Nav-CARE

Making Connections, Making a Difference

Volunteer Navigation Learning Manual

January 2019

Notes:

This manual will cover the information and tools needed to become a Nav-CARE Volunteer Navigator.

Dedication

This resource is dedicated to all the wonderful volunteers across the country who give of their time to help others. We would like to specifically thank the volunteer navigators who have shared with us what they have learned as they have worked to connect clients and their families with information, resources and their communities.

Acknowledgements

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We would also like to acknowledge the assistance of Joanne Ward at the University of Alberta, Miranda Falk and Kelli Sullivan from the University of British Columbia in making this manual a reality.

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Welcome to Nav-CARE

The Story of Nav-CARE

Nav-CARE was birthed out of research conducted in rural palliative care by Dr. Barbara Pesut and Dr. Wendy Duggleby. Through their research they discovered that rural seniors living at home were not receiving the support that they needed, particularly when they were living in the transition between chronic illness and palliative care. However, they also discovered that there were many resources in rural communities that few people knew about and that volunteers had great potential to contribute meaningfully to the care of these rural seniors. Indeed, some the greatest barriers for volunteers were lack of opportunities to get connected to the seniors who needed help. This led to the development of Nav-CARE.

Dr. Duggleby developed navigation competencies for assisting rural seniors while Dr. Pesut trialled nurse/volunteer navigation partnerships in one rural community. Nav-CARE was developed strategically through a series of research projects and has now been implemented in sites across Canada.

Purpose of the Manual

The purpose of this manual is to help you as a volunteer to learn about navigation in preparation for your new role in the Nav-CARE program. It is based on the knowledge and skills (competencies) needed to be a navigator. It is to be accompanied by a workshop on volunteer navigation. After completion of this manual and training workshop you will have the basic information required to begin as a volunteer navigator with the Nav-CARE program. However, this is just the starting point. You will need to draw upon additional materials as you learn this new role. We recommend that you join the mentorship sessions offered by teleconference so that you can learn from one another as this role develops across the country.

Organization of the Manual

The manual is organized into modules reflecting the navigation knowledge and skills that you need as a volunteer navigator. Each module has competencies, learning objectives, content, as well as reflective exercises to assist with your ongoing development.

References are available at the end of the manual if you would like more information.

Thank you for engaging in learning with us.

We welcome any comments, questions or feedback on the manual, contact:

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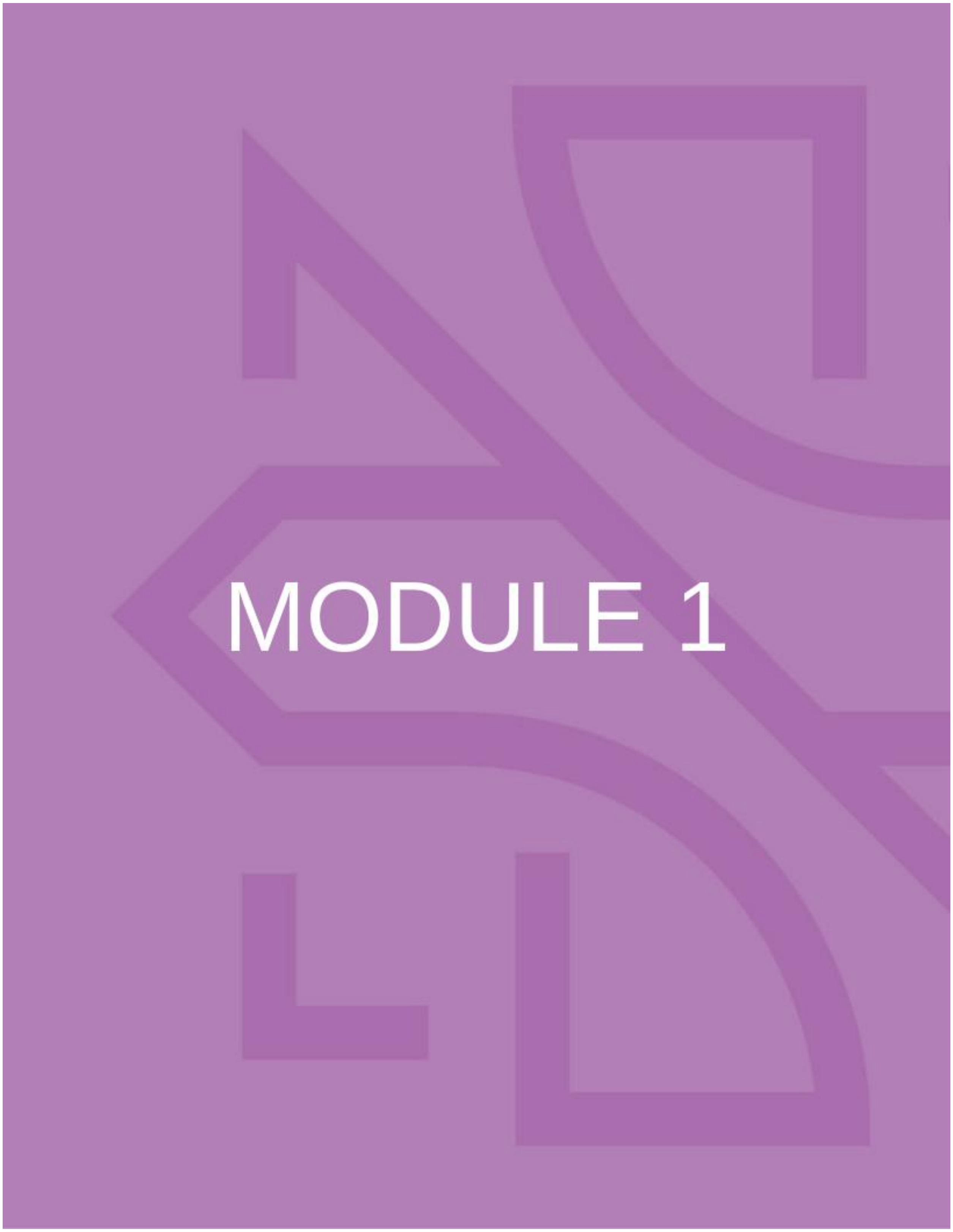


