



Nav-CARE

Making Connections, Making a Difference



The goal of Nav-CARE is to improve the quality of life of adults living at home with illness by providing specially trained volunteers to create connections to community and to provide caring, consistent emotional support.



The Story of Nav-CARE

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- Covenant Health
- Nova Scotia Hospice Palliative Care Association
- Nova Scotia Health Region
- Canadian Hospice Palliative Care Association
- Pallium Canada
- Greater Trail Hospice Society
- Castlegar Hospice Society
- Nelson and District Hospice Society
- North Okanagan Hospice Society
- Bulkley Valley Hospice Society
- Cranbrook Kimberly Hospice Society
- Desert Valley Hospice Society
- Central Okanagan Hospice Society
- Olds and District Hospice Society
- Camrose and Killam Hospice Society



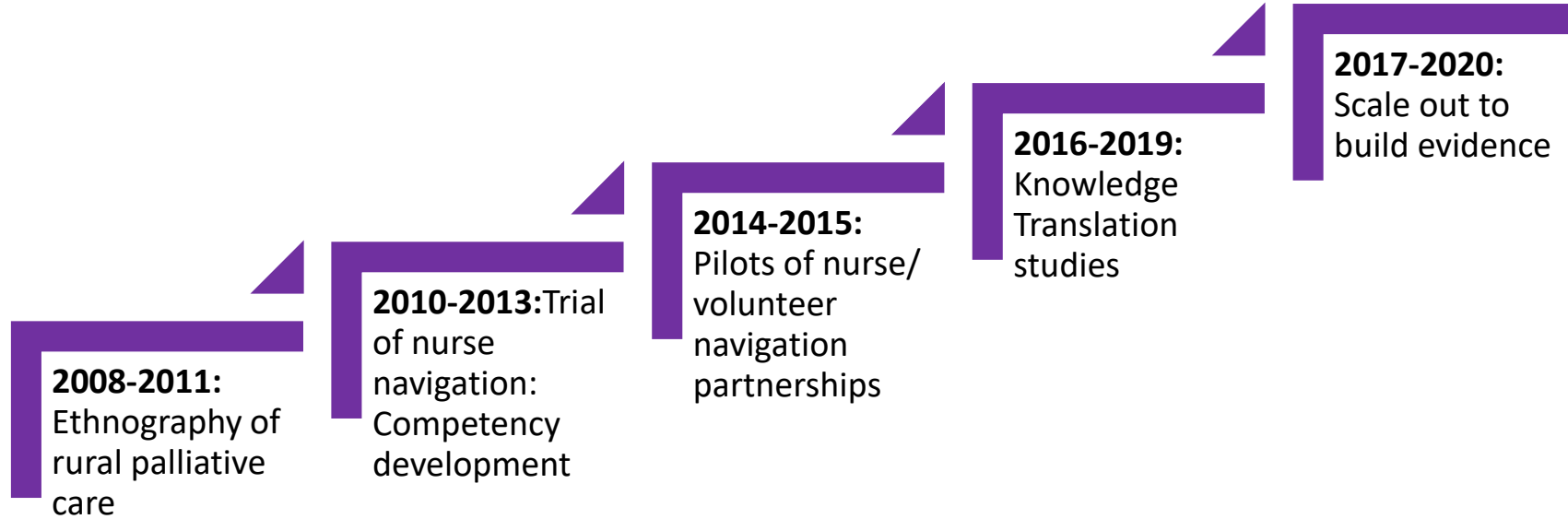
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- Comox Valley Hospice Society
- Victoria Hospice
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- Prairie Hospice Society, Saskatoon SK
- McNally House Hospice, Grimsby ON
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- Stedman Hospice, Brantford ON
- Dr. Aaron McKim, Portugal Cove NFL
- Kalein Centre, Nelson BC



