

# Final Report

March, 2017



TRI-STATE LEARNING COLLABORATIVE ON AGING

## Executive Summary

As is true for many nations, America's population is aging. Northern New England is on the leading edge of this demographic shift. Collectively, Maine, Vermont, and New Hampshire have the oldest populations by median age in the country. People who live in this region pride themselves on their independence and can-do attitude. They want to "age in place," which means to age in their own home and community safely, independently, and comfortably, regardless of their age, income level, or ability<sup>1</sup>.

Northern New England is also predominantly rural with relatively low birth rates and low rates of immigration. As a natural consequence, the region has a rapidly aging population in need of assistance with a shrinking formal and informal workforce available to meet that need. Only 40 years ago there was just over a 4:1 ratio of working age people to people over 65, while today that ratio is almost 2:1.



The gap in the need for assistance is being filled by informal caregivers. An informal caregiver is a spouse, adult child, other relative, partner, or friend who provides a broad range of unpaid assistance for an older adult with a chronic or disabling condition. Other common ways of referring to an informal family caregiver are "family care partner" and, simply, "taking care of mom or dad." The defining characteristic of an informal caregiver is that care is given as an extension of the pre-existing relationship they have with the person who needs care.

While many exciting and collaborative local, state, and regional efforts have sprung up around Northern New England to support aging in place, little attention has been paid to the critical role of informal caregivers in making it possible for older adults to stay at home as they age. We're not



alone in this. A report released in September 2016 by the National Academies of Sciences says, "As a society, we have always depended on family caregivers to provide the lion's share of long term services and supports (LTSS) for our elders. Yet the need to recognize and support caregivers is among the most significant overlooked challenges facing the aging U.S. population, their families, and society."<sup>1</sup>

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<sup>1</sup> National Academies of Sciences, Engineering, and Medicine. 2016. *Families caring for an aging America*. Washington, DC: The National Academies Press. <http://www.nationalacademies.org/hmd/Reports/2016/families-caring-for-an-aging-america.aspx>

To begin to address the challenges faced by informal family caregivers in our region, the Tri-State Learning Collaborative on Aging (TSLCA) hosted three Cross-border Conversations on Caregiving:

- November 4, 2016 at the Frank Jones Center in Portsmouth, NH,
- November 15, 2016 at the Hotel Coolidge in White River Junction, VT, and
- November 17, 2016 at the Grand Summit Hotel, Sunday River, in Newry, ME.

These gatherings helped participants discover what's currently working to meet the challenges of informal family caregiving and build a shared vision and roadmap for better supporting caregivers in our region.

Collectively, these gatherings engaged 168 people from Maine, New Hampshire and Vermont. Each began with a moderated panel of caregivers sharing their stories. They shared experiences from their caregiving journey and details on their biggest challenges and greatest sources of help. Their voices carried throughout each day as the gatherings transitioned to facilitated small-group conversations focusing on thirteen targeted topics. Caregivers, community leaders, community providers, advocates, policy leaders, business leaders, health care professionals, and researchers sat at the same tables to discuss successful models that are helping caregivers and share bright ideas on how we can replicate, grow, and adapt these across our region. The collective wisdom of each conversation was captured and combined with the whole. The conversations were charged with energy and yielded the rich and thoughtful recommendations included in this report.



The conversations identified opportunities for quick success. For instance, across our region there are more than 100 communities engaged in some sort of aging in place or age friendly community initiative. The TSLCA engages these communities regularly through webinars and other educational opportunities. These grassroots community efforts are natural starting places for immediate action and the TSLCA can help support these efforts.

The most compelling challenges offered by caregivers during the conversations were isolation, lack of information about resources, and lack of access to resources. Consistently held up as helpful were peer-to-peer caregiver support groups, caregiver training classes like Savvy Caregiver, opportunities for respite, and most critically, access to information about resources and tools that



can help. The aging in place initiatives across our region create an immediate opportunity to address these challenges and provide support to caregivers through community volunteer programs, facilitated community conversations on caregiving, and locally-hosted caregiver trainings and support groups. They can also deploy proven tools to help create dementia-friendly communities. Most

importantly, these aging in place groups can make sure family caregivers have access to information

about the resources, support systems, tools, and knowledge that can help them better manage the daily demands of caregiving.

Communities cannot do this work alone, nor should they. It is incumbent upon the social service agencies that serve these communities to help implement these activities. To accomplish this, we encourage regional social service providers to facilitate a meeting with local community groups and other providers to discuss the recommendations in this report and identify actions they can take to better support family caregivers at the local level. The conversations made clear that we'll only make meaningful progress, though, if these sorts of coordinated community efforts are also supported at the state and federal level through policy shifts and increased funding for respite, adult day programming, and transportation services.



Workplaces across our region were identified as ideal places to support working caregivers by better connecting them to resources that can help and offering opportunities during the workday for peer-to-peer support and shared learning. Caregivers shared that employers who offer flexible leave and work schedules make a difference in their ability to provide quality care while remaining in the workforce. Participants suggested that the business sector will be useful in shifting policy and leveraging resources to expand community care options that will allow employed caregivers to remain in the workforce longer. It was also clear that we need to build the return on investment case for the business sector to take action.

Finally, health care professionals were identified as a key to bridging the information gap and providing much-needed personal care to caregivers. Helpful practitioners offer honest, clear, and compassionate information about diagnoses like dementia, make warm-handoffs to social service agencies, connect caregivers with advance care planning tools, assist with complex health care navigation, and take every opportunity to ensure the caregiver is thinking about his or her own self-care needs. However, stories abounded about inconsistent interactions with health care professionals and this was identified as an area where consistency in approach would make a significant difference in the lives of caregivers.

These conversations were only a starting point. This report takes the next step. It captures and highlights the simple to complex ways we can collectively act to address the challenges informal family caregivers face across a multitude of sectors. We will share the recommendations broadly and encourage action – from our families, our communities, our workplaces, our places of learning and worship, our states, and across our regions – to implement the bright ideas offered by so many during these conversations. There is a recommended action step for everyone in this report – so please read it and choose one thing you can do!

Tri-State Learning Collaborative on Aging  
[www.agefriendly.community](http://www.agefriendly.community)  
Jess Maurer, Project Manager • [jmaurer@maine4a.org](mailto:jmaurer@maine4a.org)

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## Introduction

The Cross-border Conversations on Caregiving were convened in border communities to foster multi-state dialogues. A total of 168 people were engaged: 61 from New Hampshire, 57 from Maine, and 45 from Vermont (5 people were from outside of Northern New England). Each gathering included people from all three states and was purposely limited to fewer than 75 attendees so each individual could have an equal opportunity to contribute.

At each gathering, participants were invited to engage in a series of small-group conversations. There were thirteen tables and each was assigned a specific topic related to caregiving. No more than 10 people were seated at any one table at a time. Participants rotated to different tables



depending on their interest in the topics. A knowledgeable topic leader remained at every table to guide the conversations and build on the information shared throughout the day. Each small-group conversation lasted twenty-five minutes. After that time, participants were asked to move to a new table and engage in a new conversation on a different topic. Throughout the day, participants

had the opportunity to participate in six separate conversations on different topics.