MODULE 1

MODULE 1

Introduction to the Volunteer Navigator Role

"By having a navigator, you have someone who is committed to you, cares about you, has the time to listen to you, and is able to understand what you're going through."

Nav-CARE participant

Learning Objectives

1. Describe the role of the volunteer navigator
2. Describe the skills and knowledge required of a volunteer navigator
3. Know how to act within the limits of the volunteer navigator's role
4. Learn about some special considerations when it comes to home visiting
5. Develop rapport with clients

What is a "volunteer navigator"?

A volunteer navigator is a person who works with adults living with serious illness and their families to facilitate connections, independence, and promote quality of life. They do this by establishing relationships with clients and their families so that they learn who they are and what is important to them. They then use this knowledge to help clients connect with people, resources, and services, in their communities through a "best fit" family-centric approach (Duggleby et al., 2016). Volunteer navigators are typically experienced volunteers, often within hospice, who take on an expanded role in navigation. They begin their work with clients and families who are living with serious illness, and follow them along their illness trajectory. Their goal is to support the best possible quality of life for clients, a role that previous clients have described as making their life with serious illness "more livable."

Volunteer navigators:

- Improve the quality of life for people in their community
- Provide support and encouragement to people
- Help people to stay engaged in what is meaningful to them
- Work with families and communities
- Help individuals and families find and make sense of information
- Find resources and connect individuals and families to them
- Help individuals to stay independent for as long as they wish

Why is there a need for volunteer navigators?

Many seniors are living with illnesses that affect their quality of life as they age. Living with serious illness can lead to losses such as the ability to get around, to have sufficient income, or to stay involved in relationships and activities that are meaningful. People can find themselves increasingly dependent and despondent. The inability to get outside of the home can lead to social isolation and loneliness. But loneliness does not only happen to those with chronic illness. Many seniors live alone and require extra support to stay in their homes as long as possible as they become increasingly frail.

Volunteers can play an essential role in providing support and connecting these individuals back to community. The Nav-CARE volunteer brings community to them. Our research with volunteer navigators has consistently shown that when seniors feel connected to, and cared for by, a volunteer, their quality of life improves. They feel they have someone to talk to about important decisions, they have someone to help them when needs arise, and they feel less lonely. Knowing that someone cares, and will advocate on their behalf, provides a sense of safety. As one senior put it, “she is not going to cure my illnesses but she sure makes my life more livable”.

Volunteer navigators can also help to improve health. Lonely seniors are more likely to use healthcare services to alleviate their loneliness. Further, volunteers have the time and resources to solve the day to day challenges that are not part of healthcare services – finding the shoes that fit, the transportation that takes pets, and neighbours who will get the mail when the box has been moved beyond walking distance. Volunteer navigators make a difference.

Who can be a volunteer navigator?

Volunteer navigators are highly skilled people who are able to support those living with serious illness. They have experience with supporting clients through loss, they know their community, they know how to find things, and how to get things done.

Volunteer navigators may choose this role because they want to help people and make their community a better place to live. They bring a diverse set of skills to their role. They are knowledgeable about living with serious illness and they have been involved with volunteer community-based agencies. Volunteer navigators who choose to work with individuals and families with serious illness must have related volunteer or healthcare experience.

What qualities do volunteer navigators need to have?

- Self-awareness
- Compassion
- Flexibility
- Commitment
- Resourcefulness
- Creativity
- Courage
- Responsibility
- Integrity
- Respect
- Openness
- Acceptance

What is the role of a volunteer navigator?

The navigator role originally comes from the United States, where cancer clinics and hospitals began using navigators to assist patients through the complicated health care system (Lorhan et al., 2014). Those navigators help patients find their way through “the maze” of doctor’s appointments, tests and procedures. As community-based volunteers, Nav-CARE volunteers have a different role. Their job is to assist clients to navigate the changes and needs that arise as clients seek to live long and well within their homes. They provide a listening ear for healthcare related decisions and may help clients to find ways to communicate with healthcare professionals. They also help find resources to fill other needs, from simple things like finding a housekeeper or a meal-delivery service to more complicated needs such as building support networks and finding reliable transportation.

A Nav-CARE volunteer works with the client and family to identify their priorities for quality of life. In this sense, the role is broad and includes aspects of navigation that may not be directly related to health care. For example, helping clients to connect with friends, leisure activities or social services or simply being a listening, supportive presence can have beneficial health effects. The emphasis is on determining what is most important for the client and family within their community relationships, and facilitating access to what is most important. Furthermore, volunteer navigators begin their work with clients upstream, often before they need home-based healthcare services. This proactive approach enables supportive care to be provided early on in the serious illness trajectory, which enables clients to remain independent for as long as possible.

