown that validation therapy (acceptance of the reality and personal truth of another's experience)

is more effective in maintaining positive emotions. Validation therapy uses communication strategies to encourage people with dementia by accepting their reality. For example, if an adult living with dementia states that they had breakfast with someone that has passed away, you may wish to encourage them to tell you about the breakfast – what they had, how they enjoyed it, etc.

MYTH #7 People with dementia can't function, can't have a quality of life, and can't enjoy activities.

FACT: Because Alzheimer's disease progresses slowly, adults living with the disease can still live meaningful, active lives. Unfortunately, many people with the disease suffer more from the stigma associated with having Alzheimer's, than the actual disease itself. Adults in the earlier stages often benefit from community-based support groups and social engagement programs, such as Memory Cafes, that bring together those likely affected in a non-judgmental, relaxed setting.

**LIFESTYLE &
ENVIRONMENTAL
FACTORS
CONTRIBUTE
TO DEVELOPMENT
OF DEMENTIA.**



Wondering where to start? See our directory of Hebrew SeniorLife memory care resources on page 28.

Understanding Behavioral Changes Caused by Dementia

Behavioral changes can be one of the most difficult aspects of caring for someone with dementia. Up to 90% of people with dementia exhibit some form of upsetting behavior over the course of their illness. Examples of these dementia behaviors, known collectively as Behavioral and Psychological Symptoms of Dementia (BPSD), include:

- Disinhibition, or poor impulse control. The person with dementia may be rude or tactless, act out sexually or remove his clothing at an inappropriate time or place.
- Mood swings, which tend to happen later in someone who has Alzheimer's disease than other types of dementia. These moods can include anger, which is also a symptom of depression (particularly in older men, who are less likely to be sad and tearful than women who are depressed).
- Apathy, or loss of motivation or interest. The person with dementia may seem content to spend the day staring at the TV or into space. Apathy is also a symptom of depression — the main difference is that dementia-related apathy has no other depression symptoms.

Typically, one or more of these behaviors will appear after other signs of dementia, like memory problems. One exception is a type of dementia known as behavioral variant fronto-temporal dementia, in which behavior changes are usually the first noticeable symptom.

Medical assessment is important with any behavior changes. There are other possible causes in addition to dementia, including:

- Medication side effects
- Infection
- Thyroid disease
- Brain tumor
- Dehydration

How do you deal with upsetting behavior? If dementia is the cause, look for triggers and try to change them. For example, if being left alone seems to be a trigger, consider having someone keep your loved one company, or sign her up for social activities or adult day care.

If behavioral changes put your loved one's health or safety at risk, there are practical ways to help protect him. For example, if he tries to wander, you can install an alarm on the door (most home security systems offer a chime). There are also a number of tracking devices available.

Caring for someone with dementia can leave you prone to emotional or physical illness. Sometimes caregivers don't realize that they're over the limit until they're hospitalized for a problem. A caregiver support group, either online or in person, can be an extremely helpful way to deal with the stress.

At some point, you may have to think about moving your loved one into an assisted living community or long-term care. There's no right answer about when to do that — it's a very individual choice, and it's not an easy one. Feeling guilty is completely normal, but it's important to remind yourself that if you get ill, you won't be able to help your loved one.

5 Reasons to Seek Early Diagnosis

Dementia is one of the most feared health conditions, especially in older adults. Adults with early signs of dementia and their families are often reluctant to seek advice. In fact, more than half of adults with dementia go undiagnosed.

Until recently, an early dementia diagnosis did not necessarily make a difference in long-term outcomes of Alzheimer's disease or other related dementia. However, as we have learned more and more about dementia, its causes and how to treat it, it has become increasingly important to obtain an early diagnosis. Hebrew SeniorLife, as well as many hospitals and health centers now offer comprehensive memory disorders clinics, where adults can seek an accurate confidential, diagnosis. In addition, the Centers for Medicare & Medicaid Services requires primary care physicians to conduct an annual assessment to detect early cognitive impairment and has provided guidance about diagnostic testing, referrals and treatment options.

Here are 5 reasons to seek an early diagnosis:

1. Rule out "reversible" causes of cognitive impairment

A careful medical evaluation is crucial to excluding "treatable" or reversible causes of cognitive impairment such as anxiety and depression, some vitamin deficiencies, side effects of medications and certain brain conditions fall into this category.

2. Removal of uncertainty

Not knowing what is causing changes in memory, behaviors, judgment, etc. can be distressing to both the affected adult and their families. While a diagnosis of dementia is devastating, many adults feel empowered and the anxiety caused by uncertainty dissipates.

3. Access to treatment

Treatment of Alzheimer's and other dementia-causing diseases is typically most effective when started early in the disease process. Once more effective treatments become available, obtaining an early and accurate diagnosis will be even more crucial.

4. Access to clinical trials

Research on what causes dementia, such as Alzheimer's disease, and how it can be reversed or slowed can only move forward if adults are willing to volunteer for clinical trials. Today, there are over 200 clinical trials actively enrolling participants at over 500 sites in the United States. Researchers are testing new ways to detect, treat and prevent Alzheimer's disease and dementias, especially in the early stages. The best websites to begin searching for clinical trials include Trial Match at TrialMatch.alz.gov and ClinicalTrials.gov.