Topic leaders were identified by members of the Cross-border Conversations on Caregiving planning committee as being good facilitators with some content familiarity and expertise. These topic leaders were encouraged to avoid presenting and to instead gently build the conversations and encourage unique contributions from each individual. The conversations were driven by those at the table, with the topic leader building on the information gleaned from earlier conversations.

People who attended were overwhelmingly positive about the experiences they had. Almost half of those who participated completed an online survey (averaged response rate of 42 percent). Ninety-nine to 100 percent of participants felt that: the conversations met their expectations; they learned something new to bring back to their community and/or work; the small-group discussions brought up important points to report back to the larger group; and the caregiving topics they are most interested in were included in the discussions. Participants stated that they would attend another cross-border event around a different topic. There was also overwhelming agreement (over 92 percent) that the caregiver panels were enlightening, well organized, and that, overall, the day helped them make important connections with other people interested in caregiving.

The hundreds of rich and engaging conversations that took place have been condensed into the topic summaries that follow. The energy in each room and sheer wealth of knowledge and information shared was a beautiful thing. We hope to harness this energy and inspire others to take action.



# 1. Caregiver Voices

Each Cross-Border Conversations on Caregiving started with a panel of caregivers who shared their experiences with the group. Some of the caregivers on the panel were spouses to a person living with dementia, others were adult children. Some caregivers were still employed, while others had had to leave the workforce. Although each story was different, they contained common themes. All of them agreed that caregiving is challenging and requires patience, a sense of humor, and flexibility to make life as good as possible for all involved.

The caregivers were united in sharing that they are not perfect but are doing the best they can under challenging circumstances to honor their relationships with the person receiving care. The caregivers on all three panels said it was vital that they not expect themselves to get everything “right” in order to continue providing care. Many of the challenges of daily life they described were compounded by the need to negotiate new roles in the relationship. Tasks such as changing the lawn tractor belt, cooking, or snow blowing that had once been the responsibility of the other person, eventually had to be taken over by the caregiver. The caregivers shared a variety of solutions -- from moving to a home that requires less maintenance, to working from home, to early retirement -- that they had adopted to manage the changes in their relationship and the demands of caregiving.

A particular challenge was balancing the need of their loved one for independence and meaningful activity with concerns for safety, especially while a caregiver was at work. One caregiver described his choice to allow his wife to remain at home alone until she started to wander. Neighbors were a strong and steady source of support and called him or helped her get home safely on several occasions. Another caregiver shared the creative process she went through to design safe, meaningful, and productive work for her husband to do while she was at work.



Caregivers who were caring for children or grand-children while also providing support for a parent with dementia faced unique challenges. One caregiver talked about the day-to-day routine of caring for her dad while also caring for the grand-children she is raising. Meeting the needs of both generations required a creative balancing act that, occasionally, fell apart. Sometimes it meant that she had to cut her caregiving responsibilities;

other times the children had to miss out on activities.

Finding respite was one of the challenges that made caregiving more difficult. It was not easy for most of the caregivers on the panel to admit they needed a break, and once this was finally admitted, help was found to be very limited. For example, one caregiver described calling a nursing home to find out about short-term respite care. She was told that reservations had to be made 9-12 months in advance.

Caregivers also described the difficulty of finding appropriate, quality care that was in line with the preferences of the person living with dementia. An adult day program may be perfect for someone who enjoys social opportunities but, for a person who was happier on his own than in a social setting prior to dementia, it was not as good of a choice because it didn't honor the person behind the diagnosis. In-home care providers who were trained to work with a person with dementia were hard, or impossible, to find. When they were available, the cost was not covered by health insurance and was thus prohibitively expensive.

The challenge of finding respite care meant that it was difficult for caregivers to take care of their own needs, participate in activities they enjoyed, visit family who lived away, and maintain relationships with friends. The challenge of finding regularly scheduled care meant that it was difficult for caregivers to run errands, keep medical appointments, or attend a caregiver support group unless the person with dementia could be left alone or a friend or relative agreed to visit.



Caregivers discussed the important role that friends and neighbors play in supporting care. A few said they could not provide care if it weren't for the help they receive. Others said that it was hard to know when to accept help and what kind of help to request. They worried about burdening friends or family by over-asking. They also shared that some people had a hard time knowing how to relate to the person with dementia so avoided visiting them at home. Although the caregivers said they understood people's hesitation about visiting and trying to talk with the person with dementia, the resulting isolation was hard to bear.

Across all three panels, caregivers agreed that peer-to-peer caregiver support groups were critically important because no one else can truly understand the daily challenges except for other caregivers. In all three states, at least one caregiver identified the Savvy Caregiver Training program as a lifesaver. Caregivers acknowledged how hard it is to ask for help and how relieved they were that a few of their friends or family members "got it" – they knew to just help instead of asking how to help. Finally, caregivers on each panel discussed how hard it was to finally take the car keys away



from their loved one and highlighted programs like AARP's safe driver class as a buffer that helped the person understand it was time to stop driving. However, they also expressed frustration at the lack of available transportation after the person could no longer drive.

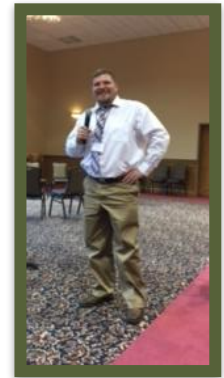
The panelists gave examples of the ways in which the current system does not give caregivers the support they need and cited several recommendations for changes that would ease the challenges of caregiving. Recommendations spanned the gamut from educating the public about dementia, to workforce policies that support caregivers, to increasing the availability of respite and in-home care. The panels recommended:



- Public education about dementia and how to appropriately interact with a person with dementia when they shop, run errands, or join in social or recreational opportunities.
- Flexible workplace policies that support caregivers would allow people to continue working without needing to face the decision to retire early or find a residential placement for their loved one.
- Expansion of respite services to allow more caregivers to find needed services.
- Increase in the number of in-home caregivers trained to meet the needs of people with dementia.
- Insurance coverage for in-home care supports.
- Early and honest diagnosis of dementia and clear and continued support as the symptoms progress.
- Help with getting their partners to stop driving and help with transportation.
- More easily accessible information about resources and services available to support caregivers.

## 2. Supporting Caregivers

Caring for a loved one or family member can be emotionally, physically, and financially demanding. One of the most common themes that emerged is that, although there are some great resources to help caregivers, the people that need them most don't know about them or don't know where to find them. The first step is effectively getting information about existing resources to the people who need them. The second is to find ways to encourage caregivers to use existing services. The final step is to expand resources to cover more people.



Many people don't actively look for resources until they are in crisis. Even when a needed resource is identified, it may not be possible to use it due to cost, lack of respite care, or lack of transportation. Isolation, resistance to asking for help, and hesitance to participate in something new (e.g. support groups) were also noted as barriers to caregivers accessing services and supports.

One way that community organizations can help caregivers identify needed resources is to make them easy to find. Employers, HR directors, libraries, churches, hair salons, town or city offices, and law enforcement are trusted sources that can provide basic information about resources. For example, a library can have a resource carousel. An HR or church newsletter can include the number for the Aging and Disability Resource Council or ServiceLink. Age friendly community groups can tap into a bigger variety of media channels (social media, public access television or radio, electronic, print, and word of mouth) to can help get the word out about programs and resources.