The analogy of driving a car to a destination is a good one for the volunteer navigator role. The client is the driver of the car and they choose the destination in accordance with what is their preferred quality of life goals. The car represents all of those assets and resources the client brings to their journey. However, cars need fuel and client’s fuel (or energy) can diminish over time as they are confronted with multiple losses or barriers as a result of their serious illness. The volunteer navigator’s role is to boost the fuel, and one of the primary ways they do this is through developing trusting relationships with clients.

Nav-CARE volunteers have the opportunity to build unique relationships with clients because of the design of the program. Each volunteer has only two clients. The luxury of time that comes with home visits every 2-3 weeks for about 1.5 hours facilitates the volunteer navigator’s ability to be a listening and supportive presence.

Some of the things a volunteer navigator might do

- Work with individuals and families to describe what is most important to them (priorities for quality of life)
- Help individuals and families find services or resources that make their lives easier
- Provide encouragement and companionship
- Help with overcoming barriers to getting services or resources
- Support and encourage individuals and families as they look for their own resources

Volunteer navigators as relationship builders

Building a relationship with individuals and families is at the core of the volunteer navigator role. As a navigator, you will meet people and enter into their lives during a transition time. An important part of building a relationship is establishing trust with individuals and families. Trust involves honesty, listening actively with the intent to hear, communicating openly and freely, and following through on promises. Rapport takes time to develop. You may find that this is the primary focus of your role for the first weeks or even months. It is tempting to feel like you are not doing much for individuals through this time. However, relationships are all about connecting. The connection between the volunteer navigator and the clients forms the basis for all other forms of connecting.

Examples of Connecting

- **Social conversations**
- **Discussions about illness, coping, and overall life impact**
- **Identification of friend and family connections**
- **Psychosocial support for disappointments that come with advancing illness**

Research has shown that social support has important links to overall health. For example, one review found that persons living with serious illness who have more personal support networks have better physical and mental well-being, better abilities to engage in self- management, and lower healthcare costs (Reeves et al., 2014). The relationships that volunteers build with clients, and the ways in which volunteer navigators support clients to connect with others, are interventions that can change health, well-being, and costs. This is why the development of relationships is so central to the Nav-CARE program.

Relationship building can:

- be a source of support and encouragement for clients and volunteers.
- help volunteer navigators understand what individuals most value in their lives.
- help volunteer navigators understand how individuals interact with their community.
- serve as a “stepping-stone” to exploring important, but sometimes difficult, topics like advance care planning.
- make the volunteer role more satisfying and meaningful.

Ways of Building Rapport

Building rapport with individuals requires the desire to get to know an individual. It also requires strong communication skills.

How do you build rapport? Here are some ways:

- Smiling
- Listening
- Giving of your time, being available
- Paying special attention to treasures in the home (e.g., pictures, memorabilia, books) and building those into conversation
- Following through on what you say you will do
- Acts of kindness

Self-reflection

How do you build rapport with others? Are you a good listener? How do you establish trust? What acts of kindness would be appropriate in a volunteer client relationship? How much time are you willing to give? How much time is too much time?

One of the things we hear frequently from volunteers is that they feel like their client really doesn't need anything. Instead, they spend most of their time socializing and connecting. Yet, their clients often tell us that this is the most important part of what the volunteer does!

Let's think about that for a minute.

A volunteer navigator is a guide. Imagine that you are embarking on a journey into the wilderness with a guide. Living with a serious illness is like going into the wilderness with all the risks, unknowns, and ups and downs. Your guide is there to journey alongside you – helping you to get to where you want to go. What would you want from your guide? First, you would want to know them well so that you could trust them if things got rough. Second, you would want them to know you well so that they could know your strengths and limitations to best support you over the journey. Most of all, you don't want the guide to take over but to just be there if you need them! The development of the volunteer navigation relationship is just like that – it's all about relationship until something is needed

"Being" versus "Doing"

Above all, volunteer navigators listen to, support, and encourage individuals with serious illness and their families. Sometimes just being there is a big thing. Volunteer navigators check in on people in their community.

"Being" with the client has many positive benefits such as promoting client engagement and reducing feelings of isolation.

What skills and knowledge do navigators need?

Learning the role of a volunteer navigator involves learning to see things in new ways and making new connections.

Skills volunteer navigators need:

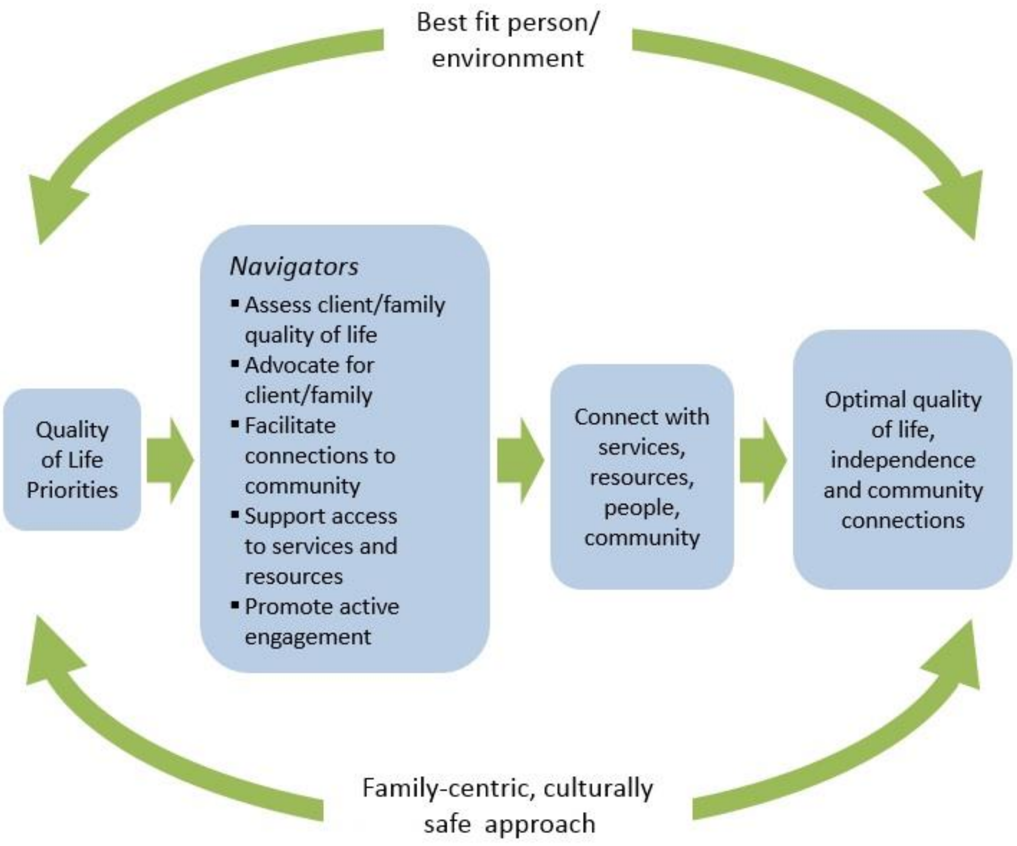
- To be excellent listeners
- To be excellent communicators
- To understand families and how they work
- To be able to treat each person as an individual
- To be able to solve problems
- To be flexible and adaptable
- To be able to speak up for others
- To know how to access resources

Volunteer navigators need to know:

- Their community
- How to access resources
- How to anticipate the needs of clients and families dealing with serious illness
- When they don't know something or when they don't have the information
- When to contact their community agency for support
- How to be supportive with their client when problems can't be solved
- Their boundaries

Developing Competence as a Volunteer Navigator

Below is the model of navigation that informs the Nav-CARE program



The model shows how Nav-CARE navigation differs from traditional models of healthcare navigation. It highlights the values of independence, quality of life, and community connections, along with a family-centric and palliative approach (Duggleby et al., 2016). A great deal of research has gone into determining the competencies that volunteer navigators should have to do their role well. The navigation education has been structured around these competencies. They also provide a good way for you to evaluate your development into the role as you think about how confident you are becoming in each of the areas.

The specific sub-competences of the volunteer navigator are outline in the tables below:

A. Assessing client and family quality of life (see Module 2):

A1. Assess client/family quality of life (QOL) concerns and wishes.	**A2.** Identify client/family values and beliefs regarding quality of life.	**A3.** Prioritize with client/family their desires across QOL areas.	**A4.** Determine how clients and family prefer to make decisions and support them in that decision-making.	**A5.** Identify client/family knowledge and perception of available options and community resources.	**A6.** Determine if there are gaps in community resources and services.

B. Advocating for clients and families (see Module 3):

B1. Identify client/family needs for resources.	**B2.** Assist family in making decisions.	**B3.** Identify barriers to need resources.	**B4.** Advocate to meet client/family needs.	**B5.** Assist client/family to overcome access barriers.	**B6.** Advise client/family on negotiating for care and services.	**B7.** Facilitate strategies for self-navigation (e.g., Changes Toolkit and location of care guide)

C. Facilitating community connections (see Module 4):

C1. Perform windshield survey of what is available in community.	**C2.** Identify community resources for client/family.	**C3.** Identify best-fit client/family with community resources.	**C4.** Communicate to local leaders and/or professionals about community resources gaps.	**C5.** Assist client/family to build and connect, or reconnect, with community networks/connections.

D. Supporting access to services and resources (see Module 5):

D1. Identify client/family needs and concerns.	**D2.** Assess client/family need for support.	**D3.** Develop plans reflective of client/family needs and concerns.	**D4.** Provide family with caregiving and support resources.	**D5.** Coordinate access to needed services.	**D6.** Assess client/family service usage.	**D7.** Facilitate beginning discussion with client/family regarding advance care planning and goals of care.	**D8.** Assist client/family with access to services for loss, grief, and bereavement support.

E. Promoting active engagement (see Module 6):

E1. Determine effective and appropriate ways to meet client wishes.	**E2.** Identify level of desired client/family involvement in self-navigation.	**E3.** Build capacity with client/family towards their desired level of independence and engagement.	**E4.** Promote desired engagement in decision-making and self-navigation by client/family.	**E5.** Develop opportunities for engagement in activities meaningful to client/family.

Navigating the Boundaries

At times you may find it difficult to decide what a volunteer navigator should or should not do. Each situation is different and sometimes you will have to make decisions about what you can and cannot do for individuals and families. A common misunderstanding with clients is that you are there to do the practical things such as driving, respite, or pet care. It takes time and education for clients to realize that your role is to assist them to get access to those things for the long term. For example, if a client is admitted to hospital in an emergency, they may ask you to feed the cat. You may decide that is a good thing for you to do at this time. However, your role will be to help them to find a long-term solution for emergency pet care. Volunteer navigators need to be clear about their role with the client.