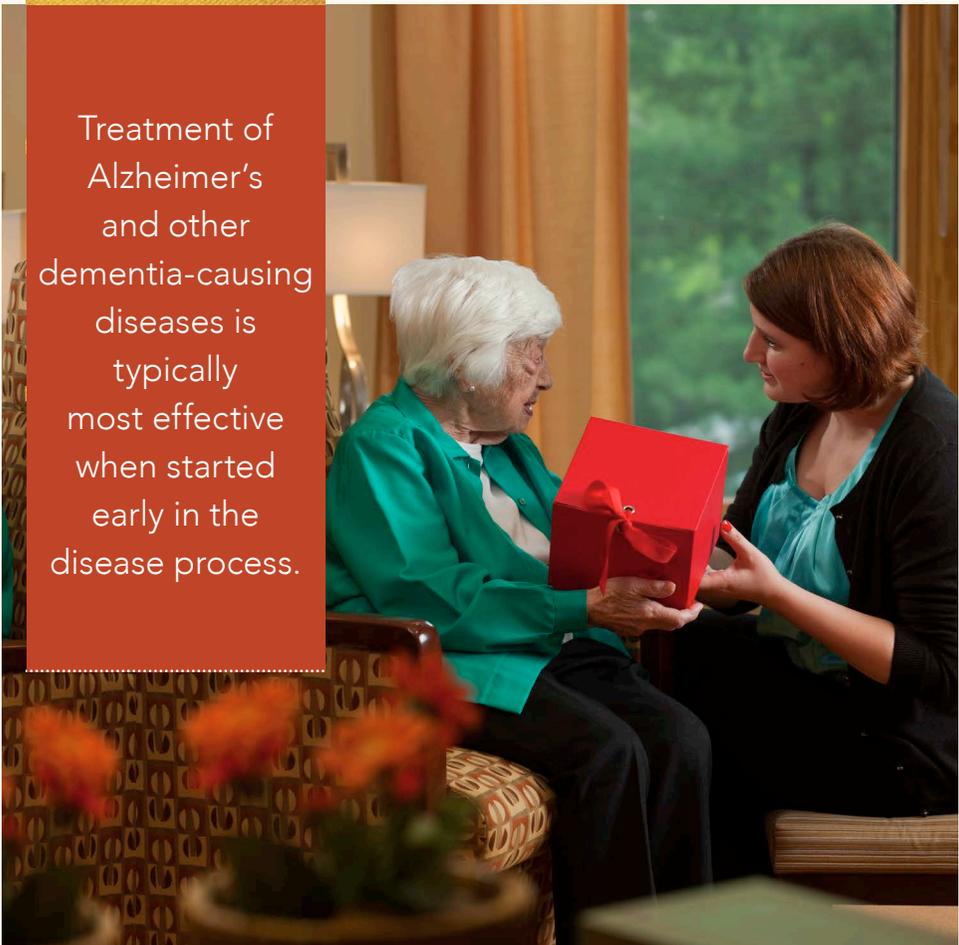
5. Access to support services

Having the correct diagnosis is important for getting the right advice and support. Today, there is much information available for both those with dementia and their family care partners including:

Wondering where to start? See our directory of Hebrew SeniorLife memory care resources on page 28.

- Help at home or in the community, such as from local or regional Councils on Aging, social services, adult day centers, and advocacy organizations such as the local chapters of the Alzheimer's Association.
- Advice regarding legal planning, financial benefits, and planning for the future.
- Advice about driving, medication management and home safety.
- Advance care planning enables a person to be involved in discussions about their future when they are still able to do so effectively.
- Access to community-based support groups tailored to specific diagnoses.

Treatment of Alzheimer's and other dementia-causing diseases is typically most effective when started early in the disease process.



Depression and Dementia: Double Trouble

Dementia is one of several medical conditions associated with increased rates of depression. Depression in Alzheimer's disease, the most common form of dementia, occurs in up to 25 percent of patients, and is more frequently diagnosed in patients with mild to moderate Alzheimer's disease. Even higher rates of major depression have been linked to dementias associated with Parkinson's disease and strokes.

Understanding what makes dementia patients particularly susceptible to depression is a focus of current research. One hypothesis is that depression occurs as a psychological reaction to the diagnosis of and limitations brought on by dementia. However, studies have not conclusively shown a correlation between rates of depression in patients with dementia and their awareness or insight into their disease.

**DEMENTIA IS A
FAMILY AFFAIR,**
and everyone
in the family
can benefit
from education
and support.



A second hypothesis is that physiological causes of dementia may also play a role in the development of depression. Post mortem studies of Alzheimer's disease patients have revealed the loss of certain brain cells that are also associated with depression. Also, the high incidence of depression seen after stroke has led researchers to explore how reduced blood flow to the brain that occurs with stroke may cause cellular damage that may also be linked to depression. However, research has yet to reveal conclusively that dementia and depression share pathophysiological mechanisms, underscoring the need for further investigation.

Distinguishing symptoms of depression from those of dementia can be challenging, even for clinicians experienced in this area. Diagnosis of depression in a patient with dementia should take the following into account:

- **Other medical causes** – The first step in the evaluation of an older adult with possible depression, with or without dementia, is to rule out possible medical causes through a careful history, and physical and laboratory evaluations. The patient’s medical history should include a review of medications, and the physical examination should screen for infections, metabolic disorders and malignancy.
- **Family and other caregivers** – Because dementia is likely to affect a patient’s memory, it is important to involve those close to the patient in providing medical history.
- **Symptoms that are unlikely to be mimicked by dementia** – Symptoms of dementia including apathy, impaired concentration, and loss of appetite may be difficult to distinguish from similar symptoms of depression. Symptoms more closely associated with depression include feelings of guilt and hopelessness, the belief that one is being punished, and thoughts of death or suicide.
- **Personal or family history** – Personal history of depression or history of depression in first-degree relatives are both risk factors for developing depression late in life.