Participants wanted resources to not be restricted to support groups, but instead be available where people are. Caregivers need to feel supported in their relational networks and towns, not just from professionals or structured support groups. Participants identified neighbors as a tremendous help and encouraged the idea of facilitating community conversations that focus on the challenges of caregiving and the way neighbors can help.

There are many great things happening across our region to support caregivers that can be expanded upon and/or replicated. Programs that provide needed services such as respite care, training, peer support, and social engagement are shared throughout this report.

One bright new idea was First Contacts, an initiative being developed in Maine. The program will train "first contacts" (grocery store clerks, town officials, oil delivery workers, salon professionals, etc.) to identify warning signs that indicate when an older adult may need help and will give "first contacts" resources to direct people to the right resources.

Driving re-evaluation resources are also helpful for caregivers. With loss of a driver's license comes a loss of freedom and independence. By using this resource, a caregiver doesn't have to carry the burden of forcing the care recipient to stop driving. As a caregiver stated on the morning panel, it was a huge relief when someone else took her husband's license away. Her husband was angry at the "system" for taking his license instead of being angry with her.

New Hampshire's [ServiceLink Aging and Disability Resource Center](#) was also noted as a great existing resource, and one that could benefit from additional staff and funding. This NH Department of Health and Human Services Program connects individuals with services and supports, such as the [Family Caregiver Support Program](#). Various services are available to caregivers, including respite – a frequently noted unmet need. Local [Alzheimer's Association Chapters](#), [Veteran Affairs Offices](#), the [Aging Resource Center at Dartmouth](#), [Maine's Aging and Disability Resource Center](#), Area Agencies on Aging and the [Maine Council on Aging](#) were noted as helpful sources of information and guidance. The TSLCA has compiled a comprehensive list of aging resources available in Maine, New Hampshire, and Vermont. Please visit [www.agefriendly.community](http://www.agefriendly.community) for more information.

Support groups, particularly those that connect people with similarities, and those that provide a respite component, are working well. Having an on-site respite care option provides caregivers with peace of mind, allowing them to actively participate in the support group while knowing that their partner is nearby and safe. Programs that caregivers can participate in with their caregiver, such as Memory Cafés, Music in Memory programs, or support groups for couples, are well received and build normalcy for the couple.

Other ideas on how to improve supports for family caregivers included:

- Look at ways to expand existing friendly visitor or senior companion programs to serve more people and ensure those efforts do not discourage any potential volunteers or recipients.
- Explore the application and usefulness of time banking as a way to give and receive help.
- Explore how technology can be used to better support caregivers (e.g. technology that can allow caregivers to easily monitor the well-being of care recipients, support groups that are hosted online via Zoom, etc.). High schools and colleges are some great places where volunteers for tech coaching could be recruited.
- Allow people to sign up for services in advance – before they're needed – so that if and when they do need them they'll be able to receive immediate help versus being on a long wait list.
- Sponsor learning and networking events for caregivers that offer respite stipends.

Participants identified the need for more low-cost community-based programming that aids caregivers and their care recipients, such as respite and transportation programs. For more information on what's working in our region and how communities can implement these types of programs, please see section 5 of this report, [Creating Community Volunteer Programs](#). Many conversations on supporting caregivers also brought up challenges, successes, and ways to improve working with health care providers (see section 7, [Navigating the Health Care System](#)). Lastly, supporting caregivers includes encouraging them to take time and care for themselves. Please see section 9, [Care for the Caregiver](#), for information on existing tools and ideas that help caregivers recharge and stay sane and safe through their caregiving journey.

### 3. Building Dementia-Friendly Communities

There aren't enough opportunities for people with dementia and their caregivers to fully engage in ordinary life and participate in community settings. Doing everyday "normal" things, such as grocery shopping or stopping at the bank, can be a challenge. This makes even the simplest chore daunting and leads to significant isolation.

A lack of understanding and knowledge about dementia among friends, family, local businesses, employers, and community members makes it extra challenging. Building dementia-friendly communities may seem like a big concept, but there's great news: we don't need to reinvent the wheel! There are some incredibly effective tools already created and tested by other platforms that we can borrow for our own applications.

[Dementia Friendly America](#) and [ACT on Alzheimer's](#) out of Minnesota have developed comprehensive, user-friendly, and publically available tools to engage every member of a community in becoming dementia-friendly step-by-step (e.g. how to talk with your minister about making your church dementia-friendly). The Tri-State Learning Collaborative on Aging hosted a webinar with them to highlight their work. The recording of this webinar and details on online resources for dementia-friendly community development are [available on the TSLCA website](#).

Practical and logistical changes in community settings and increased education/training around dementia are needed. The [age-friendly community initiatives across our region](#) are well-suited to integrate some of these dementia-friendly tools and add a dementia lens. Innovative ideas on what else we can add to dementia-friendly communities include:



- Establish a driving service modeled after Uber but specifically for people with extra needs. This driving model provides easily accessible and affordable transportation. Or, can we collaborate with Uber to train drivers who would like to learn more about memory disorders so they can safely transport those with dementia and Alzheimer's?
- Normalize and expand conversations about dementia. One suggestion is to create a toolkit for house parties. Talking amongst friends is a great and safe place to start having these conversations. What's it like for people with dementia? What if we get dementia... or what if our parents do? Another way to promote discussion is by hosting community conversations, potentially with resource specialists who can inform first contacts (such as first responders, town office staff, etc.), caregivers, and dementia specialists to explore the question: What do we want our communities to be like for people with dementia and their caregivers? Workplace lunch-and-learns also provide an opportunity to normalize discussions on dementia and share resources among colleagues. These kinds of conversations will help reduce the stigma associated with dementia.

- Bumper stickers or business cards can be an easy, low-cost way to help caregivers in community settings. Handing out a card with a message such as, “The person that I’m with has dementia. Please be patient. Thank you.” can make a big difference on the type of experience a caregiver has when she or he is out in the community. We need to be thinking of ways to create simple tools like this for caregivers to use as they’re navigating all systems.
- Use a “neighborhood watch” for people with dementia. With training, volunteers can know which of their community members have dementia, and how to appropriately help them if they wander or get confused.
- [Front-porch Forum](#), a no-cost online forum helping neighbors connect in Vermont can be tapped to start community conversations on dementia, raise awareness, or create informal local support networks. It’s also a place community members can turn to for help, advice, and neighborhood concerns.
- Businesses and public areas should have at least one large unisex bathroom where different-gendered care providers and recipients can take care of needs with sufficient room and privacy.
- Businesses can offer special hours of operation for people with dementia and their caregiver or provide in-business volunteer respite for shoppers.
- Restaurants can provide large print, limited-item menus along with special training for wait-staff on how to engage people with dementia.

While not specifically for caregivers, many concerns were raised about financial exploitation of community-dwelling people living with cognition issues. Two specific efforts in Maine were lauded by all participants – a volunteer financial management assistance program called [Money Minders](#) and a financial institution program aimed at preventing financial exploitation called [SeniorSafe](#), which provides training to bank and credit union staff.



## 4. Dementia and Alzheimer's Caregiving

There are a lot of misconceptions and stigma associated with dementia and Alzheimer's. Those caring for people with dementia or Alzheimer's face many of the challenges we've already highlighted: lack of awareness about available services, affordability and accessibility of services, lack of workplace support, lack of available respite and adult day services, etc. However, they're also faced with the additional challenge of handling the emotional and behavioral changes associated with Alzheimer's and dementia, and often don't know about the tools that are available to help them. Caregivers talked about finding it especially hard to cope with isolation and to balance care for themselves with care for their partners.