It is also important to think about the volunteer navigator role in relation to formal healthcare services. We have found that many volunteer navigators have healthcare professional backgrounds. This may be a valuable asset in the role. However, it is important to draw boundaries around the volunteer scope and to be clear with clients that you are working in a volunteer capacity. Further, it may be appropriate for you to discuss elements of client's health care with them by helping them to sort out information or to make decisions. In some cases, you may want to attend healthcare appointments with them to provide support and be an extra ear of understanding. However, it is an important courtesy to check with healthcare professionals first and to stress that you are only there in a supportive and listening capacity.

Volunteer navigators work in partnership with community-based agencies that will have policies and guidelines for volunteers. The following are some examples of what volunteer navigators may be asked to do (see below) based upon our research. If there is ever uncertainty about the volunteer navigator role, the community-based agency through which Nav-CARE is being implemented should always be consulted.

Things volunteer navigators CAN do:

- Help clients and families to identify their quality of life concerns
- Help the client and family arrange services, such as meal or grocery delivery, and transportation
- Help a client of family fill out forms
- Spend time having coffee, looking at photo albums and listening to stories

- Accompany a client on public transportation
- Help a client or family make phone calls to arrange services
- Pick up items such as wheelchairs, commodes, etc.
- Run errands for clients
- Help a client access a computer and/or the internet
- Give clients or families information about community resources and services
- Advocate for clients and families to help them meet their needs and improve their quality of life

Things volunteer navigators QUESTION whether or not to do:

- Drive clients to doctor's appointments or events
- Grocery shop for clients or families
- Perform housekeeping or yard maintenance tasks for clients or families
- Buy gifts for clients or families
- Invite a client or family to an activity or party
- Give your personal phone number to a client or family

Things volunteer navigators should NOT do:

- Accept money or gifts (other than tokens) from clients or families
- Charge a fee for any supportive service such as housekeeping or foot care
- Lend money to an client or family
- Give medical advice to clients or families
- Give medications or provide direct nursing care to clients
- Give financial advice to, or do banking for, clients or families
- Share information about clients or families with others
- Agree to be a person's power of attorney
- Agree to witness a client's will
- Start a discussion on Medical Assistance in Dying (MAiD) with clients or families
- Preach or attempt to convert a client to your own religious beliefs
- Give psychological counselling to a client or family

- Become romantically involved with a client or family member
- Refer to clients, families, or your role as a volunteer navigator on any social media

Self-reflection

Can you think of a time when you did something for someone else, thinking it was the right thing to do, and then realized later that it wasn't helpful for that person? Sometimes we do things for others because it's easier for ourselves, but it might not always be the best way.

What do volunteer navigators need to know about home visiting?

A delegate from the community-based agency will conduct a home assessment prior to the volunteer navigator's first visit. While most home visits are routine and pleasant experiences, there is always a possibility that volunteer navigators will be faced with a hazard or potential hazard. Ensure that you are familiar with health and safety procedures. The following are tips for ensuring your safety during home visits:

- Carry a cell phone with you and/or ensure your client has a phone line
- Make sure that someone knows that you are visiting a client
- Be sensitive of cultural and language barriers
- During your visit, stay in the living room or dining room if your client is ambulatory
- If a situation with a client or family member becomes stressful, stay calm, keep about six feet between you and let the person know that you are listening
- Leave the home immediately if you feel unsafe
- Stay home if you have a cold or flu
- Do not transfer or reposition clients with mobility issues
- Always contact the designate of your community agency to report hazards, potential hazards or if you have questions about your safety