A common misconception about persons with dementia and depression is that they are unable to benefit from psychotherapy. A growing body of research disputes that belief. Depending on how far the dementia has progressed, a patient may respond to cognitive-behavioral psychotherapy, and persons with advanced dementia may still benefit from behavior therapy as well as individualized art, music, and recreational therapies.

Antidepressant medication may benefit some patients with dementia and depression. Drug therapies come with a unique challenge for these patients: because cognitive impairment can affect medication compliance, there needs to be a system in place to ensure that patients take their medication as prescribed.

Depression can compound the disability experienced by patients with dementia. While diagnosing and treating depression can be challenging in these cases, the effort can be rewarded by improved quality of life for patients. Additional research is needed to identify effective therapies for this increasingly prevalent condition.

What is Advanced Dementia?

Although there are different causes for dementia, all types of dementia get worse over time. Advanced dementia refers to the final stage of the disease. The final stage comes at different times for everyone. On average, patients reach the advanced stage of dementia anywhere from 3-6 years after they are first diagnosed. The length of time people live with the advanced stage is also different for everyone and can range from months to years.

What are typical features of a patient with advanced dementia?

Over time, dementia affects not just the brain but also the entire body. Although everyone is different, patients with advanced dementia often have such serious memory problems that they may not even recognize close family members. At the most advanced stages, patients with dementia are unable to move around on their own, and depend on others for all their care needs. They usually cannot speak more than about five words.

What are the most common medical complications that occur in someone with advanced dementia?

Eating problems and infections are the most common complications in advanced dementia. Close to 90% of patients with advanced dementia will develop problems eating. When problems with eating begin, it often means that the end of life is near. Almost half of patients with advanced dementia experience infections or fevers. The most common type of infection is pneumonia.

Is advanced dementia a terminal illness?

Yes, dementia is a terminal illness. This means that patients with advanced dementia commonly die from complications caused by this disease. Some people have a difficult time understanding that dementia is a terminal illness. It may help to imagine a patient who died with widespread cancer. If this patient had pneumonia or eating problems in the last few weeks of life from the weakened state caused by the cancer, most people would still consider cancer the underlying cause of death. In the same way, the bodily functions and defenses of patients with end-stage dementia are weakened. As a result, they often get pneumonia or eating problems near the end-of-life, but advanced dementia is still the underlying major illness leading to these complications and death.

It's important to keep in mind that every patient is different. This information provides general guidelines to complex decisions, which must be adapted to each individual situation. Always refer to a health care provider or support team for specific questions related to a loved one's diagnosis or illness.

PART 2: LIVING WITH ALZHEIMER'S DISEASE & DEMENTIA



Choosing a Medical Specialist

Alzheimer's disease, a form of dementia, is a chronic brain disease characterized by the progressive deterioration of memory, language, visual perception and activities of daily living.

If you have a loved one with memory problems, it's important to see a clinician who has expertise in Alzheimer's to receive a proper diagnosis and treatment plan. That may be the patient's primary care physician, or the PCP may refer you to a specialist. Neurologists and geriatricians are two types of specialists who diagnose and treat Alzheimer's disease.

Neurologists diagnose and treat disorders that affect the central nervous system, including the brain and spinal cord. Because neurologists may specialize in different areas, it is important to consult a neurologist who has experience with Alzheimer's patients.

Geriatricians are internists or family physicians who undergo additional training to manage the health care needs of seniors. Because of their special training, geriatricians usually see frail, older patients with complex issues and significant impairment.

If your loved one has memory problems, you may want to consult with a geriatrician if:

- The patient is seeing a number of health care professionals for multiple health concerns
- Family members are under significant stress as caregivers

Depending on the patient, the geriatrician can serve as the primary care physician or as a consultant who sees the patient periodically for specific health care needs with the PCP managing day-to-day medical care.

Geriatricians generally use a team approach to caring for older people and supporting their family members. Working with a memory disorders clinic, geriatricians take a multidimensional view of Alzheimer's and other dementias, evaluating these memory disorders in light of what else is going on in the patient's life — other medical conditions, available social supports and the patient's living situation, for example.

Geriatricians can offer a proactive approach to memory loss, and put a strong emphasis on education. When meeting with a patient and family to discuss the diagnosis and recommendations, a good geriatrician will frame those in the context of the family and what they can do in terms of short-term and long-term planning.

In addition to providing diagnosis and treatment to the patient, geriatricians help family members focus on their own health and emotional wellbeing as they cope with their loved one's memory loss. Dementia is a family affair, and everyone in the family can benefit from education and support.

Tips for Communicating with someone who has Alzheimer's Disease*

*based on the complete list of "Learning the Language of Alzheimer's" contained in "Dr. Ruth's Guide for the Alzheimer's Caregiver"

1. Pay careful attention to your body language. People with Alzheimer's, especially in the latter stages, have problems understanding words. Observe what their body language is telling you. Smiling sets the tone for the conversation and is uplifting.
2. Make certain that you have your loved one's attention. Look her in the eye and say who you are. Use gentle touch to make sure she is focused on you.
3. Use simple phrases. Repeat what you have to say if you don't get a reaction. Use specific names and terms because they are easier to understand.
4. Phrase questions so she can give you a yes or no answer. Try not to offer choices.
5. Learn to listen with your eyes and observe what her body language is telling you.
6. Try to end every conversation on a positive note. If the overall feeling of the conversation was positive, it will have a more lasting effect.
7. When you're talking with her, keep other distractions to a minimum.
8. Don't try to initiate conversation when you're short of time, because your loved one may need to get her thoughts together.

