Successfully navigating the legal, medical, and ethical challenges posed by dementia was a central theme of a recent conference hosted by Somerville-Cambridge Elder Services (SCES).

The program featured a panel discussion of local experts, who offered perspectives on common dementia ethical issues. In organizing the discussion, SCES Clinical Director Annie Fowler said the goal was providing guidance for common—but often difficult – dilemmas.

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“There are a lot of challenges that come with dementia, so we wanted a program that would empower people by providing education and concrete steps they could take,” said Fowler.

The panel discussion featured attorney Neal Winston, psychiatrist Rebecca Warner, and Home Care Aide Council executive director Lisa Gurgone. The following is drawn from their responses to six ethical dilemmas posed by the discussion moderator:

**What factors do you consider when an individual shows increased signs of dementia and a family member wants to get the individual to sign a Health Care Proxy?**

A Health Care Proxy gives another person permission to make health care decisions, and Winston said the key questions are if they trust the potential proxy and if they’d feel comfortable with them making decisions about their care.

Warner said her goal in that scenario is preserving the person’s autonomy while also balancing safety and comfort. She indicated it’s best to have those discussions before severe dementia sets in, to get a clear idea of what the person wants.

**A person with memory loss often doesn’t recognize they can no longer manage certain tasks. What are the options if they decline assistance and have not been medically determined to lack capacity?**

Gurgone said Home Care workers are often in a position to see things that cause concern, adding it’s important to work closely with case managers and medical providers to address problems.

Warner advised working with the individual to find mutually agreeable supports, saying solutions should be non-confrontational and voluntary, when possible. She also advised contacting Adult Protective Services if the person is in danger.
Clients with mild to moderate dementia often can maintain routines and don’t qualify for Home Care. But they may be at risk for wandering or unsafe driving. How best to assist those clients?

Home Care staff are mandated reporters, which means they’re required to report safety concerns to Adult Protective Services. Gurgone cautioned that Protective Services discussions often involve balancing public safety with the person’s right to make their own decisions; but she also advised filing follow-up reports, if the first one doesn’t resolve the issue.

An ID bracelet or GPS device were also suggested as measures to mitigate wandering concerns.

A client with moderate dementia is still driving and has had some minor accidents. What is the best way to intervene?

The RMV has a Medical Recommendations Department that investigates reports of unsafe driving, and can require vision tests and other evaluations to maintain licensure. However, Winston cautioned that such reports are subject to disclosure to the reported driver if requested.

Another alternative is DriveWise, a national testing model that provides an independent and objective assessment of the driver’s abilities, along with a recommendation on whether they should continue driving.

A caregiver who is Health Care Proxy and Power of Attorney is making medical or financial decisions that professionals involved disagree with and think may put the client at risk. What options do they have?

Disagreements between family members are a common source of friction, but Warner said medical providers are still responsible for providing their own clinical judgment when faced with directives they think are unsafe.

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**Dementia: It’s Not Just Alzheimer’s**

Dementia comes in several common forms, and Dr. Serena Chao offered guidance on the distinguishing characteristics of those disorders as part of a recent conference hosted by Somerville-Cambridge Elder Services (SCES). Chao, who is Chief of Geriatrics at Cambridge Health Alliance, said the distinctions are important, noting that various disorders call for different treatments.

“Cholinesterase inhibitors, such as donepezil (trade name Aricept), have been FDA approved for Alzheimer’s disease and Parkinson’s Disease with dementia, but not other forms of dementia,” said Chao. “While cholinesterase inhibitors can be used in all clinical stages of Alzheimer’s (i.e. mild, moderate, or severe), memantine (trade name Namenda) has only been found to be effective in moderate to severe stages of Alzheimer’s.”

SCES Clinical Director Annie Fowler cited the various disorders as another example of how dementia as a complicated issue that defies one-size-fits-all solutions.

“Memory impairment is a common thread of dementia, but it’s important to remember that there are several kinds of dementia and that each manifests differently with each individual,” said Fowler. Chao outlined the following distinguishing characteristics for the most common disorders:

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**Alzheimer’s Disease (mild)**
- Short term memory deficits are prominent
- Preserved social skills
- Problems with complicated daily activities
- May have symptoms of apathy, irritability or depression

**Dementia with Lewy Bodies**
- Visual hallucinations in mild/early stage
- Presence of parkinsonian features, such as bradykinesia, shuffling gait
- Fluctuations in cognitive impairment
- Early on memory deficits are less prominent

**Vascular Dementia**
- Stepwise decline in cognitive and physical functioning over time
- Radiographic evidence of cerebrovascular disease
- Language deficits and executive dysfunction sometimes more prominent than short-term memory deficits

**Frontotemporal Dementia**
- Younger onset age than Alzheimer’s (50 to 60)
- Behavioral variant: interpersonal skills decline, including increased disinhibition, hyperorality, compulsive behavior, emotional blunting
- Language variant: progressive non-fluent aphasia (effortful, non-fluent speech), impaired word comprehension (empty circumlocutory speech)
inappropriate, or not in a patient’s best interests. She advised reporting to Adult Protective Services, if a health care agent or Power of Attorney is making poor decisions on an individual’s behalf.