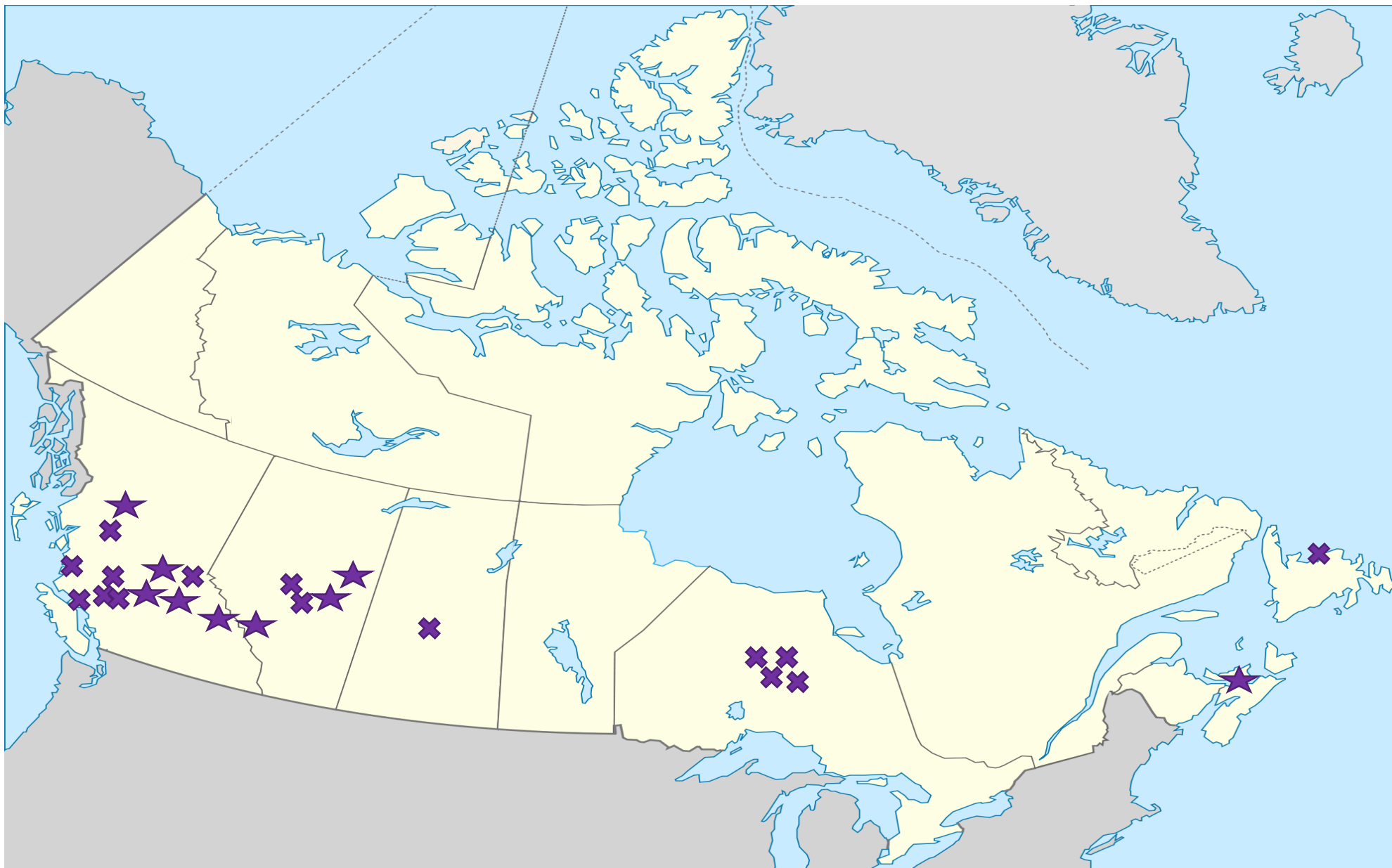


Building the Evidence: The twelve year journey





2017-2020: Scale Out





How Does Nav-CARE Work?

Compassionate-Communities Initiative

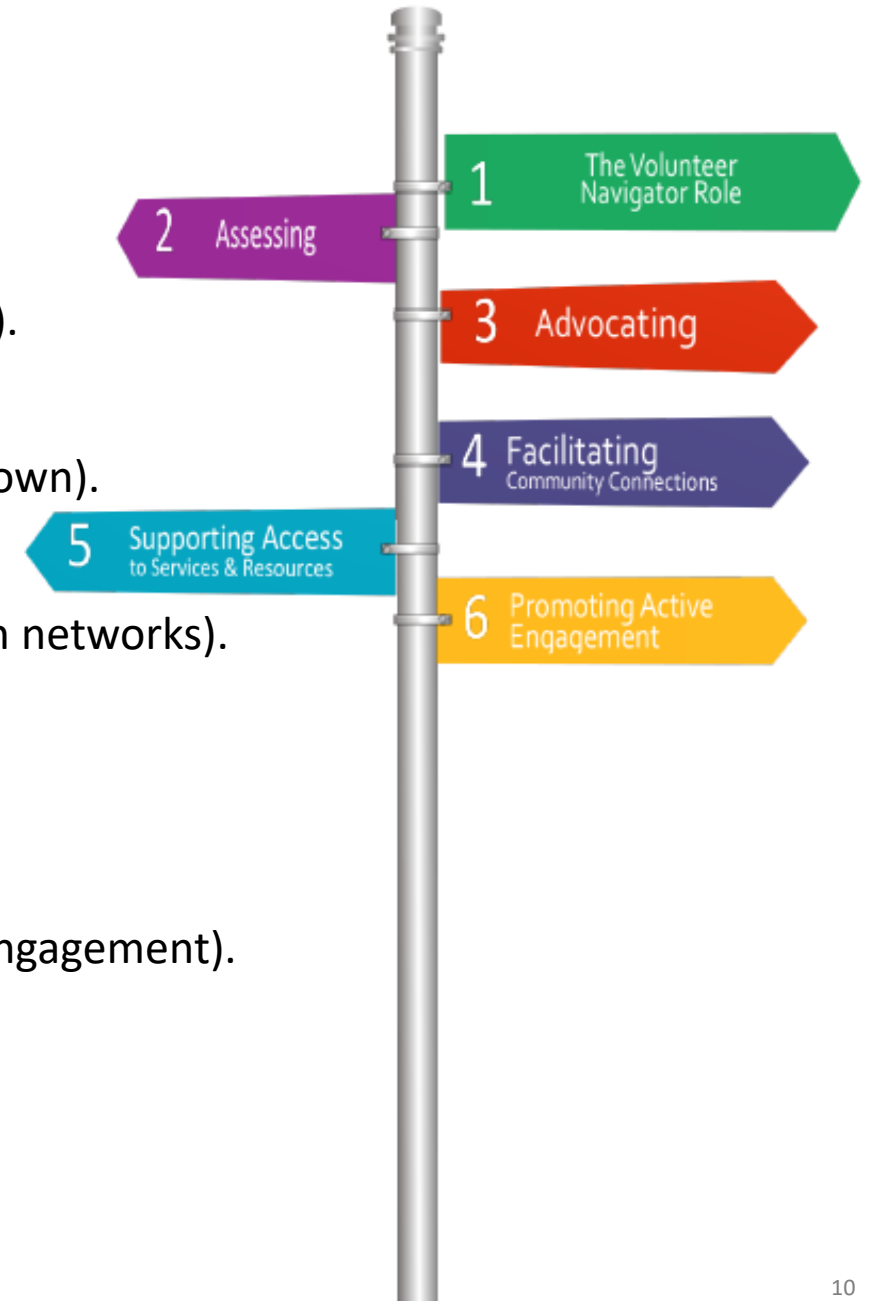
Living in a community that cares for each other makes us happier, keeps us connected and helps us find meaning in life.