The Spouse as Caregiver: A Conversation with Dr. Ruth Westheimer



Dr. Ruth Westheimer interviewed the Hebrew SeniorLife Dementia Research, Medical and Care Team for her book, "[Dr. Ruth's Guide for the Alzheimer's Caregiver: How to Care for Your Loved One without Getting Overwhelmed... and Without Doing it All Yourself.](#)"

Dr. Ruth recognized the Hebrew SeniorLife team with a special thank you in the acknowledgements section of the book.

Some of the Hebrew SeniorLife professionals who contributed to Dr. Ruth's book had the opportunity to interview her regarding the book and what Hebrew SeniorLife believes to be some of the most pertinent information contained therein.

Hebrew SeniorLife: What makes you passionate about this topic, caring for the Alzheimer's caregiver?

Dr. Ruth: Thankfully I have not had to deal with caring for a loved one with Alzheimer's. But a number of friends who did share this burden came to me for advice. When they told me what they were experiencing, I started asking them questions, just as I do when people come to me with a problem about their sex lives or their relationship. I gave them guidance, which they've told me over and over again they've found very useful. I'm hopeful that what I learned in the process, together with my training in counseling, will help the caregivers who read this book.

Hebrew SeniorLife: What is the most important piece of advice that you would give to a spouse caregiver?

Dr. Ruth: Take care of yourself, both physically and mentally. If your health deteriorates you won't be able to act as a caregiver, so don't neglect your own medical needs. Get some exercise, eat properly, go for checkups. And also take care of your mental state. If you're depressed, that's going to affect the quality of the care you give. Plus, your loved one wouldn't want to see the quality of your life diminish so drastically. So don't feel guilty about taking some pleasure out of life.

Hebrew SeniorLife: How can Alzheimer’s disease and dementia impact the emotional and physical intimacy in a marriage?

Dr. Ruth: It will in a million different ways. In some cases it will rip the fabric entirely, especially in the later stages. But before that, certain parts will still exist and the challenge will be finding those parts. For example, a couple’s sex life might be a way to maintain the relationship, even though having sex is going to be much different. But once a couple starts, some of the old emotional ties may be reestablished for a time. Each couple has to experiment. In some cases sex just won’t be possible, but don’t let your sex life die because you’ve made the false assumption that it has to.

Hebrew SeniorLife: How we communicate with people with dementia, both verbally and non-verbally, is very important. “Learning the language of Alzheimer’s” is such an important step. Can you talk a bit about what this means for the caregiver?

Dr. Ruth: Here’s what I have to offer from my experience as a behavioral therapist: If you’ve been communicating with someone for a lifetime in a certain way and you see it’s not working, don’t just give up. Try every method you can to get through. We all get into ruts and it can be hard to get out of them – not that talking should be considered a rut, it’s how we communicate. Remember the story of Helen Keller. She couldn’t see or hear but eventually she was taught how to communicate. Hopefully with a little practice you can find ways to get through, though of course it will be on a limited basis.

Hebrew SeniorLife: Do you have any tips on partnering successfully with a professional caregiver?

Dr. Ruth: Let me give you my perspective. When I first came to this country I had a young daughter and needed to work to support her. I didn’t speak English and so the first job I found was as a housekeeper. I made 75 cents an hour but it kept a roof over my head. I remained friends with the couple that first employed me so you see, I was treated right. But from that experience I always treat those who help me with courtesy and kindness. In other words, the way I wanted to be treated. So to get the most out of such a relationship, you have to make sure that you treat the professional caregiver with respect.

Hebrew SeniorLife: You’re saying you can help prevent difficulties and foster a positive working relationship with a professional caregiver, whether in the home or in a care setting, through good communication and collaboration. Your efforts will also be stronger when you work together as a team.

Dr. Ruth: Absolutely. Now there are some people who may try to take advantage of you if they think you’re too nice. What I would do is get rid of that person as soon as possible. Most people will respond positively to being treated like a human being. If you happen to have gotten a bad egg, don’t waste time fighting but move on.

LAY THE GROUNDWORK

for getting help
as soon
as possible.



Hebrew SeniorLife: Many people think that keeping their loved one at home is the ideal – and consider anything else a failure. Your book describes well-researched benefits to both patients and caregivers of Alzheimer’s day programs and memory care assisted living options. Can you elaborate?

Dr. Ruth: Fighting Alzheimer’s and dementia is a battle nobody can win. The question is, how badly are you going to lose? If a spouse or other family member tries to shoulder the entire responsibility, after a while they too might fail. Their life may succumb to the disease and that’s just too high a price to pay. Plus, then what happens to the person in your care? So you have a duty to both your loved one and yourself to get help. And the longer you delay going for help, the worse will be the outcome. If you wait until you’re overwhelmed to start looking for the best ways to get help, you’ll never be able to be both a caregiver and a researcher. And as a result you may jump to the wrong conclusion.

Hebrew SeniorLife: Yes and it’s important to know that help is available in day programs for short-term assistance and assisted living for longer-term housing and care. The benefits of both include increased socialization, assistance with activities of daily living, a safe place with medical oversight, a structured environment, and nutritional needs provided for daily. We often suggest that people research and visit several day programs or assisted living communities and gather information in advance so they’ll be prepared when decisions need to be made quickly.

Dr. Ruth: I’m not saying you have to get help right away, but you do have to lay the groundwork for getting help as soon as possible. Your loved one’s condition is going to deteriorate though in each case how long he or she goes from one stage to the next will vary. But since you can’t know at what point in the future things will get so bad that you’ll need help, you have to take action right away. Be prepared so that when you need help you’ll know exactly how to get it.

Wondering where to start? See our directory of Hebrew SeniorLife memory care resources on page 28.