Memory Cafes Provide Essential Social Connections

By Colleen Morrissey

Maintaining a social life is one of the many challenges of dementia. Many individuals report being avoided, treated differently, or not included in activities. Due to stigma associated with the disease, some choose to conceal the diagnosis as long as possible.

Enter memory cafes – social gatherings for people with dementia and their care partners. They offer safe, inclusive spaces where no one is asked their diagnosis, and the focus is on strengths instead of limitations, explained Beth Soltzberg, who coordinates the statewide memory cafe network.

“A memory café is a welcoming social gathering,” said Soltzberg, at the recent Somerville-Cambridge Elder Services (SCES) dementia conference. “It’s not a place you go for a lecture, it’s a place you go for social connection.”

Originating in Holland in 1997, memory cafes only recently made their way to America. The first U.S cafe appeared in 2008, and there are now a few hundred nationwide, including one at Cambridge Family & Children’s Services.

While each café is unique, all are free and physically accessible, with activities geared toward a wide range of cognitive abilities. They also provide a place where guests can gather with others who understand what they’re going through, and explore new activities in a stigma-free environment.

SCES Executive Director John O’Neill is a fan of the memory café model, and said the agency is evaluating prospects for launching a memory café in partnership with the Cambridge Council on Aging.

“We’re exploring it,” said O’Neill. “It’s something we’ve been interested in for a while, and the conference spurred some momentum there.”

Find Memory Cafes in Massachusetts www.jfcsboston.org/MemoryCafeDirectory

For more information
Beth Soltzberg
bsoltzberg@jfcsboston.org.

Power of Attorney allows another person to make financial decisions, and Winston said most common conflicts involve potential misuse of assets, saying those sometimes wind up in the courts. He listed a trusted relative and careful vetting of the situation as key components of entering those arrangements.

What are the ethical issues of using antipsychotics and benzodiazepines to treat symptoms of dementia?

Warner lamented that better medications for dementia are not available, citing risks with both types of prescriptions. With antipsychotic medicine, she said that’s typically a discussion with the family about quality of life for the patient, noting death is a possible side effect.

With benzodiazepines—such as Valium, Ativan and Zanax – Warner said a common problem is trying to reduce usage by patients who’ve taken those medications for much of their adult lives. Longtime users often want to increase their dosage to reduce anxiety, but that exacerbates symptoms such as fall risk and memory loss.

“You’re going in the wrong direction if you’re doing that,” she said. “You need to talk about tapering off instead, but that’s usually not popular with the patient, because they’re used to it.”

The SCES dementia conference was funded through an Executive Office of Elder Affairs grant.

Lisa Gurgone is Executive Director of Home Care Aide Council, a non-profit trade association that develops and maintains standards of best practices for home care aide services. Rebecca Warner is a geriatric psychiatrist, who works with SCES Adult Protective Services. Neal Winston is a principal at Winston Law Group, which specializes in a variety of elder law issues.
Training Helps Caregivers Successfully Navigate Challenges

By Jeanne Leyden and Nathan Lamb

Providing live-in care for a friend or loved one can be rewarding, but complex and difficult challenges sometimes come with the territory.

In those instances, caregiver training can make all the difference for maintaining health and well-being at home.

Monthly training is one of the many ways that Adult Family Care (AFC) supports family caregivers. As a MassHealth-funded program dedicated to helping people provide the best possible care at home, our nurses and social workers see the benefits of training firsthand.

This trend was quantified in a recent University of California study, which followed the progress of 6,000 in-home caregivers who were trained in CPR, first aid, and other health related topics. The study, which was publicized in a Kaiser Health News article, found that the rate of repeated emergency room visits declined by an average of 41% within two years of the training.

Those figures are not surprising. We know that people come to be caregivers from all walks of life and, as with most other pursuits, training offers a better chance of success.

At AFC our curriculum is a mixture of MassHealth-mandated topics—such as heart health and managing medications—along with materials that fit the household’s specific situation. In practice, this can range from providing information on fuel assistance to dietary advice for a diabetic.