- BC Centre for Palliative Care



Volunteer Competencies

1. Provide client/family assessment (e.g., understand quality of life priorities).
2. Advocate for client/family (e.g., assist client and family to make wishes known).
3. Facilitate community connections (e.g., assist client/family to connect with networks).
4. Facilitate access to services and resources (e.g., computer assistance).
5. Promote active engagement (e.g., build capacity toward desired level of engagement).





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Who Does Nav-CARE Serve?





Seniors Living at Home with Illness

- Lack of early supportive care.
- Lack of knowledge of resources.
- Loneliness and isolation.
- Multiple complex decisions.
- Heavy symptom burden.



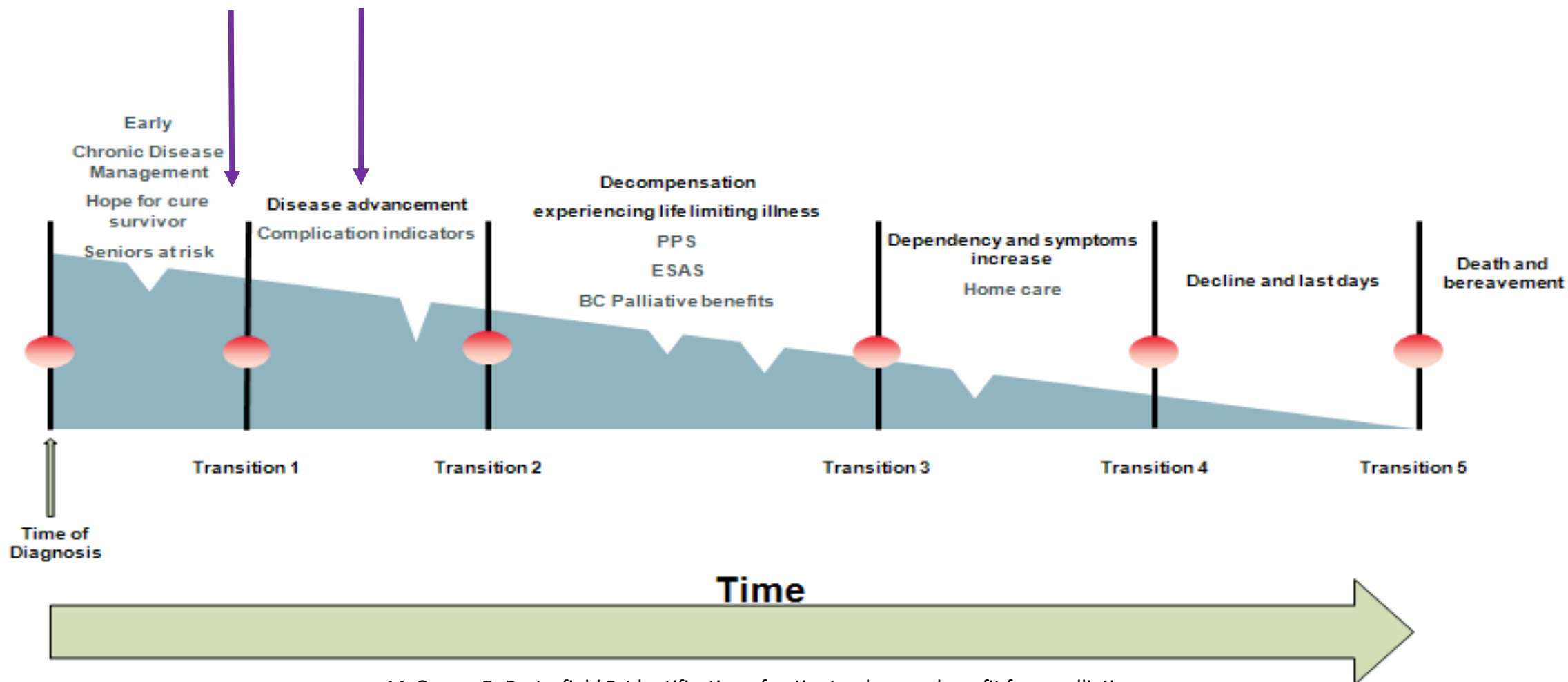
*Did you know? One in five seniors report that they experience emotional distress and have difficulty coping day-to-day. **