Complementary and Alternative Therapies

As dementia progresses, brain cells are damaged, causing cognitive symptoms to worsen. While current medications cannot stop disease progression, they may help lessen or stabilize symptoms for a time by boosting certain chemicals involved in carrying messages among the brain's nerve cells. However, these drugs have unwanted side effects, or have little effect in some individuals. Given no cure and limited treatment available, it is no surprise that there is high public interest in complementary and alternative therapies when it comes to treating dementia.

Complementary and alternative therapies are a broad range of treatments used outside of conventional medicine to either complement, or provide an alternative to, standard treatments. The area of complementary medicine can be controversial because the effectiveness of these therapies are often unproven, there is a lack of high quality research, or because their safety profile is in question. Nonetheless, there is still high interest in complementary and alternative medicine (CAM) to treat Alzheimer's disease and other dementias.

One good example of the popularity of CAM is the use of vitamins and herbal extracts. While their use is associated with side effects, potential serious drug interactions and mostly unproven efficacy, research has shown that nearly half of dementia patients are receiving them.

Some of the more promising CAM therapies are those used to manage common symptoms associated with dementia including apathy, insomnia and agitation. A number of studies have addressed the use of acupuncture for treating insomnia in persons with Alzheimer's disease and vascular dementia. Aromatherapy, based on the theory that oils derived from plants have beneficial properties, have been shown to be useful in helping people with dementia relax. Diluted lavender or lemon balm can be added to a bath or used to gently massage the skin. Another area that is being researched is bright light therapy. Sleep problems or "sundowning" behaviors are commonly associated with dementia and can be very stressful on both the individual and their caregivers. Bright light therapy includes using stronger general lighting at home during the daytime to enhance the sense of night and day.

Music therapy is another promising CAM for treating neuropsychiatric symptoms of dementia. Music can have powerful effect on the individual with dementia's state of mind, evoking memories from one's youth, and soothing unwanted agitation. Treatment usually involves playing music that the individual enjoys for up to 30 minutes in a quiet room.

Before considering the use of CAM in persons with dementia, it is important to speak to their physician. Many herbal remedies interact with prescription medications, which can result in serious side effects. It is also important for consumers to ascertain information about CAM from sound, reputable sources.

When a Loved One Wanders

Adults with dementia often feel compelled to walk about. This behavior has routinely been called “wandering” by clinicians, researchers and informal caregivers. About 60 percent of adults with dementia will experience wandering, which most commonly occurs in the middle or later stages of dementia. Wandering can be prompted by a desire to look for something or someone, such as a family member or friend, or by a need to fulfill a former obligation such as going to work. Some adults with dementia express a desire to “go home” even if they are living comfortably in their own homes. Wandering can also be a response to stress, pain, disorientation, lack of sleep, or unmet needs, such as loneliness, boredom or hunger.

Wandering or pacing can be beneficial in terms of relieving anxiety and providing exercise, for example. However, what is a very serious concern for families, caregivers and law enforcement officials is known as “elopement” or “critical wandering,” which can lead to what is known as a “missing incident.” A “missing incident” occurs when the whereabouts of a person with dementia are unknown to the caregiver, and the person is not in the expected location. Because dementia impairs a person’s ability to recognize that he or she is in danger or to independently take action to return home safely, missing incidents can pose a serious threat to an individual with dementia’s personal safety. Research indicates that about one half of those who are not found within 24 hours risk serious injury or death.

TIPS FOR WANDERERS



Consider purchasing an identification bracelet and an electronic tracking GPS device that helps track the whereabouts of the individual and manage their location.

Many municipalities respond to missing incidents with “Silver Alerts.” A Silver Alert is a public notification system to broadcast information about missing persons – especially persons with Alzheimer’s disease, dementia or other mental disabilities – in order to aid in their recovery. In Massachusetts, the [Silver Alert program](#) was signed into law in 2010. It is run by the Executive Office of Elder Affairs (EOEA) and the Massachusetts State Police, and mandates that adults with dementia be treated as a missing person regardless of how long they have been missing. In addition, about a dozen or so Massachusetts municipalities now offer Silver Alert registries which contain information such as date of birth, medical condition and caregivers’ phone numbers. The information is kept on file with local police departments to be used in case a person is found wandering or family members report someone missing. The registries may also include a recent photo, physical description of the person and description of the person’s favorite places to visit.

Missing incidents are unpredictable, can happen while the person is doing seemingly normal and routine tasks, and occur in all care settings, including ones that are professionally staffed. In a long-term care setting, the term, “unsafe exiting,” may be used to describe the unplanned and unsupervised departure from the facility. Unsafe exiting can also lead to a serious missing incident.

Wondering where to start? See our directory of Hebrew SeniorLife memory care resources on page 28.

Here are some tips for managing critical wandering or elopement in the home setting:

- **Maintaining a routine and structure** to each day is important to the person with dementia. If wandering occurs at certain times of day, have an activity planned for that time.
- **Remember that wandering can be beneficial** if done in a safe, secure environment. It can relieve boredom and provide much needed exercise.
- **Avoid busy malls or shopping centers** that can be confusing and may place the person at risk for a missing incident.
- **Ensure that basic needs are met.** Hunger, lack of sleep, pain, loneliness and boredom all can trigger wandering behaviors. Use night lights to ensure the person with dementia can find his or her way to the bathroom at night.
- **Do not correct someone with dementia who is asking to “go home” or to work.** Instead, redirect them to another activity such as sitting down for a cup of tea, a puzzle or listening to music.
- **If wandering tends to occur at night,** limit daytime napping when possible. Many people with dementia lose the ability to distinguish between night and day. Leave only night lights on at night and use shades or curtains to reduce light intrusion from outside sources.
- **Never leave someone with dementia in an unlocked home or vehicle.** If the person is at high risk for unsafe exiting, you can consider installing locks on exit doors above the line of sight. Keep keys in a very handy location. Door alarms that signal when a door or window is opened may also be considered.
- **Contact local law enforcement to learn if they maintain Silver Alert registries.** Keep a recent up to date photo handy and make a list of places that the person may wander.
- **Consider purchasing an identification bracelet and an electronic tracking GPS device that helps track the whereabouts of the individual and manage their location.** Little data exists to support the benefits of tracking the whereabouts of a person with dementia at the risk of limiting one’s personal liberty. **A decision to use an electronic tracking device should be made with the consent of the person with dementia whenever possible.**