How can we better support dementia and Alzheimer's caregivers? Education is a starting point. A frequently noted bright spot, the [Savvy Caregiver](#) training helps create more successful caregiving experiences for participants. Family members caring for a person with Alzheimer's or dementia can take advantage of this free training to gain knowledge and tools that will help them better manage the many demands and stresses of caregiving. This national training program is delivered year-round throughout the region and can be offered anywhere. The TSLCA can help get the word out to aging in place and age friendly community leaders that this training is available.

Creative engagement programs for people with memory disorders and their caregivers, such as those provided through the [Aging Resource Center at Dartmouth](#), are working well and can also be easily replicated. These intergenerational programs are great examples of how effectively engaging people with dementia and their caregivers can be a fun, rewarding community effort. Recollections, a singing group for Dartmouth college students and people with memory disorders, their family members, and their caregivers, meets regularly and holds public performances. Perspectives, a monthly art viewing program is also for people with dementia and their caregivers. See the [TSLCA webinar on Creative Aging](#), and section 8 of this report, [Creative Caregiving](#), for more information on programs like these.

Through engaging in training or creative caregiving programs such as those mentioned above, caregivers build organic support networks. Peer-to-peer support is a powerful tool. Implementing more support groups for those with dementia and their caregivers that are specific to the different stages (i.e. early stage on-set) would be helpful. Gender-specific support groups was also mentioned as an idea to better support male caregivers and encourage their participation in support groups.

Reducing stigma and increasing education and awareness across the board is important. These caregivers need to be better supported by their physicians, service providers, family members, and even their neighbors. Some specifically emphasized needs and ideas include:

- For physicians, identifying and naming an early and accurate diagnosis is critical.
- Improve care coordination and information sharing among all team members while observing HIPPA compliance – a dementia diagnosis should be met with the same care coordination as a breast cancer diagnosis.

- Increase and advance education around dementia. Specifically, it would be great to have more education and training about what is literally happening in the brain of someone experiencing dementia.
- Increase education on how to identify signs as early as possible.
- Implement better policies and training for memory care unit staff.
- Increase dementia-friendly community efforts.
- Expand evidence-based caregiver training.
- Create programs aimed at youth, as early as middle school, that share information on Alzheimer's and dementia.
- Create a public media campaign that encourages families to talk about dementia and Alzheimer's and connects them to tools that can help start and guide that conversation.

The Alzheimer's Association serves as a tremendous source of information for people with dementia and Alzheimer's, and for their caregivers. Their online [Caregiver Center](#), training programs, and guides (i.e. [Talking with Kids and Teens](#)) are comprehensive and user-friendly. They also have a [24/7 hotline](#) with knowledgeable staff ready to help.

For people with dementia and Alzheimer's, advance care directives are incredibly important. See section 11, [Advance Care Planning](#), for more information. For their caregivers, the need for self-care can't be emphasized enough. As one participant said, "The single best thing you can do for a person with dementia is to care for the primary caregiver. That's not happening, and the primary caregiver is not asking." See section 9, [Care for the Caregiver](#), for more.

## 5. Creating Community Volunteer Programs

Caregivers are better supported when services are locally available and when the services protect their privacy and honor their desire for independence. In Northern New England, this is possible because we have a long tradition of neighbors helping neighbors. However, informal helping can feel awkward because people often don't want to "interfere" or don't know how to help. Community initiated volunteer programs can be the most effective way to help people get and give needed help.

Services such as support and affinity groups, friendly visitor programs, adult day and respite care are all working well. However, access can be a problem. Some programs are fee-for-service or are only provided to people via public benefits. If caregivers can't afford the service, or don't qualify for the benefit, they may not be able to use the service. Another barrier is our geography. Northern New England is vast and rural. Many caregivers have to travel 30+ minutes to get to a service. Lack of transportation for the person receiving care, particularly if adult day is in one direction and work is in another, can make the program more of a problem than a solution. These conversations explored what it would take to implement solutions at the community level with volunteer support.

Building a volunteer program is not an easy task. Before building any community volunteer program, it is important to know what is needed and who would use the program (see the [TSLCA webinars on assessing individual and community needs](#)). Once there is a clear understanding of need, it's easy to learn from other programs already operating across our region. To learn more about running a volunteer program, see the TSLCA webinars, [So You Want to Run a Volunteer Program](#) and the [Care and Feeding of Volunteers](#).

Recruiting, retaining, vetting, training, and organizing volunteers were all noted as challenges to creating community volunteer programs. More thoughts and ideas on how to overcome some of these challenges are included below:

### **Recruiting & Retaining Volunteers**

- Have a clear description of need and what you want the volunteers to do.
- Have a clear communication and outreach strategy using a combination of electronic sources (i.e. websites and social media), print sources (newspapers and flyers), and word-of-mouth. Tap local schools, churches, civic groups, libraries, etc. to recruit potential volunteers.
- Partner and collaborate with other organizations that are working on the same issues.
- Recognize and sincerely appreciate volunteers often.
- Explore ways to offer internships to university students and to capitalize on service requirements of local high school students.

## Vetting Volunteers

- It's always a good idea to vet volunteers and run background checks. Partner with another organization, such as the local police or recreation department, to vet volunteers.
- Explore different ways to offset the cost of running background checks or to raise some funds to support your effort (see the [TSLCA](#) fundraising webinar series designed for community leaders engaged in aging in place initiatives for some great ideas).
- Discuss the level of background check needed (i.e. criminal background, DMV, etc.).

## Training & Organizing Volunteers

- Providing comprehensive volunteer training protects everybody involved, but the time and resources needed for that can be a challenge.
- Consider the scope of training and the amount of time required for volunteers to be effective, and how that may impact recruitment and retention.
- Train the trainer approaches can be effective.
- Start by assigning volunteers with small, discrete tasks that you can build on.
- Find the right fit for volunteers and match their tasks with their capabilities.
- To more easily manage volunteers, form teams with a rotated team leader.
- Explore web-based services to help manage your effort like [volunteermaine.org](http://volunteermaine.org), [lotsahelpinghands.com](http://lotsahelpinghands.com), [idealist.org](http://idealist.org), or [Google Groups](#).

Creating intergenerational volunteer programs was an oft-repeated theme. It's a great way to bring the entire community together. Hosting a town-wide day of service was a repeatedly mentioned idea. This model brings a pool of volunteers together on a regular basis to address the physical needs of older and disabled neighbors, such as home maintenance, lawn care, etc.

Caregivers underscored the great need for volunteer transportation networks and volunteer respite. Affordable and reliable transportation for older adults, caregivers, and volunteers is desperately needed. Volunteer transportation programs could serve other volunteer efforts within the community (i.e. volunteer drivers transporting friendly visitors). Groups like [Friends in Action](#) (ME) and [Volunteers in Action](#) (VT/NH) have established volunteer transportation models from which we can learn. The [TSLCA](#) has highlighted these models in the [Transportation Networks webinar](#).