In addition to the ongoing training, AFC provides live-in caregivers with a tax-free stipend of up to $18,550 and two weeks of paid time off annually.

The program is provided at no cost to the person receiving care, provided they are eligible for MassHealth Standard or CommonHealth and have a chronic medical or psychiatric diagnosis that necessitates assistance with at least one of the following: bathing, dressing, toileting, transferring between positions, ambulating or eating.

Caregivers must be able to meet those needs and live in the same home as the person receiving care. Friends and family are eligible to become live-in caregivers—but legal guardians and spouses are not.

At AFC we know many caregivers come into the process with much to learn. Through training and ongoing support, our goal is helping them become the best care providers they can be.

Nathan Lamb is Director of Outreach and Community Relations for Somerville-Cambridge Elder Services (SCES). Jeanne Leyden is Director of Adult Family Care, a non-profit program at SCES that supports in-home caregivers across the Greater Boston, North Shore, and Merrimack Valley areas.
A growing body of research indicates that music therapy can significantly improve the quality of life for people with dementia. It’s a practice that many are only just learning about, but there’s apparently no shortage of interest in giving it a try, explained Rory Silvia, an operations manager at Somerville-Cambridge Elder Services (SCES).

“Every single client I called said they were willing to try anything, if we thought it would help,” said Silvia.

SCES recently incorporated the Music & Memory program into their range of services available to clients in the Greater Boston area. The grant-funded program uses music to trigger memories and help dementia patients reconnect with the outside world, by providing each participant with an iPod and a tailored playlist of music that’s meaningful to them.

“It’s not just music therapy, it’s personalized music therapy,” said Silvia. “That’s why it’s been so beneficial for people with Alzheimer’s and dementia, because it taps into their memories.”

Program benefits include reduced agitation, increased cooperation with care, and enhanced socialization. Music & Memory has been the subject of numerous studies, including a 2015 report from the Front Porch Center for Innovation and WellBeing that found memory care clients using this intervention
SCES is now providing personalized music therapy for people with dementia through an innovative program coordinated by Operations Manager Rory Silvia (front row, right).

saw average mood improvements of more than 38%, with 57% of caregiving staff reporting a more positive outlook and reduced behavioral symptoms of dementia.

The concept was pioneered by Music & Memory founder Dan Cohen, who started the program as a music-loving volunteer in 2006, before scaling things up to non-profit status in 2008. There are currently more than 3,300 certified organizations worldwide, including the Wisconsin Department of Health Services, which provides Music & Memory for more than 100 nursing homes.

Music & Memory is increasingly offered at adult day health and institutional settings, but Silvia said the SCES implementation is unique in Massachusetts and reflects the agency’s commitment to providing community-based services.

“What we’re doing is a bit different, because we’re bringing Music & Memory to people in their homes, and training the family on how to use it,” she said. “We’ll check-in once per month to see how things are going, but families and volunteers are helping to ensure the clients are using it on a daily basis.”

SCES earned the Music & Memory certification in September, and has since provided iPods for 10 clients. The initial grant provided startup resources to serve more than 100 participants, but Silvia plans to keep things going by soliciting old iPod donations.

“That’s a big part of how a lot of programs sustain their resources,” said Silvia. “People who have an old iPod they no longer use can donate it and we can repurpose it in a way that’s really meaningful.”

To date, 20 SCES case managers, nurses and social workers have been trained on how to use the program. While the initial effort has focused on clients with Alzheimer’s and dementia, Silvia plans on expanding it to help any SCES client who could benefit—whether they’re coping with depression, cognitive impairments, or could simply use a boost while undergoing dialysis or chemotherapy.

“We want to provide this for our clients and show them how it can help change their lives,” said Silvia. Silvia is Operations Manager of Adult Family Care, a caregiver-support program that serves much of the Greater Boston Area.

For More Information

For more information about SCES Music & Memory contact Silvia by calling 617-628-2601 or by emailing rsilvia@eldercare.org
Free Elder Care Advice Consultation

Struggling with issues related to aging or caregiving? SCES offers a free consultation with an Elder Care Advisor who can provide information, advice and education to older people, their partners, families, and caregivers. Elder Care Advisors offer in-home, in-office or phone consultations to residents of Cambridge and Somerville or to individuals caring for an older person who lives in either of the two communities. Services include: information about community resources; advice about care options; assistance with planning for care; education about issues of aging and connections to a wide range of community services including those services offered by Somerville-Cambridge Elder Services.

For more information:
Call The Aging Information Center at 617-628-2601

Questions, Comments, or Suggestions

Contact the editor, email nlamb@eldercare.org or call 617-628-2601