10 Tips for Coping with Repetitive Behaviors

It is well established that the underlying cause of loss of sense of time is related to short term memory loss and confusion related to the progressive damage to brain cells caused by Alzheimer's disease. In the case of repetition, the person may simply not remember that she or he has just asked a question, nor do they remember the answer. However, recent studies also note that they may be trying to express a specific concern, ask for help, or cope with feelings of frustration, anxiety or insecurity that often accompany memory loss.

Here are some important steps to remember when dealing with repetitive dementia behavior:

- 1. First, stay calm.** Being asked the same question over and over can be trying, but do your best to not show your frustration.
- 2. Focus on their emotions or the reason behind the repetitive questioning.** Rather than reacting to what the person is asking, think about how he or she may be feeling. Try to imagine not knowing what day, month, or year it is. Are they bored, lonely, anxious, worried? Knowing the time may not be as important as the need to be reassured that they will not be late. Reassuring the person that you will ensure they are not late may be more effective than constantly reminding them of the time. The overall goal should be to create an environment that feels very safe and very secure.
- 3. Avoid arguing or scolding for repeating the question or attempt to correct them.** This is important. Avoid saying, "Don't you remember what I just said?" Alzheimer's disease affects memory and the person may not remember that he or she asked the question already. Also, the person with dementia may become angry and upset with the caregiver when they are told that they are repeating themselves, which can lead to further behavioral expression.
- 4. Try distraction or reassurance.** If the person seems bored or lonely, sit with them and try to redirect to a new activity or conversation. A gentle hand massage and offering reassurance in a calm, gentle voice may be enough to allay their anxiety or frustration.
- 5. Provide an answer to the question that he or she is asking for, even if you have to repeat it several times but remember to keep the answer simple and brief.** If the person with dementia is still able to read, write it down and post it in a prominent location.
- 6. Use memory aids such as clocks, photographs, calendars, and notes.** Make it a habit to refer to the day and month every day. Displaying a daily or weekly schedule is also helpful.
- 7. Engage the person in an activity.** The questioning may simply be boredom and needing something else to do. Try engaging the person in an enjoyable activity.
- 8. Travel with the person to where he or she is in time.** If the person's memory is focused on a particular time in his or her life, engage in conversation about recollections with an understanding that this is his or her current reality.
- 9. If all else fails, ignore the question.** If none of the above suggestions work, you may find that the only solution is to simply ignore the questioning. The person may eventually realize that he or she will not get an answer and stop asking the question.
- 10. Share your caregiving challenges with others.** There are many caregiver support groups that can offer support and advice. Finally, try not to take it personally and if needed, take a break and leave the room for a few minutes.

Wondering where to start? See our directory of Hebrew SeniorLife memory care resources on page 28.

Physical Fitness: “Everyone is Equal in the Gym”

When you think of therapies and supports for a senior living with dementia, your first question may not be “how often can she get to the gym?” But the latest research shows that physical exercise may be an effective treatment – not only for risk reduction – but also to help those already suffering from Alzheimer’s Disease and vascular dementia live better lives.

At Hebrew SeniorLife, we offer robust, research-based fitness programs for all seniors to prolong independence and improve quality of life, including those with memory loss and dementia. For example, at NewBridge on the Charles, our continuing care retirement community in Dedham, MA, geriatric fitness specialists work with each memory care assisted living resident to develop a personalized fitness plan.

“We contact their doctors, review medical histories, and connect with family members,” explains Christina Foley, Director of Fitness. “We discover their passions and then work to build fitness programs around what they’ve always liked and enjoyed.” The fitness goal for many residents is prolonging self-sufficiency in the tasks of daily living – such as dressing, eating and moving about independently.

Fitness specialist Teresa Boughner incorporates cardio, strength, balance and flexibility training in her popular supervised exercise sessions -- and also a bit of humor. “So many of our residents enjoy exercising and often find their moods boosted. The gym puts them at ease. The wonderful part is that I can lead a small group and incorporate conversations, storytelling and jokes as part of it. We’ve developed a trust that leads to participation.” She notes the goals are the same for seniors with dementia as they are for any adult looking to stay fit: thirty minutes of exercise a day. “We’re all equal in the gym.”

In addition to the four sessions Teresa leads each week, memory care assisted living residents at NewBridge are also offered weekly yoga, tai chi, walking groups, and dance movement therapy. The uniquely designed campus allows for lengthy indoor walking routes no matter the weather in addition to miles of paved outdoor walking paths.

Our residents are as enthusiastic as our fitness specialists!
“They participate so well,” says Teresa. “It’s a joy.”



**THE GOAL IS
PROLONGING
SELF-SUFFICIENCY**

in the tasks of
daily living –
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independently.