Volunteer respite programs are also possible. The Helping Elders Live in Place (HELP) program, an aging in place initiative in Rangeley, ME, utilizes volunteers to help provide caregivers in the community four hours of respite on a weekly basis via their [Adult Respite Care Program](#). The [Legacy Corps](#) program through Spectrum Generations provides up to 10 hours a week of respite care to veterans and military families in Maine. Many organizations and age-friendly community groups are managing volunteers for a number of different services. Through engagement of these groups, we can identify ways to meet the needs of care givers and their care recipients through localized volunteer efforts.

## 6. Advancing New Caregiver Policies

Family members, neighbors, and service providers all do their part to take care of people who need help because of illness or disability. We need strong federal, state, and local government leadership to address some of the structural and financial challenges that make it difficult to provide care. Many good policies have been enacted in northern New England but have not been shared across borders. How can we better facilitate cross-border sharing and collaboration?

Policies that benefit caregivers include the CARE (Caregiver Advise, Record, Enable) Act. Maine and New Hampshire have passed this legislation that allows a patient to designate a caregiver to be engaged in all health care decisions and transitions when entering a medical facility. (See the [Maine Care Act](#), [CARE Act Wallet Cards and advocacy efforts from AARP Maine](#), and the [New Hampshire Care Act](#) legislation). Advocates in both Vermont and Maine have focused attention on paid family medical leave (FMLA) programs that would provide paid leave for working caregivers of older adults. Maine is also working to expand a caregiver tax credit that would reimburse caregivers for expenditures they make for respite, home care, and assistive technology.

All three states are experiencing significant shortages of direct care workers. Paid direct care workers are low-wage earners doing hard work, often on a per diem basis and without benefits such as health insurance and paid time off. It was recommended that the TSLCA could bring paid direct care workers from all three states together to share information, learn from one another, and educate our combined Congressional delegations in the importance of addressing federal issues, like creating tuition reimbursement and loan forgiveness for students who work as paid caregivers.



Creating tax incentives for businesses, such as deductions for employers who offer flexible work schedules or adult day care, will help encourage workplaces to provide the flexibility needed for caregivers to remain in the workforce. Many people leave the workforce to provide care for a loved one without understanding the financial ramifications on their retirement funds. Employers could be encouraged to help family care providers better understand the long-term

financial impact of leaving work early on their social security and other benefits.

Advocates need to educate Congressional delegation about the need to take action to protect the financial well-being of caregivers when they have to leave work to care for a loved one. Paid family medical leave often isn't long enough to cover the amount of time a person needs to be separated from work to provide care.

Additional bright ideas and outside-of-the-box thinking on how to advance caregiver policies include:

- Create a mobile application for accessing respite and home care, much like what Uber does for transportation. [Uber](#) is an app that quickly connects people who need a ride to an Uber



driver. Volunteers often have an hour or two to offer but cannot commit to long-term volunteer work. That short period of time could allow a caregiver to go to the grocery store, run errands, etc. This would require some simple certification, training, and background checking for volunteers, but is an exciting new concept to explore.

- To increase adult day services, particularly in rural areas, consider targeting universities, hospitals and large businesses that already have child care centers/programs and provide financial incentives for them to create adult day programs.
- Identify and address any penalties related to Medicaid benefits when a person moves from an independent living situation to living with their caregiver. If a caregiver's income is now considered for eligibility, the person receiving care may lose a critical benefit without any consideration for the financial burden a care provider experiences .
- Create better policies to address medication access and management – for instance, Maine has a prescription drug management program that could be used to monitor the drug interactions of multiple drugs prescribed to older adults – particularly for those who cannot say what impact a new drug may be having on them.
- Implement more training for code enforcement officers and HR directors.

Policy is complex and multi-layered. To effectively advance efforts we need to overcome some challenges. Sometimes a good policy falls flat when there's nobody to champion it or there aren't dedicated resources to ensuring it gets passed and implemented. Negative perceptions on raising taxes, assumed fraud, and an opposition to partners or coalition members that worked on a bill are other reasons behind why policies may be blocked or delayed. When policies are enacted, we're then faced with the challenge of moving them into effective practice. Implementation requires intentional time, training, and capacity. Some great tips on how to effectively create, advance, and advocate for policy changes were shared:

- Take a model policy and localize it.
- When developing policies, identify legislators and decision makers who have caregiving experience to help champion the effort.
- Name policies strategically – i.e. neighbors helping neighbors.
- Actively engage caregivers in policy and documentation. This type of advocacy is new and requires champions both in and outside of government. People have been advocating for their children for a long time, but advocating for aging parents and older adults is relatively new for our culture. We need not only shifts in laws, but a shift in the way we talk about aging.
- Pictures, videos, and personal conversations can go a long way in gaining support. View the TSLCA webinar, [No Fear Advocacy](#), to find out what it takes to be an effective advocate and why your voice matters.
- Convene a Tri-State Legislative Conversation on Aging to allow law makers to share information.

## 7. Navigating the Health Care System

What rights do we have as a caregiver? How can we fully engage in care planning? What can health care providers do to fully integrate caregivers into the care team?

It is challenging to navigate the health care system—hospitals, rehabilitation, primary doctors, and specialists -- for someone else while trying to work and care for children and balancing the caregiver's own chronic conditions. Hearing impairment and language barriers can exacerbate these challenges.

One oft-repeated theme was the inconsistent way caregivers are treated within health care. Some are recognized as a part of the care team while others are ignored and feel invisible and helpless. While some patient-centered primary care practices provide care coordination and management, this is not always the case. Caregivers are left to coordinate non-medical services between multiple providers.

Many caregivers have a hard time finding transportation to medical appointments for their loved one. When a ride is not available, caregivers have to take time off work to provide transportation themselves. The good news is that volunteer transportation networks can help. However, they aren't always designed to meet the needs of caregivers. For instance, some only provide rides to and from medical appointments and will not take someone on errands or to a support group. Others are available for any kind of ride, but cannot provide daily trips because it's too hard to find volunteers who can make that commitment. One bright spot is that a transportation funding bill in Maine contains considerable funding to build out these volunteer transportation networks.

Another bright spot highlighted was the community nursing pilots in eastern Vermont and western New Hampshire. These nurses do not provide direct care, but instead act as a bridge between medical care systems and community care. Another bright spot is Maine's pilot to pair Aging and Disability Resource Specialists from the Area Agencies on Aging with frail elders who are at risk of health crisis. These specialists do an in-home assessment and work collaboratively with health care professionals to design a plan of care that addresses challenges like transportation, personal care, and food. Others mentioned community care coordinators operating out of senior centers. Putting professionals in the home who can help in these ways is showing significant promise.

There is a general lack of geriatric expertise in primary care practices and limited knowledge and information about dementia diagnosis and treatment protocols. Caregivers told stories of working for years to get a diagnosis of dementia, even when it was absolutely clear that this was the issue.

While primary care concerns were raised, participants were most concerned with hospital care where patients and their caregivers were generally not known by the health care professionals. Discharges can occur quickly without enough notice, making the transition to home more difficult for the caregiver. Many caregivers said they had difficulty understanding discharge plans, medical recommendations, and with completing appropriate documents. Caregivers expressed frustration with the lack of information they were provided about community support services and, in the worst cases, with inappropriate or premature discharge from the hospital. For instance, a discharge might

occur when home care services are needed, but haven't yet been secured, and the caregiver is unable to meet the needs of the patient. Or, alternatively, the patient may have a significant mental health challenge or be exhibiting difficult behaviors associated with dementia that the caregiver is not equipped to handle, but there is no rehabilitation facility that would accept the patient. One bright spot was the Long Term Care Ombudsman Program, which can assist with these transitions.