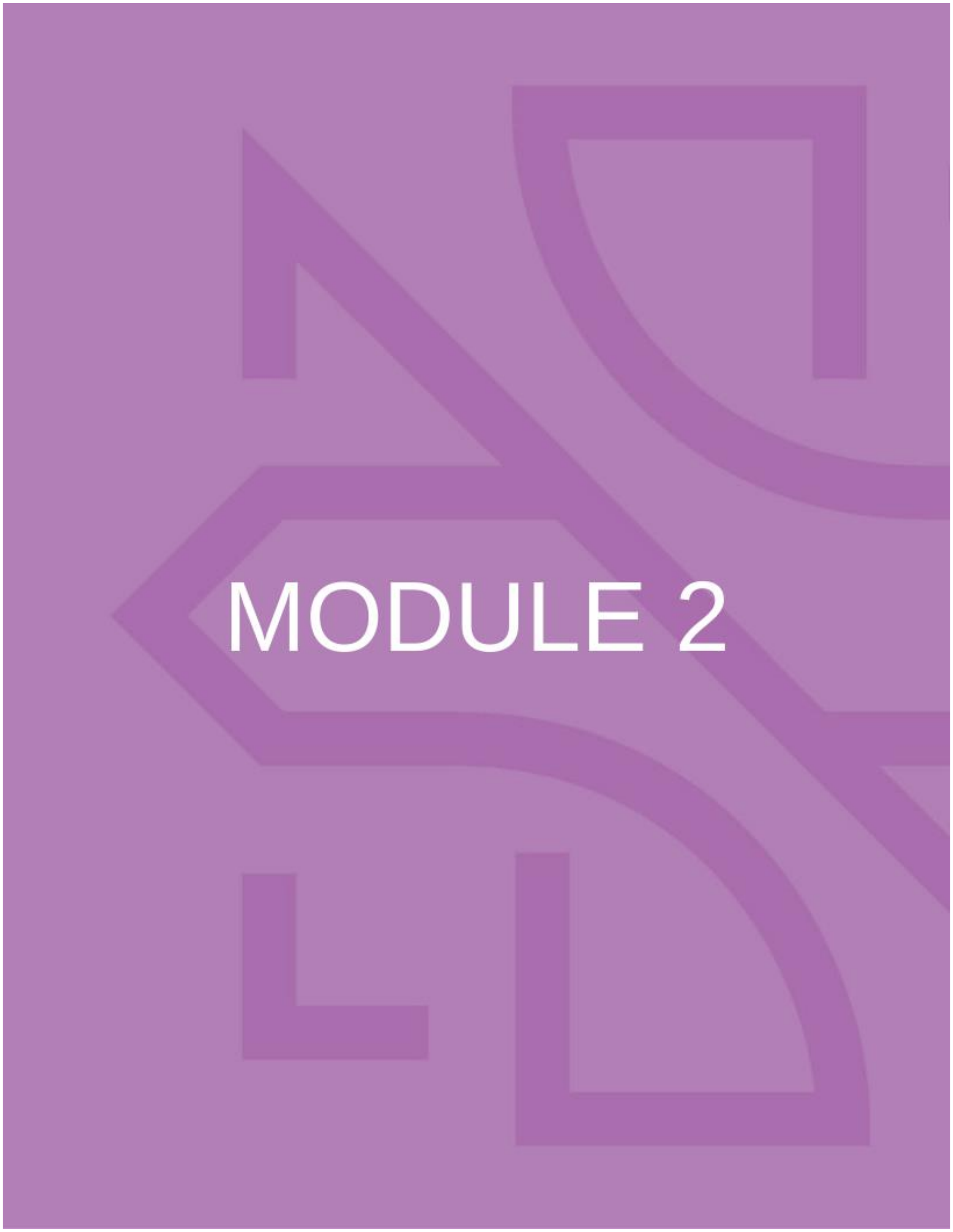
A Nav-CARE story

Bob lived alone with a disability that left him unable to work. The recent loss of his wife had resulted in him feeling lonely and depressed. Bob's family did not live in the same community and so he found himself increasingly alone. He withdrew from most activities that he and his wife had done together. Bob saw an ad in the paper for Nav-CARE and decided to have a volunteer. Over the course of a year, the volunteer stayed in touch with him by phone and through visits. When asked how the service benefited him he replied, "The volunteer kept me company. She helped me just by talking to me. I think I would have gone into a very deep depression without her. She assisted me to plan trips to see my family. Now I feel productive again."

Moving forward (and referring back)

You will be learning more about what volunteer navigators need to know in the next module of this curriculum. As well, you will be continually learning through practical experience in your role as a volunteer navigator. It is also important to remember that your previous training and experience as a volunteer serves as the foundation for this work. You do not need to know everything right now. It is important to remember that you cannot know and do everything, but as a volunteer navigator you definitely can help!

MODULE 2



MODULE 2

Assessing Client and Family Quality of Life

"We talked about what I felt I need to talk about. The visits fit my needs better each time." Nav-CARE Participant

Competencies:

At the end of the module, volunteer navigators will be able to:

1. Assess client/family quality of life (QOL) concerns and wishes
2. Identify client/family values and beliefs regarding quality of life
3. Prioritize with client/family their desires across QOL areas
4. Determine how clients and family prefer to make decisions and support them in that decision making
5. Identify client/family knowledge and perception of available options and community resources
6. Determine if there are gaps in community resources and services

Learning Objectives

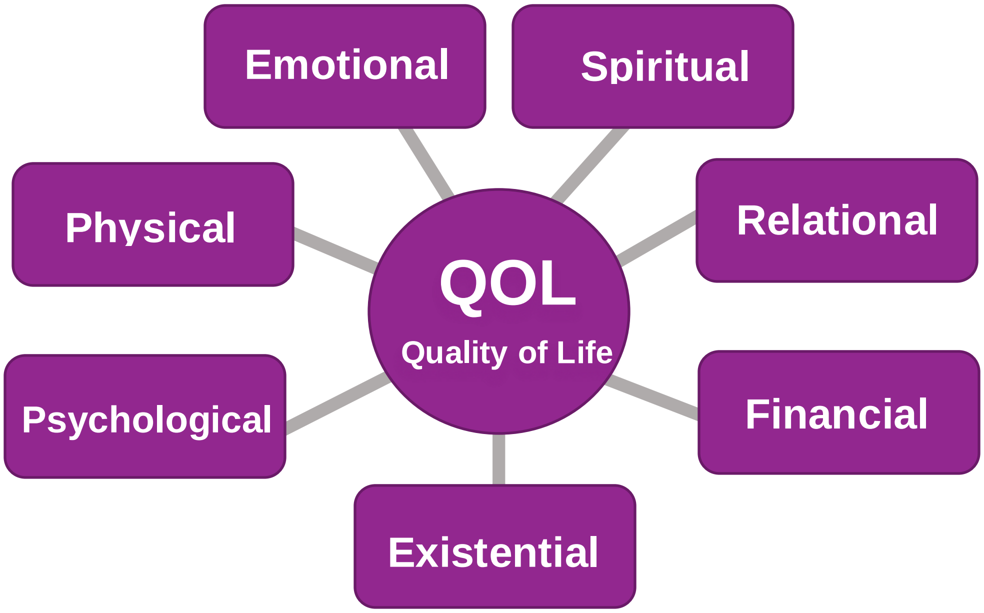
- Describe the benefits of relationship for the volunteer navigator role
- Define the concept and areas of quality of life (QOL)
- Describe the impact of serious illness changes on an individual and/or family's QOL
- Define transitions and describe the four transition themes
- Explain how the environment impacts the process of adapting to change for individuals and families
- Describe individual/family values related to beliefs about death and dying
- Describe individual and family assets
- Identify an individual or family emergency
- Develop an action plan to use in the event of an individual or family emergency
- Describe how to identify the positive parts of a person's