Loneliness and social isolation are significant predictors of healthcare utilization

*Canadian Institute for Health analysis based on Commonwealth Fund 2016 survey of seniors in 11 countries.



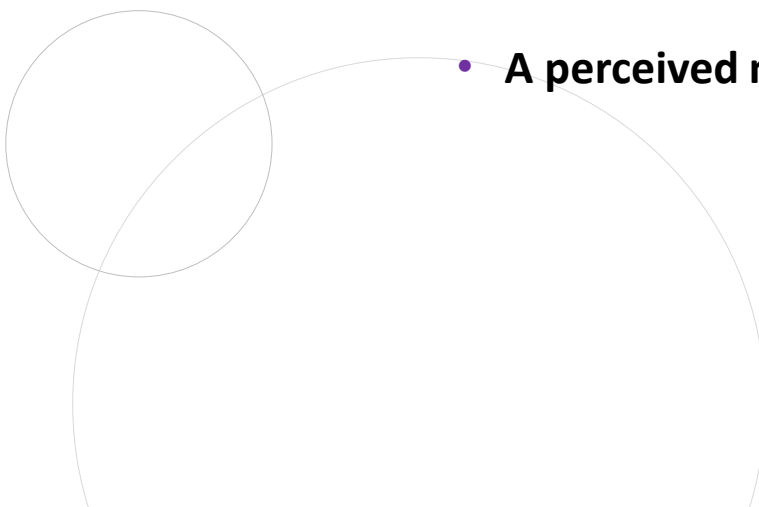
Nav-CARE Target Population





Quality of Life Issues: Candidates for Nav-CARE

- Loneliness or social isolation.
- Recent loss.
- Mobility or sensory challenges.
- Multiple concurrent life changes.
- Increasing disengagement.
- Coping with multiple decisions.
- Difficulty finding/accessing information or resources.
- **A perceived need.**





Day-to-Day Challenges: A Role for Nav-CARE Volunteers

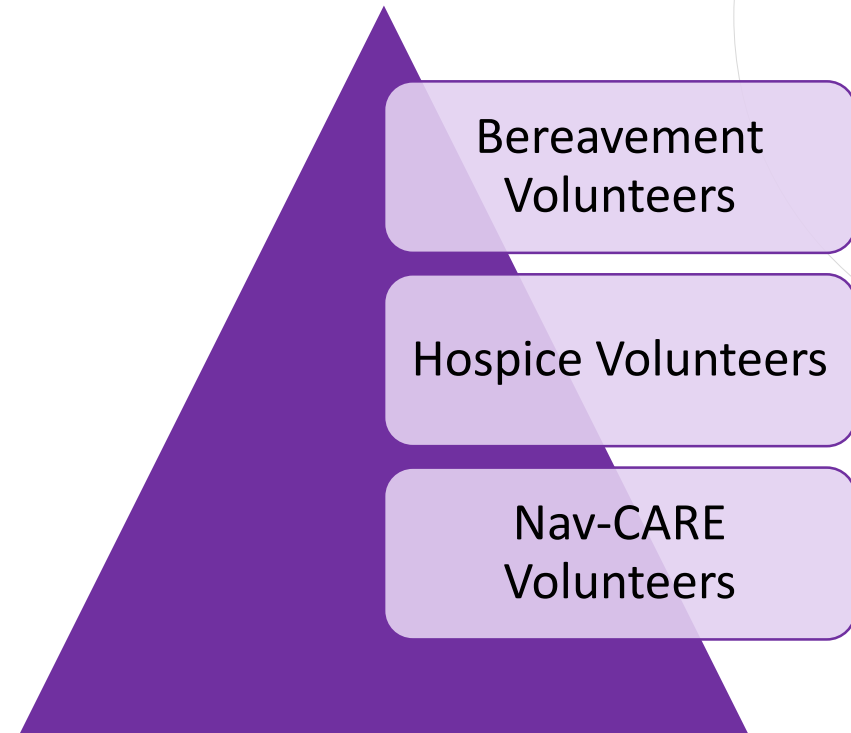
- Changes in eyesight and hearing.
- Financial concerns.
- Energy levels.
- Family and pet concerns.
- Grocery shopping and meal planning.
- Maintaining friendships.
- Relocation and housing.
- Home and vehicle maintenance.
- Uncertainty around illness.
- Outlook on life and death.
- Weather barriers.
- Managing technology.
- Reviewing life.
- Caregiver respite.