Memory Cafés Offer Social Support to Those Facing Memory Loss — and their Caregivers

When Alzheimer's disease becomes part of a marriage, or a family, caregivers can usually find resources to support the family member facing memory loss or to support the family caregiver seeking peer connections and information. Yet, until the last few years, there wasn't much designed to support the evolving spousal or parent/child relationship itself. All that changed with the advent of the "Memory Café" concept in the Netherlands, a unique model of social programming designed as a welcoming place for caregivers and their loved ones with memory loss to relax together in a stigma-free environment that offers both socialization and support.

In 2014, NewBridge on the Charles began a monthly Memory Café program within our continuing care retirement community that focused mostly on our independent living members who were experiencing some kind of cognitive impairment. For these residents of our community, accessing the full array of community life at NewBridge had become complicated by dementia, yet participating in our day program or moving to our Memory Care Assisted Living residences were not yet the best options.

"We really saw an unmet need, and an opportunity for those facing memory challenges to enjoy programming in a stigma-free space," said Janet Gottler, who as community care advisor at NewBridge helped launch the program on campus.

"Café Connect," as it was named, offered an afternoon of interactive music, art or other entertainment. The program blossomed, and grew to include more participants as well as the involvement other community members who became boosters and volunteers.

In the meantime, Memory Cafés have grown in the Boston-area, learning best practices from each other with the help of Boston's Jewish Family & Children's Services "Percolator" Network. Taking place in libraries, senior centers, and places of worship, each Memory Café has its own unique feel. Ours for example, has been greatly enhanced by the NewBridge emphasis on the importance of multi-generational interaction, frequently incorporating the involvement of area high school students who add energy and interest to every program.

In early 2016, Café Connect opened its doors to the broader community so that non-residents who would benefit would benefit could now attend. The response has been strong – not only from families in the area, but from other nonprofits interested in starting their own Memory Cafés.

We've also begun collaborations with local community institutions – one senior center and one synagogue – to sponsor and support their Memory Cafés as well. By doing this, we are creating stronger relationships with the broader community, as well as gaining expertise and resources to bring back to Café Connect.

Learn about our next Café Connect program by calling Janet Gottler at 781-234-9214.

Memory Care Assisted Living: Redefining “Living Space”

When family members explore a memory care assisted living community for a loved one, it’s easy for the apartment itself to become the focus of attention. How big is it? Does it have a nice view? Will her furniture fit? For adult children especially, it can be very hard to think about a parent downsizing to a studio-sized apartment.

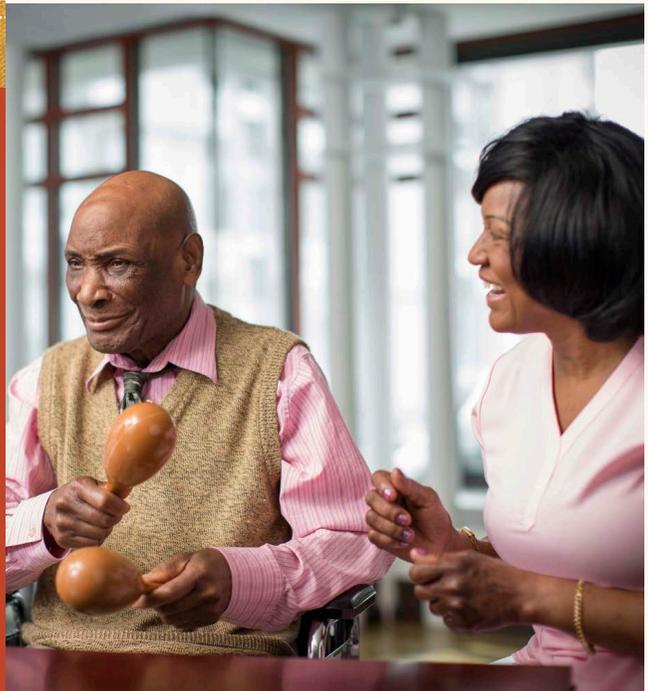
For people with dementia and/or Alzheimer’s disease, the goal of memory care assisted living is to encourage socialization, self-expression and to maximize cognitive stimulation. The keys to these goals are not the real estate, but the quality of staff, the nature and extent of programming offered, as well as the culture of the community. As long as the apartment is personalized and comfortable, the ideal memory care assisted living apartment is often a small one.

Family members are often surprised by the way their loved ones respond to their new accommodations. For example, a family needing an immediate placement might reluctantly take an apartment overlooking a parking lot instead of a more scenic view, only to discover their parent is comforted by the hustle and bustle of cars, evoking her earlier memories of city living.

Selecting a memory care assisted living community is so much more than selecting an apartment. It’s important to recognize that what mattered before may not matter as much now. It is important to look beyond real estate for a community that can best meet your loved one’s needs as they are today.

THE GOAL OF MEMORY CARE ASSISTED LIVING

is to encourage
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and to maximize
cognitive
stimulation.



Traveling with Dementia

When you are caring for someone with dementia, the thought of a vacation may be wonderful, but the reality of the experience can be stressful and complicated. Caregiving is a 24/7 job wherever you are. Dementia doesn't go away like some of the other worries we leave at home while on vacation. In fact, the change in routine can make symptoms even worse.