One hospital bright spot was the [Mt. Ascutney Hospital Community Health Team](#) which supports patients and families through education and skill building to deal with chronic illness, apply for insurance, manage medications, address ongoing transportation problems, arrange home visits, coordinate community services, trouble-shoot getting to appointments, and prevent readmission to the emergency department of inpatient units.

Another positive force for change that is bridging hospital, primary care, and community care is the [Thriving in Place](#) (TiP) grant project funded by the Maine Health Access Foundation. The TiP grants provide funding to bring health care, social and community services, and volunteer networks together to coordinate, streamline, and improve the efficiency and effectiveness of their work in the community. The TiP project is working to reduce admissions and readmissions.

Finally, another identified place for growth and change was for caregivers to become actively involved in hospital-based patient and family advisory councils and advocacy programs. Only if caregivers are honest about their health care experiences, can councils guide changes in how these institutions support older adults. We need more caregiver/advocates to join these groups.

Recommendations from these conversations included:

- Create state and regional commissions to study and make recommendations on how to build a clear, safe, and supported path from hospital to community that address the challenges raised above.
- Build strong community-based volunteer health-care navigation services that can be deployed to both primary care and hospital settings to assist with Medicaid/Medicare counseling, prescription drug confusion, community services, etc.
- Support, fund, and grow volunteer transportation networks that are integrated into other public transit options to build a strong network able to meet the transportation needs of older adults and their caregivers.
- Host community lunches with pharmacists, physicians, and nurses that create a safe and easy space where caregivers can ask questions outside of the practice setting.
- Measure outcomes of community nursing projects and pursue funding based on cost savings.
- Educate age friendly community initiatives about these challenges and have them invite health care providers to talk with them about the community's needs.

## 8. Creative Caregiving

Emerging research shows a strong link between the arts and physical and mental well-being. Conversation participants noted that creative expression is good for the soul, offers hope, and allows people with dementia to connect with their life history and values by communicating them to formal and informal caregivers when other avenues may no longer be available. For people with dementia, the type of arts programming that works best changes with the advance of the disease, but research shows that even in the late stages of a disease, music lights neural pathways and can help people relax. Table participants emphasized that arts programming is not a “bit of fluff” but is essential. To learn more about programs available in northern New England, download the TSLCA webinar on [Creative Aging](#).

Creative caregiving programs are available throughout northern New England but several barriers to participation were identified during the conversations. Family caregivers, especially those who are older, may be intimidated by the “arts,” may see them as an unnecessary “extra” rather than something important for health and well-being, or do not know how to locate a program or how to find the time to involve their loved one in an existing program. Community based organizations face the difficulty of finding qualified artists who understand how to work with people who have dementia and/or caregivers as well as the challenges of finding funding to cover programming costs.

One of the spouses who shared her story in a morning caregiver panel talked about the vital role the [Perspectives](#) program at Dartmouth College plays in their lives. She and her husband were both art majors. The Perspectives program provides an opportunity for Dartmouth students to display their artwork for caregivers and those living with dementia to comment on the work. The program allows her husband to share his expertise and to feel productive.

During table conversations, participants talked about the importance of engaging in meaningful activities—singing, writing, poetry, storytelling, dance, painting, sculpting, etc.—that allow a person to draw on skills or memories from the past to communicate with others or to help cope with current challenges. Participants talked about a number of programs—recreation and art therapy, day care services, and information on the [National Center for Creative Caregiving](#) site—that are working well to increase access to the arts.



To encourage the development of arts programming to meet the needs of informal caregivers and their loved ones, participants in the conversations made the following

recommendations:

- Educate the public, community based organizations, and medical providers about the importance of creating arts programming for people with dementia and their caregivers.

- Provide opportunities for people to participate in the arts at community centers, museums, and libraries -- not just at senior centers, which may carry stigma, especially for people with early-onset dementia.
- Working with higher education/researchers to document the benefits of participating in the arts.
- Provide opportunities for caregivers to take part in creative art programming while the person they are caring for participates in another type of program. Arts are potentially a good respite opportunity for caregivers, but not if they have to provide care while doing the art.
- Disseminate information about the [Maine Arts Commission Creative Aging](#) that trains artists to work with older adults and people who have dementia, as well as offering small grants to communities that want to offer local creative programming.
- Identifying funding and other partnerships—connecting with arts commissions and other resources-- to offer creative opportunities for the aging.
- Encourage aging in place community efforts to reach out to the artists in their community to start a conversation about the benefits of creative caregiving projects and encourage them to take action in designing local opportunities.
- Find and disseminate tools that capture a person’s story early in their experience of dementia in order to help formal caregivers and family members know the person, rather than just the dementia.

While not specifically in the category of creative caregiving, during these conversations, another creative engagement tool was highlighted - [COVE’s Savvy Seniors](#) in Vermont, a group of volunteers that put on theatrical performances that predominantly address safety issues like medication management, Medicare fraud, and financial exploitation. Theater is an excellent medium for engaging the broader community in thoughtful creative discourse. This medium could certainly be used to address issues of caregiving.



## 9. Care for the Caregiver

Caregivers acknowledge that self-care is critically important. However, finding time, knowing what will be the most helpful, and finding the desired program can be challenging. Social attitudes that discourage self-care are also barriers to seeking and participating in self-care opportunities.

Caregiving is applauded and considered socially acceptable, but taking time away from caregiving responsibilities is seen as “selfish.” Guilt often prevents people from seeking self-care. Health care professionals focus on treatment of the person receiving care, while often neglecting to check in with the caregiver to see how they are coping. We heard many stories of caregivers who put off their own needed medical treatment, and never even considered doing anything to help themselves cope with the challenging job of caregiver.

The caregivers uniformly agreed that support groups and the Savvy Caregiver classes were a very important means for identifying effective ways to cope with the demands of caregiving. However, in some areas, it is difficult to find a class or a support group that meets at a time when the caregiver is free to attend. A spousal caregiver on one of the morning panels who was still working shared her search for a support group. A friend had advised that, if she did nothing else, she needed to find a support group because they were the “bee’s knees.” She was skeptical but decided it was worth a try. However, the only local support group was scheduled for midday. To find a support group that worked with her schedule, she had to travel to a nearby community. All caregivers were in agreement that, even when a support group or other self-care opportunity is available, it can be hard to carve out time for self-care.

Caregivers also shared the importance of support from friends to get needed self-care. For example, one caregiver during the morning panels shared that she valued her husband’s friends who took him for walks once or twice a week. Prior to his Alzheimer’s diagnosis, her husband relished long strenuous hikes. Although those are no longer possible, he can still enjoy a walk with friends and she can get some much-needed time to herself.

Participants in the conversations made the following recommendations to make it easier for caregivers to seek and access needed support:

- Use technology to better engage folks in self-care.
- Educate health care professionals to see caregiving like a “chronic condition” – to ask questions about caregiving (if not known), to inquire about the health of the caregiver, even if the appointment is for the person receiving care, and to know how to make referrals to appropriate self-care options available for caregivers. Include social work as part of the medical care team to make sure that caregivers and the person who needs care are connected with needed services.
- Better advertise for the Savvy Caregiver training and other programs that provide help for caregivers.