Quality of Life

What is quality of life?

Quality of life (QOL) refers to each person's understanding of how good or bad their life is at a certain moment in time (Ferrell et al., 1997). Others have described QOL as the gap between our expectations of our lives and our experiences of it (Carr, Gibson, & Robinson, 2001). This means that our perception of QOL is dynamic. As our expectations change and/or our experiences change, our QOL changes.

Quality of life is a broad concept made up of seven areas of our lives. Together, these seven areas make up the total concept of quality of life. The seven quality of life domains are physical, emotional, spiritual, relational, financial, existential and psychological (Duggleby et al., 2014).



Each area contributes to a person's quality of life in a different way, either positively or negatively. Further, persons may weigh these quality of life domains differently at different times in their lives.

Self-reflection

Think for a moment about your own quality of life. Do you see how each of the domains adds to, or detracts from, the quality of your life? Are some domains more or less important to you? Have those changed over time? In what ways might your quality of life needs be different or the same as those of a person with a serious illness?

Serious illness and quality of life

Quality of life is related to priorities. A serious illness may alter an individual's and/or family's priorities in such a way that some areas may become more important than others (Tang et al., 2014). For example, physical symptoms such as pain, fatigue, or breathlessness may sometimes become a pressing need for individuals with serious illness (Hermann & Looney, 2011). In addition, priorities may change rapidly depending on each individual's or family's circumstances. For example, family members must sometimes take time off work to assume a caregiving role, which may affect the financial QOL of the family. It is important for volunteer navigators to consider the ways in which serious illness may impact a client's or family's QOL. An individual's or family's beliefs about illness, suffering, and death will also influence their QOL. This is particularly important for persons living with serious illness; they may engage in a "life review" and take time to clarify what is important to them.

What is assessing for quality of life?

- Assessing involves getting to know individuals, families and communities. It can help to identify needs so the navigator can work with the client or family to connect them with community resources and services.
- Assessing is also an important safety process because it involves looking for and identifying a concern before it becomes a problem.

How to assess quality of life

It is important to remember quality of life is a subjective concept; it is what the person says it is. Only the person living the life is able to assess their own quality of life. Also, remember that you don't have to use the term "quality of life" to understand what is important. You simply want to know what is most important to them during this time, and then to work with them around those priorities.

A simple way is to ask a person the following:

- What is most important in your life right now?
- What are the three most important things affecting how you are doing today?

Quality of life is not just about individuals. Families have quality of life goals and priorities as well. So, when exploring quality of life with an individual, it is important to consider the whole family's quality of life. Ask each family member about their quality of life priorities and notice similarities and differences in their replies. How do the areas of quality of life vary among individuals? Do some family members see things differently? Might they have different goals? What might this mean for their needs as a family? Think about how you may work with them to meet their needs as individuals and as family members.

Self-reflection

Think about how your quality of life priorities shift over time and according to different circumstances. Have you ever been faced with a serious illness? How did your quality of life priorities change during that time? How did your family's quality of life priorities change? How did you feel when your quality of life was less than you wanted it to be? What steps did you take to solve that challenge?

The power of story

There is no better way to learn about someone's quality of life than to allow them to tell their stories. Storytelling is powerful both for the teller and the listener. Through stories you learn what is most important and meaningful to people, and how those things have changed over time. Through those changes you may also learn about what individuals still aspire to do or be.

Story telling also helps to support dignity. Dignity-therapy is a powerful intervention to help restore hope and meaning (see www.dignityincare.ca). Life stories help people to remember who they are, even amidst changes that seem to strip away their dignity. Through these stories you will also learn about their strengths such as resiliency, honesty, loyalty, or a sense of hope and belief.

In particular, as you listen to their stories, think about:

- What their stories are about
- If they tell you about significant others
- How they characterize their identity and strengths
- Whether or not they express hopes or fears
- What brings them joy

> *"To be a person is to have a story to tell."*
>
> Isaak Dinesen

Self-reflection

You have an opportunity to write your memoir. What stories will you tell? Why did you choose those stories? What might others learn about you from those stories? What do those stories teach you about yourself?

The family-centric approach

Volunteer navigators get to know families to identify their quality of life priorities and to determine the "best fit" for services and resources. A family-centric approach means that while the focus of the volunteer navigator is on the individual client, the client often lives within family relationships that are also essential to consider. Volunteer navigators work with individuals and families, helping them identify and make the most of their strong points and resources (Orte et al., 2014). It is important to keep in mind that there is no universal definition of "family". The definition of family will vary from individual to individual depending on culture, ethnicity, beliefs, sexual orientation, gender identity and even situational experiences. In other words, a family member may be a son, daughter-in-law, same-sex spouse, neighbour, or a close friend.