All of these concerns directly impact health and healthcare, but do not fall within the responsibility of healthcare practitioners.



Hospice

An Upstream Role for Volunteers Within Hospice





Nav-C.A.R.E.

Connecting, Accessing, Resourcing, Engaging.

What do volunteers do?





Connecting to Others

- Building rapport through social conversations.
- Identifying and building social connections by being a companion or planning for companionship.
- Being the safe space discussions around illness, coping, and overall life impact.
- Providing the means through which to communicate with others (e.g., those with sensory challenges)



Accessing Available Services and Resources

- Strategies to work with healthcare providers (e.g., identifying priority problems, planning conversations, attending visits as a 'second ear')
- Mobility and transport options.
- Companion for errands and outings.
- Technology assistance.



Resourcing According to Need

- Home services (e.g., gardening help)
- Available living options in the community (e.g., rentals that accept pets).
- Life changes (e.g., downsizing possessions).
- Comfort adaptations (e.g., replacing old shoes).
- Senior resources (e.g., ombudsman, office of senior's advocate, senior's centre, adult day program).
- Policy changes/services that affect seniors (e.g., information about changes to MSP premiums for low-income earners)



Engaging with Life

- Renewing old hobbies (e.g., coloring leading to art classes, games).
- Seniors activity planning.
- Advance care planning (e.g., funeral home visits, writing out things that they want healthcare providers to know).
- Facilitation of plan for client's volunteer work (e.g., helping refugees moving into the community).
- Strategies for preparing for stressful events (e.g., renewing driver's license).



Adult Client and Family Reasons for Participating

- Talking to someone about their illness who had some knowledge of the disease trajectory but who was not affected by the illness.
- Learning about potential resources in their community.
- Overcoming loneliness and social isolation.





Benefits: Volunteer and Client Perspectives





Chronic Illness Experiences

Why Nav-CARE was important

When you've been sick for a long time [voice breaking], after a while everything disappears, and all your stability [crying] (Client).

So this is a whole new experience now. It is life changing...I am here and I am alone. Am I lonely? Well yes, I guess I probably am (Client).

Illness causes a feeling of isolation and aloneness. Others treat you differently (Client).



Companionship: Volunteer perspectives



*We became very attached to each other. It was like we knew each other for a long time. I liked being able to support her staying in her home. She had many services already that she had looked into on her own, but I was able to help her with a few things. **But mostly, I just listened** (Volunteer).*



Companionship: Client Perspectives

My two boys are in the city and especially in the winter, they can't come down because they have their own jobs and families to look after. So it was nice to have someone in the community to talk to and connect with (Client).

There are a lot of people out there who are ill and no one knows it, and they suffer in silence, which also causes depression (Client).

She [the Volunteer] sang karaoke and we went and listened to karaoke and I met her spouse and children...we really made a friend connection (Client).



Trusted and Caring Listener Volunteer Perspectives

Well, they often tell me that they feel so much better after the end of our visit and really I have to be honest, that I haven't done anything except listen (Volunteer).

She was able to speak freely. She knew that I really do care (Volunteer).

*I think the most that I've been able to contribute to both of these families is just caring about them and giving them an opportunity **to talk about things** that might be bothering them (Volunteer).*

Trusted and Caring Listener Client Perspectives

I've learned to live with what I have and I don't talk about it all the time. But to be able to talk to someone who understands you, really understands what you're going through, has been a relief to me (Client).

*It just gave [me] some peace of mind in this situation that I am in to think that **she could hear me**. When I needed to talk we would just go for a walk (Client).*

You need someone who understands and is supportive. You can't rely on doctors because most of them have never been sick in their life. They don't understand the amount of pain that you go through (Client).





Safety and Stability



I need something that's reliable in my life. The navigator is usually a minute early. Because when you're in this condition, you really need stability and security knowing that this is one thing you can hang on to as things go sideways...It really has been profound. I've told her this, but I haven't been weeping when I told her. I'm getting all weepy as I think about this (Client).

It was just knowing that I could pick up the phone and call her, I guess. That was the most important thing. (Client)



Family-Centered but NOT Family

Ideally, Nav-CARE would replace the role of the extended family in those cases where the family are either too far away or not well enough to provide support (Volunteer).