- Encourage caregivers to find support and to prioritize self-care soon after taking on the role – put your oxygen mask on first!
- Make dementia coaching a billable service. RNs working through VNA provide individualized dementia and Alzheimer’s Coaching. If such services were billable, more home care services may be willing to offer the service.
- Create local opportunities for caregiver self-care (e.g. churches, libraries, community centers) that include respite components, making it more likely that the caregiver can participate.
- Increasing awareness of caregiver respite options.

## 10. Veteran Caregiving

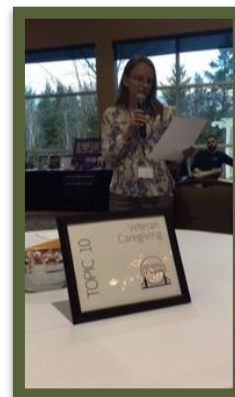
Veterans from WWII, the Korean War, and the Vietnam War are aging, which may be accompanied by physical and psychological changes that require a family member/informal caregiver to meet the special care needs of a veteran. The VA's mission is to provide the best healthcare possible to veterans, but supportive services are provided to caregivers only when those services are directly related to the veteran's healthcare needs. Available services include education, training, and respite opportunities. However, the VHA cannot provide mental health services solely to caregivers separate from the vet's treatment plan.

Because the VA recognizes that caregivers play a vital role in the successful health outcomes of veterans, it has offered a comprehensive national caregiver support program for the past decade that provides points of contact in all VA medical centers to connect caregivers with available services. Currently, the VA has focused on eight major areas of caregiver support: respite care, education and training, VA supportive services, community resources, caregiver wellness, emotional and spiritual health, emergency preparedness, and home safety.

Participants agreed that it could be difficult to know which services were available and to connected with needed VA services. A further complication was that state VA services frequently don't work together for the benefit of the veteran who needs care or their informal caregiver. However, when the right connection had been made, the services for caregivers and for people with care needs can be superior to offerings in the civilian medical system.

One program that was cited as working well to provide respite for caregivers of qualifying veterans was the Vet-to-Vet program in Maine. Having someone to talk with who shares a similar experience is valuable to the veterans who receive the service and for their caregivers. Another idea cited as working well was medical foster homes that allow a veteran to live in the community with paid support from the person who provides the medical foster home. Participants agreed that the CHOICE Program, which gives veterans in need of nursing home level care the ability to hire the person of choice for in-home caregiving was an important benefit that could work well, if it was widely available. (The program is currently limited to 100 people and there is a long waiting list.)

The biggest challenge to gaining access to services through the VHA is awareness of eligibility. Many family members and people who served a short time have no idea that they are eligible. One suggestion from the cross-border conversation was to increase marketing of their programs and of eligibility by providing information to the civilian medical system, community-based organizations providing services to caregivers and/or to people with care needs, and to increase awareness for the public. The table participants also suggested that the VHA should have an easily accessible, one-stop source (preferably a helpline, a "no wrong door" system) for information about eligibility for services.



When services are identified, working between civilian and military services can be challenging, as can be working with more than one state VA system. This is particularly true of challenging care situations. One example of a challenging care situation discussed was undiagnosed PTSD and other mental health or personality characteristics that manifest when a person has dementia. Civilian long-term care facilities are ill-equipped to meet the special needs of veterans, and long-term care through the VA is not always available or, when available, is not always close-by or convenient. Similar observations were made about in-home care.

Participants in the conversations made the following recommendations to make it easier for veterans and their eligible dependents to seek and access services through the VHA:

- Create a volunteer vet-to-vet type program to provide regular phone-based support to veterans who are caregivers.
- Train community and medical-system based social workers to ask the question “Have you ever served in the military?”
- Include someone with expertise in veteran services in the ADRCs.
- Warm hand-off between civilian medical care system and VHA.
- Expand CHOICE program to hire and pay the caregiver of choice, including family, friends, and other existing unpaid caregivers.
- Create vet-to vet creative arts programs to support physical and mental well-being of vets and their caregivers.
- Investigate ways to use technology to improve in-home care of vets with service needs.
- Expand Spectrum Generation’s Legacy Corp and SMAA’s Vet-to-Vet program to include other areas in northern New England.

## 11. Advance Care Planning

Too often, fear of disability and death keeps us from planning for how we want our health to be managed if we're unable to make our own health care decisions. Too often, we put off these hard conversations until there's a crisis that forces us to start planning. In the face of declining health or mental acuity, we know that it's time to make sure everyone knows what our wishes are and how we want them carried out, and yet still we sometimes fail to act. This session explored the legal tools needed to make sure the caregiver could support the health and wishes of the person receiving care, as well as the barriers to using such tools.

Participants agreed that it's time to normalize the conversation about advance care planning and to decouple it from end of life planning. Conversations about advanced care planning need to focus on what it means for the person to live well and how they would want care if they can't ask for it. The conversations need to be less about legalities and more than simply filling in blanks on a form.

It's often uncomfortable for older parents and adult children to talk about advance care planning, particularly if the subject comes up after a diagnosis of dementia or another terminal disease. These challenges are magnified when adult children are spread out across the country and have different values and views about life-sustaining treatments. That's why participants thought it was critical to avoid crisis planning around difficult news and, instead, start these conversations early – particularly in high school – and to have them often, so the conversations can evolve as we age. It's also important to have these conversations with neutral people first. Participants thought it would be beneficial to design peer-to-peer discussion tools that young folks could use with their friends or work colleagues. Lunch-and-learns at work are another opportunity to have a conversation outside of a charged or challenging situation.

A lot of the discussion revolved around a general lack of understanding of the benefit of advance care directives. Many people have questions while completing the form, but do not know who they can ask for help. If people have one, they don't always talk to their designated agent about their wishes. They don't share completed forms with their primary care provider, and if they do, the primary care provider doesn't have an electronic means to share with a local hospital. If all the pieces are in place, and the years march by, they might never update the form even though their wishes have changed or their designated agent has died. There is a general distrust that the document will work when it's time to use it.

Participants highlighted several examples of what is working across the region during the discussions. Vermont maintains an [Advance Directive Registry](#) that offers a simple form that can be completed online and immediately uploaded into the registry and printed. Folks in ME and NH used the documentary [Nine to Ninety](#) to start community conversations about advance directives. These events were well attended and hosts found that a facilitated conversation after the film was a great way to start the conversation. NH uses its Medicaid application process to ask applicants if they have an advance directive and, if not, if they want to complete one. Some participants described the ways in which colleges and long-term care facilities are requiring advance directives as

part of the admissions process. Others talked about hospital-based educational programs and death cafes where conversations were supported by professionals.