If you decide that travelling is important and that it brings value to you and your care partner's life, the following suggestions may help make the process easier and safer for both of you:



1. **TRAVEL WITH MORE INFORMATION THAN YOU THINK YOU NEED.** Bring copies of medication lists, doctor's names/numbers, a photo of your loved one, copies of medical proxies/emergency contacts.
2. **REGISTER YOUR CARE PARTNER IN THE ALZHEIMER ASSOCIATION'S SAFE RETURN PROGRAM,** a 24-hour nationwide emergency response service for individuals with Alzheimer's or a related dementia.
3. **PLAN EVERYTHING IN ADVANCE.** This includes meals, lodging, transportation and activities. It is better to know in advance what some of your challenges may be than to be blindsided in the moment.
4. **MAINTAIN YOUR CURRENT ROUTINE AND STRUCTURE** as much as possible while you are away.
5. **SCHEDULE A DRESS REHEARSAL.** Go for a day trip that includes traveling, activities and meals. This will give you an opportunity to practice some of the challenges you may face on your actual trip.
6. **BRING ALONG ANOTHER FAMILY MEMBER AND/OR A PROFESSIONAL CAREGIVER.**
7. **EXPECT THE UNEXPECTED.** Even with all of the planning you will do, something will happen that you could not have anticipated. 1) Accept this in advance and 2) try to keep a sense of humor, it is what it is.

If the prospect of all the planning feels overwhelming, you may decide that travelling with your care partner is not a viable option. Additionally, you as a full-time caregiver may need a break. An occasional vacation from caregiving is a crucial part of maintaining the ability to provide care over the long term. It is something caregivers do for themselves that positively impacts their care partner, both in the short- and long-run.

In these cases, look for memory care communities that offer something called “Respite Care.” These are temporary assisted living stays – typically ranging between several days and several weeks. The benefit to you is peace of mind as well as the chance to recharge. Your care partner enjoys their own vacation in a community designed specifically to support persons with dementia; a win-win for both of you.

CAREGIVING
IS A
24/7
JOB WHEREVER
YOU ARE.



Hebrew SeniorLife Memory Care Resources

Memory Disorders Clinic

Hebrew Rehabilitation Center in Boston offers diagnosis of memory disorders such as Alzheimer's Disease for patients in Greater Boston. Our clinicians can help determine if memory loss is part of the aging process, medications being taken, or a sign of dementia. Provided by Hebrew SeniorLife's Harvard-affiliated Department of Medicine located at Hebrew Rehabilitation Center in Boston.

Contact: 617-363-8539 • www.hebrewseniorlife.org/memory-disorders

Adult Day Health: "Great Days for Seniors"

Great Days for Seniors, Hebrew SeniorLife's Adult Day Health Programs, are located at two locations in Boston – Hebrew Rehabilitation Center in Roslindale and Jewish Community Housing for the Elderly in Brighton. Seniors who would otherwise be isolated at home maintain – or regain – their independence and maximize their potential. The programs are staffed by professionals and provide nursing care and supervision for older adults experiencing dementia.

Contact: Suzie Kaytis • 617-363-8515 • www.hebrewseniorlife.org/adult-day-care

Assisted Living and Memory Care Assisted Living at NewBridge on the Charles

NewBridge on the Charles offers a new approach to Assisted Living and Memory Care for seniors near Boston, Massachusetts. Our rental Assisted Living and Memory Care residences allow seniors and their families to redefine their expectations of aging. Stimulating programming, a green campus, healthy dining, easy access to premier medical care – all come together to transform the experience of aging.

Contact: Ellie Belanger • 781-234-9421 • www.newbridgeassistedliving.org/

Memory Café at NewBridge on the Charles: "Café Connect"

Café Connect is a monthly program at NewBridge on the Charles that serves as a welcoming place for adults experiencing memory challenges and their care partners. Attendees are invited to bring a spouse, family member or a friend and meet new friends of all ages! Café Connect offers a special participatory program or guest facilitator each month, with an emphasis on multigenerational programming. There is no cost to attend, but RSVP REQUIRED.

Contact: Janet Gottler • 781-234-9214

The Aging Brain Center at Hebrew SeniorLife's Institute for Aging Research

The Aging Brain Center is dedicated to advancing medical knowledge about delirium and the interface between delirium and dementias, such as Alzheimer's disease. Each year, more than 12 million older Americans develop delirium, an acute medical condition that presents as an abrupt confusion or a sudden change in cognitive abilities. Delirium is especially common in patients with Alzheimer's disease, and prevention of delirium in this group of patients is of critical importance.

Contact: 617-971-5300 • www.instituteforagingresearch.org/research/aging-brain-center

Harvard College Alzheimer's Buddies Program at Hebrew Rehabilitation Center

Harvard College Alzheimer's Buddies (HCAB) is a student organization responding to the profound isolation and social disengagement experienced by people in the intermediate-to-late-stages of Alzheimer's disease (AD). We build meaningful emotional connections with dementia residents during weekly one-on-one visits. We focus on what is still present in our buddies and improving the life that they have despite limitations. We currently visit residents at Hebrew Rehabilitation Center in Boston, Hebrew SeniorLife's flagship campus.

Contact: Robin Stewart • 617-363-8258 • <https://alzheimersbuddies.org/>

Further Reading

"Advanced Dementia: A Guide for Families," Hebrew SeniorLife and Beth Israel Deaconess Medical Center. This guide provides information to the family members and individuals responsible for making health care decisions for patients with advanced dementia.

Download the guide at: <https://www.instituteforagingresearch.org/resources/assets/advanced-dementia-guide-families>

- *"Dr. Ruth's Guide for the Alzheimer's Caregiver: How to Care for Your Loved One without Getting Overwhelmed...and without Doing It All Yourself,"* Ruth K. Westheimer, 2012.
- *"Being Mortal: Medicine and What Matters in the End,"* Atul Gawande, 2014.
- *"The 36-Hour Day: A Family Guide to Caring for People Who Have Alzheimer Disease, Related Dementias, and Memory Loss,"* Nancy L. Mace, Peter V. Rabins, 2012.