I find that sometimes there might be something about their family that they're upset about and just being able to tell someone else who isn't part of the family can make it all almost go away. You know...it must makes them feel better about it (Volunteer)





Family-Centered but NOT Family. Volunteer Perspectives

That seems to be their biggest concern. Their family comes and does things because they're obligated. And healthcare does what they do because they are obligated. But I wasn't obligated (Volunteer).

I know it's pretty hard to be stuck at home 24-hours, seven days a week with your family and loved ones. And so, just to give them a change to go out and breathe and do something else for a couple hours, that was important (Volunteer).

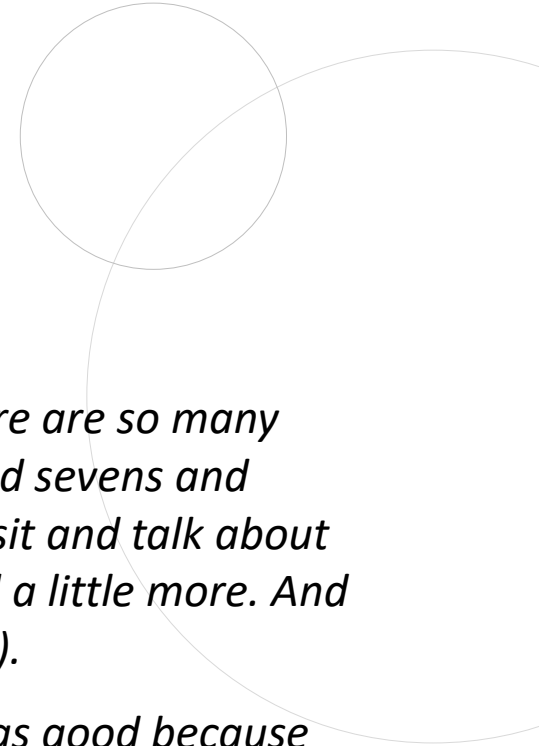




Family-Centered but NOT Family. Client Perspectives



I have a lot of friends and at first, I thought that Nav-CARE would be a waste of time. But, you know, the navigator is absolutely amazing. She's talked me through things that I couldn't tell friends and family. She helped me figure out what was necessary for my kids to know and how to tell them (Client).



Transition Support

Everything comes at you so fast and there are so many decisions to make and you're all sixes and sevens and when your volunteers come out we can sit and talk about this and that, and it helps us understand a little more. And oh, what a difference that makes (Client).

We took a couple visits outside which was good because the physical activity was good for me. We went to Hospice House the one time, which I figured I needed help with...she introduced me to people there and we had a tour of the place. It just made me a lot more comfortable...becoming a bit more familiar with it (Client).



Engagement



I was surprised by how much it does help the minute she comes in. And later on I said to someone, 'You know, I did this and I didn't realize that I could still do it' (Client).

Before he came into my life I was just sleeping all the time and not doing anything. I would cancel my doctors appointments, just not go. And he made me see that the doctors appointments were important. And to be honest with the doctors and not to be afraid to ask for help (Client).

Nav-CARE is focused on living – living the best you can with whatever you've got each day of the year. That has been a real bonus for me from this research. It has led to other connections. (Client)

I'm a late-stage palliative. So, that was a bit of reality upside the head but it was good, it was really helpful, so that I could move on. She was helpful as I began to look at getting my Power-of-Attorney and my Representation Agreement and all that in place. (Client).