Across all three states, the message was clear: we need more professionals and volunteers who can start and lead the conversation about advance care planning. We need to normalize the idea that we all need to have an advance care directive. Some ideas for accomplishing this include:

- Consider coupling completion of advance care directives with other state-based electronic applications – for instance, online driver’s license application or automobile registration (like for organ donation), state income tax, etc. Do you have an advance directive?
- Saturate the system. In communities, there could be facilitators like ministers, town clerks, librarians, merchants, real estate agents, home health, and HR directors who could display a decal so you know you are safe to go there for help w/ this conversation.
- Get creative. Talk about the care we would/would not give to our pets as a way to start the conversation about ourselves.
- Integrate advance care planning activities with aging in place initiatives via community conversations and volunteer efforts which are run in partnership with local hospitals.
- Create one form and national registry that can be accessed by all health care providers 24/7/365 and that prompts regular updating of the form. Once established, create a simple application that can be used on any device.
- Make the review of your advance directive a regular part of your annual wellness visit with your primary care provider.
- Capture and use actual experiences and real outcomes to start the conversations.



## 12. Death and Dying

Dying is a part of what it means to be human, but it's one of the most difficult subjects to discuss. These conversations focused on how we can create a cultural shift around death and the dying process.

Participants agreed that hospice is a critical support that works well to help meet people's goals around living and dying, but that too many people didn't use hospice because of the drive for a cure, the stigma around "giving up," and the pain associated with giving into grief and loss before a person passes. People agreed that shifting these concerns will involve culture change and can only occur through thoughtful and consistent conversation and messaging. Participants also agreed that the process of illness before death without significant planning means that people aren't able to die at home as they wish. Facilitating the culture shift means that eventually people will be able to age and die the way they want, but this change will take time and we all need to be involved.

Part of this cultural shift needs to come from the medical profession. From undergraduate programs through medical school, there needs to be equal emphasis on the life goals of the patient as there is on treatment and cure. How do we want to live as we're facing death? What is important to us – being at home or having every heroic measure? We need medical professionals to give us options, not just about cure, but about comfort if cure won't work. We need medical leaders to help us understand the difference between palliative care and hospice, and how they can work together or be deployed separately. We need early referral to hospice, even if medical treatment might still prolong death. And we need to understand the pressures that our medical providers are under and be responsible for our own care by asking these questions as informed health care consumers.



Within the context of conversations about death, it's critical to pay attention to cultural diversity across the board and to recognize that there is no one right way to die. We need to consider and respect ethnic differences, gender issues, economic pressures, and religious beliefs, and, most importantly, need to not superimpose our own moral views on those of others.

- Find a way to normalize conversations about end of life. One way to do this is to identify local speakers who are willing to present and facilitate community conversations. Age Friendly Communities might be interested in hosting some of these conversations. Libraries are another great place to host these conversations.
- Just like we have organ donor listed on our driver's license, why not have DNR sticker on license as well?
- Use storytelling in PSAs to help people understand advance care planning, hospice, and palliative care, and how to produce them in a way that they can be shared via social media.

- Provide end of life care training for people in long term care settings.
- Use books like Being Mortal to facilitate community conversations.
- Increase community-based Death Cafes – which is a great venue to bring people together and start the conversation.
- Shift the end of life conversation from “how do you want to die?” to “what do you want your death to be like?”
- Educate all health care professionals about how to establish end of life goals with patients.

## 13. Making the Transition to Facility Care

Transitioning to a nursing home is not easy. Most caregivers do not want their loved one to move to a facility, and most people who need care don't want to go. Planning, as much as possible, for a transition in care is vital to making the change as easy as possible. Because caregivers and care recipients are so certain they don't want to transition to facility based care, they don't plan for that potential eventuality. "Planning" takes place in response to a medical crisis or when a caregiver is worn out. Reactive moves are much harder for the caregiver and for the recipient of care than proactive moves.

One bright idea was the development of resources to help families make contingency plans in case they find that staying home is no longer a viable option. Educational programs, such as Savvy Caregiver, are crucial in helping families prepare for a transition proactively when it is highly likely that the progression of a chronic illness will lead to the need for institutional care.

Health care professionals and social service providers need tools to help people talk about what they want before they're in a situation of being cared for or disabled. Similar to a "last wishes" document, people need a document that asks, "what would you want if you had this limitation or that limitation?" A document, and the conversation that happens when the document is prepared, would allow a person to plan for their future long term care needs. In order to help folks make realistic plans, the conversation would need to be truthful about what type of impairment they are facing, and should include a discussion of what the resources and options are as an illness moves from one stage to another stage to another stage.

There was considerable discussion about remaining positive after the transition to a facility. One common suggestion was the need to educate caregivers to understand that caregiving doesn't end when someone enters a facility, it simply becomes a different kind of care. Bright ideas included:

- Getting to know the facility team before a transition and focusing on the benefits to the person who needs help and to the caregiver.
- Using the care planning team approach combined with medical home model, which makes the care planning team available to caregivers before their loved one needs nursing facility care. Having access to a medical home model or some kind of care planning team before a crisis (i.e. a fall) happens encourages caregivers to talk about transitioning proactively.
- Educating the public generally, and caregivers specifically, about what nursing facilities really are. Stereotypes of nursing homes aren't always reality. The conversation would be easier if it took place in a context of understanding the role of nursing facilities and what they're actually like.
- Promoting and developing new models of care at the community level. Helping communities understand what development options exist and how to pay for them.
- Promoting Long Term Care insurance and other income support for facility based options and in home care.

- Person-centered and holistic care should be integrated into the medical model.
- Support groups – peer to peer information exchange with people who have been through it ahead of a family caregiver—may help a reluctant caregiver to take small steps to accept help as it is needed, starting with day care and then transitioning to respite care, assisted living, and to a nursing home.
- Community forums held at nursing homes and assisted living facilities allow people to meet residents and see the facility without feeling pressure.
- Bright Idea: Assisted living housing vouchers.
- Bright Idea: Neighborhood health watches.

## Conclusion

Informal family caregivers are the backbone of our long term care system, but, as a country and a region, we've done little to intentionally understand all of the challenges of caregiving and to systematically begin to address those challenges. These conversations were the start of the conversation. Now it is incumbent upon advocates, providers, policy makers, employers, community leaders, and family members to take the next step to instituting real change across our region that supports caregiving in all its facets. Please do what you can personally and share this report widely so that others may be encouraged to action.

## Appendix

We're grateful for the hard work and dedication of our staff and planning committee and for the inspired vision of our funders who are committed to building this collaborative. We're also appreciative of the fabulous sponsors who helped make these conversations possible.

### A: Cross-border Conversation Planning Committee Members

Angie Bordeaux, TSLCA

Jean Crouch, NH Department of Health and Human Services

Laura Davie, Center on Aging and Community Living at UNH

Laura Dyer, TSLCA

Lori Fortini, Dartmouth-Hitchcock Aging Resource Center

Laurie Harding, Upper Valley Community Nursing Project

Kelly Laflamme, Endowment for Health

Jess Maurer, TSLCA; Maine Association of Area Agencies on Aging

Lisa Miller, Bingham Program

Nate Miller, SeniorsPlus

Janet Nunziata, UVM Center on Aging

Tracey Tarr, NH Department of Health and Human Services

### B. Cross-border Conversation Sponsors

Alzheimer's Association – ME Chapter, VT Chapter, and the MA/NH Chapter

Tufts Health Plan Foundation

Center on Aging and Community Living at the University of New Hampshire

The Center on Aging at the University of Vermont

Disability Rights Maine/Maine Relay

### C. TSLCA Funders

The Bingham Program

Endowment for Health

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MEHAF

NH Charitable Foundation

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