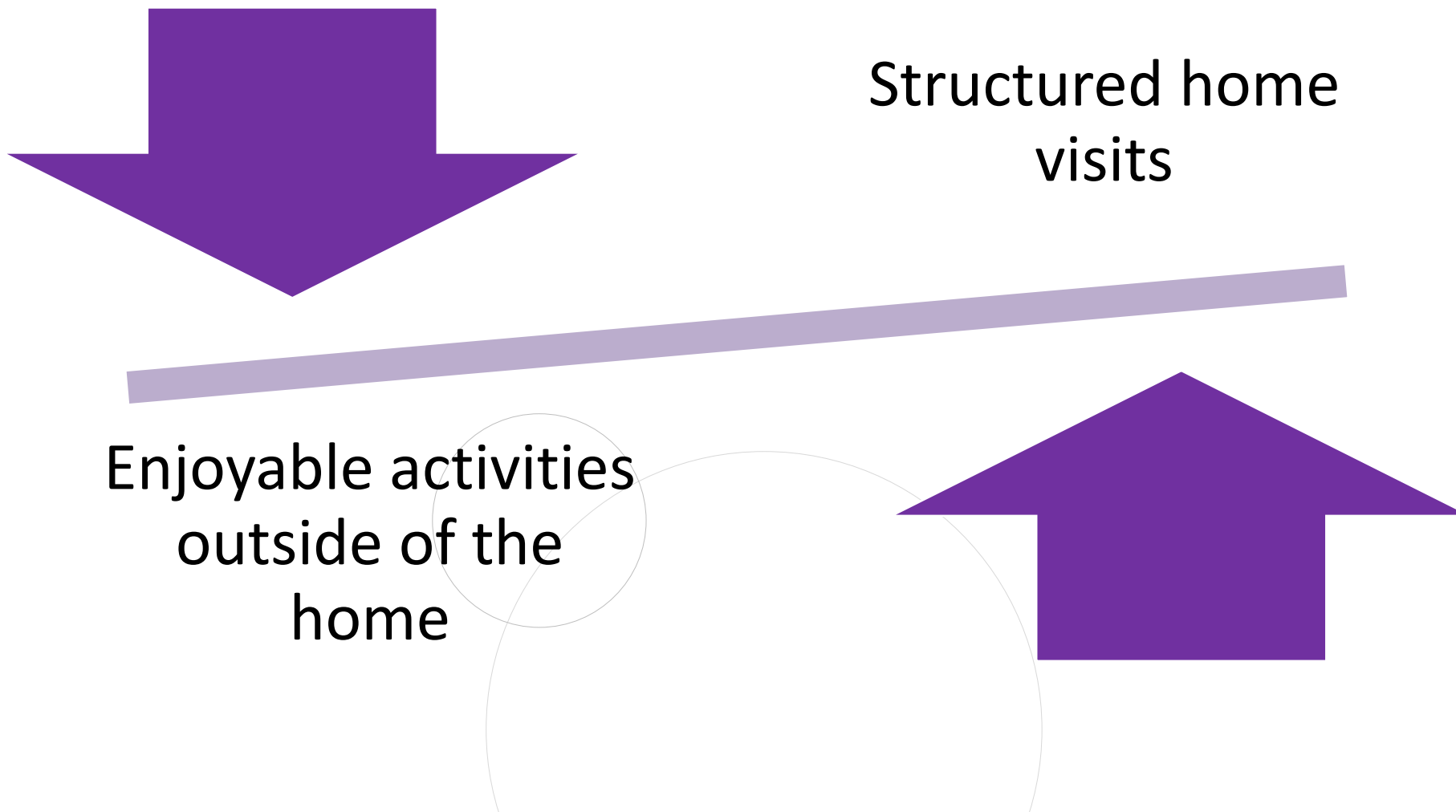
One really important thing was having a will drawn up. I didn't have anything in place at all and my volunteer helped me get into a pro bono program where they helped me out financially...and showed me an awful lot that I wasn't aware of that is required in a legal will nowadays. It really helped a lot (Client).

Planning





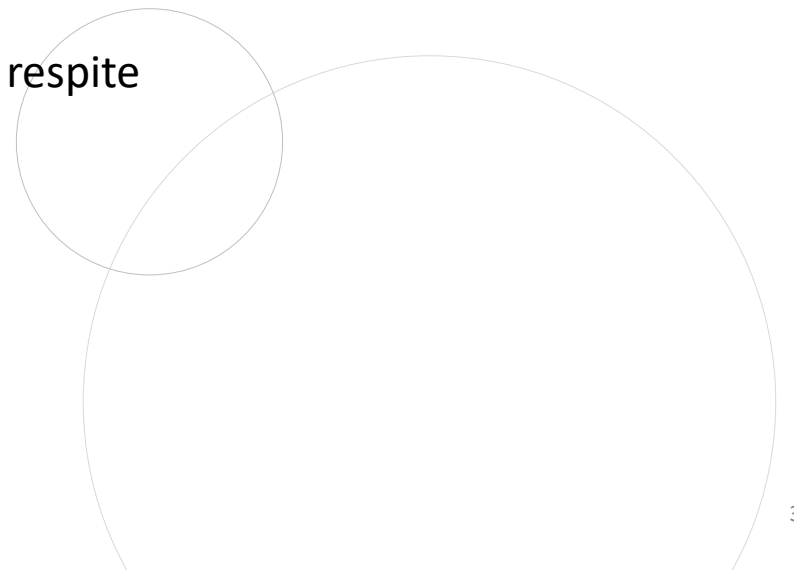
Client Desires for more community-based activities





Family Perspectives

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- Benefit of emotional and physical respite
 - Social support
 - Help into bereavement
 - Sign-posting
 - Access to resources





Family Perspectives

She ended up being a valued member of the family, almost where she would just say, 'Okay, what do you need?' And I'd just say, 'I gotta get some ladies in here to give Mum communion'. And she's like, 'I'm on it'. She would just go and do it. And I mean, she is an amazing human being...she kind of knew what we needed and she knew what Mum needed and was just, you know, a friend (Family Caregiver).

When you're feeling really low, like, 'Oh my gosh, how much more can I take?' Then she would build you up. She would say, 'You're doing something amazing and you're making a difference in your Mum's life and your kid's life' (Family Caregiver).

They'd just talk about normal things. Things that were real life stuff that took Dad away from the heaviness of his day-to-day life. And really, truly, Dad felt like this person enjoyed being with him (Family Caregiver).





Volunteer Concerns



- Too much emphasis on relationship rather than navigation (e.g., companioning).
- Lack of perceived need from the client.
- Reluctance on the part of clients to pursue available options.
- Establishing personal limits on the role (e.g., time, transportation, errands, social outings, attending healthcare visits).
- Negotiating professional knowledge and skills in the volunteer role.
- Prolonged time in developing relationships.
- Intense bereavement after long term relationships.



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Barriers and Facilitators

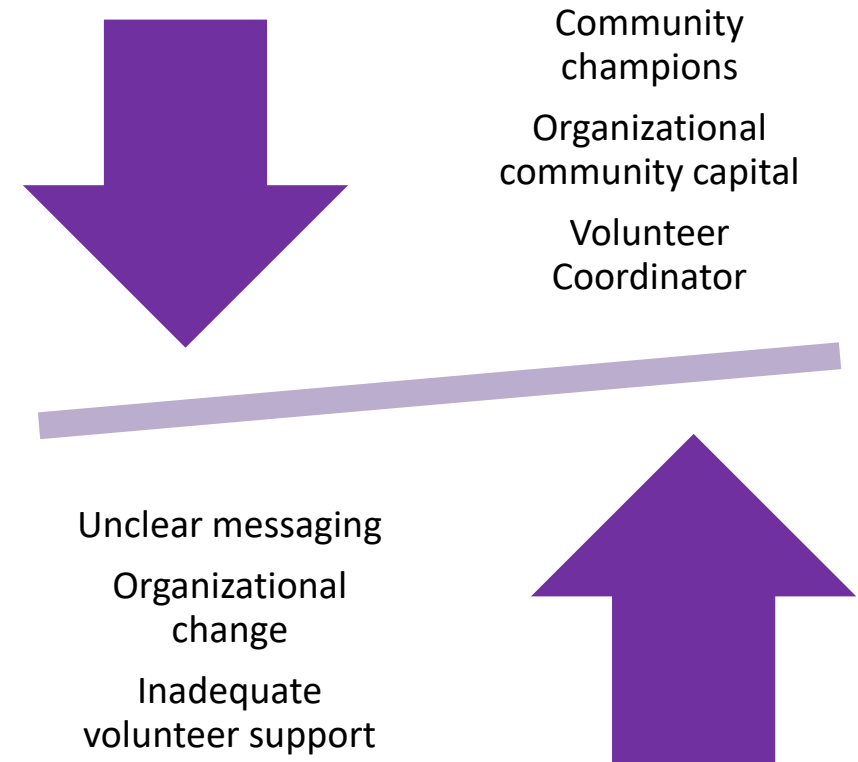
to Implementing Nav-CARE





Implementation Lessons

- The number one barrier to implementing Nav-CARE is **client recruitment**.





Client Recruitment

- Initial fears of over-recruitment and insufficient capacity.
- Few programs realized full recruitment.
- Recruitment was labor intensive.
- Strategies for recruitment included
 - Healthcare integration
 - Partnerships with family physicians
 - Public advertising
 - Church groups
 - Layered onto, or partnering with, agencies that are already in contact with the population of interest



‘Getting it Right’ with Language

- Palliative is confused with dying.
- Navigation means that you are replacing professionals.
- Care is only done by professionals.
- Cancer never gets ‘advanced’ or ‘serious’.
- Research means an invasion of privacy.
- Volunteers are nice, but not necessary.

A possible antidote: Nav-CARE ‘branding’ completed in 2018



Organizational Factors influencing Nav-CARE

- Competing initiatives → Limiting capacity.
- Organizational changes → Political influences and changing perceptions of program value.
- Hospice barriers → Perceptions and underutilization.
- Professional relationships → Gatekeeping.
- Geographic influences → Rural versus urban sites.
- Advisory committees → Limited use(fullness).
- Existing community relationships → Integration and infiltration
- Resources → Underestimating resources required for a new initiative.



Volunteer Factors that Ensure Success

- Suitable background and expertise:
 - Familiar with illness and healthcare experiences.
 - Comfortable working one on one in the home.
 - Clear boundaries.
 - Problem solver.
- Preparation:
 - Adequacy of preparation depended upon the volunteer background.
 - More focus on role and boundaries needed.
- Attrition of volunteers if clients were not recruited in a timely manner.
- Ongoing education for the role is important.
- Network of support, respite, and self-care required because of their client relational commitments.



Community Readiness





Reasons for Developing a Nav-CARE Service

- Creating strong community outreach and connections.
- Reaching clients earlier to improve quality of life.
- Revitalizing a home visiting program.
- Expanding existing services.
- Creating a stronger surveillance system.





Essential Characteristics for Success

- Well-developed mechanisms to support volunteers.
- Experienced volunteers willing to dedicate 2-3 hours per week.
- Integration with local health and community resources.
- Strong champions who are familiar with the goals of Nav-CARE.
- Adaptations to Nav-CARE that suit the community context.



THANK YOU



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