Working with families as a navigator

Family members will choose different ways to be involved with you and the client, and this involvement may change depending upon the client's illness trajectory. Remember, you will be working with clients who are still relatively well and so their families may not yet be acting as 'caregivers.' In addition, even those that are doing caregiver roles may not see themselves as caregivers. It is important to be available to family while respecting their desired level of involvement.

One of the most common challenges that arises for volunteers when working in the home with clients and families is navigating long-term family conflict. This requires a great deal of wisdom and skill. Remembering the following principles may help.

⇒ Your primary role as a navigator is with the client.

⇒ Listening is always appropriate; advice on family conflict is not.

⇒ Boundaries around what you will discuss or be involved in are acceptable and necessary.

⇒ Keep your focus on support and solving practical challenges as identified by the client.

Sometimes the conflict experienced by families is associated with sharing the experience of living with the serious illness. Research by Carole Robinson (2017) revealed that even though one family member is diagnosed with the illness, all family members can have a relationship with the condition. Families may experience burden when trying to balance life and illness. This can cause stress on family members and relationships.

One resource that may be beneficial is the **Family Caregiver Decision Guide** (Robinson, Pesut, & Bottorff, 2015. Available at www.caregiverdecisionguide.ca). This workbook gives caregivers the opportunity to think about and plan for their family member's care. The workbook guides caregivers through the following four steps:

1. Think about their caregiving situation *now*.
2. Think about how their caregiving situation *might need to change*.
3. Explore *caregiving options* in their area.
4. What are their *best options* if the needs for caregiving change?

By encouraging caregivers to document what aspects of care they can provide on their own, with the support of other family members, and with support from other resources, the stress of the illness burden is shared. This type of decision-making around care can result in family directed innovative strategies that promote living well.

Identifying family strengths

Working with families means volunteer navigators need to be able to identify their assets, or things they are good at as a family. Engaging the family members in conversation about past events can help determine their coping styles, or the ways in which they deal with stress/stressful events.

Some questions that may help you to explore family strengths include:

- How have you coped with stressful situations in the past? What helped the most? What did not help?
- What do you think your strengths are as a family?

- How have you solved problems in the past? Have you ever used resources or community services to help solve problems?

Forming strong and trusting relationships with individuals and families is the foundation of the volunteer navigator role. A supportive relationship will help you to explore important, but often private or personal, information related to quality of life.

The impact of transitions on quality of life

Quality of life is both influenced by, and influences, transitions which are significant changes in a person's life. Transitions are "ongoing processes characterized by change for an individual during which a new situation or circumstance is incorporated into their lives" (Duggleby et al., 2010, p. 1472). Transitions are often sudden and can be disruptive, and people may feel a wide range of intense emotions during a transition.

Just as quality of life occurs in many aspects of our lives, so do transitions.

The four main areas of transitions during aging are:

- **Environmental**, such as making changes to the home environment to accommodate serious illness (oxygen concentrators or commodes as "furniture")
- **Relationships and roles**, such as changing from spouse to caregiver
- **Physical and mental health**, such as changes in appearance or cognitive abilities
- **Activities of daily living**, such as the loss of independence in doing things formerly taken for granted, like driving, personal care, housework and cooking

Adjusting to these transitions is a complex process and depends on many factors. For example, living in a rural area can make the transition process easier for individuals and families in some ways and more difficult in others. Rural areas may have fewer services or resources than large centres, leaving individuals and families to rely more on themselves and on others for support and assistance. Many individuals choose to live in rural areas because they value both their individuality as well as connection with others and with their community (Duggleby et al., 2010).

Adapting to change requires information, support, and resources, either personal resources such as hope or external resources, such as community services.

Volunteer navigators can help individuals and families adjust to these changes. Research suggests that rural families facing transitions depend on each other, their communities and services to help them adapt (Duggleby et al., 2010). Volunteers are part of that community support.

Providing information, support and access to services and resources are important roles for volunteer navigators and can help to improve quality of life for individuals and families.

Self-reflection

Think for a few moments about some of the transitions you have encountered in your life. What have been the most difficult transitions for you? Have some been easier than others? What helped you to adapt? What didn't help?

Serious illness transitions

When we speak of serious illness in this manual, we are thinking of an advanced chronic disease or diseases that will lead to death in the near future. Therefore, it is difficult to talk about a serious illness without also talking about palliative care and how the two fit together. The journey of serious illness is characterized by a number of transitions that have implications for how individuals and families experience illness. For example, there is usually an early phase when the disease is well controlled and the ability to do important activities of daily living is maintained. During this time, individuals may experience little impact on their quality of life. However, through a series of transitions over time, individuals begin to experience increased symptoms that lead to decline and dependency.

The role of the volunteer navigator changes over these transitions. During the early phases of serious illness, the volunteer's role in relation to quality of life will be fostering connections to relationships, resources, and services that promote independence and engagement. However, as clients move down the illness trajectory, volunteers will find themselves working more within the traditional hospice volunteer roles as clients become involved with formal palliative services. You can expect your role to remain important during this time, however it may change. What is important to note is that volunteer navigators travel with clients along their journey, adapting their approach to what is most needed by clients and families during that time (e.g., hospital stays, respite). Individuals often struggle to troubleshoot how best to manage their needs, seek out appropriate resources in the community, and find answers to their questions about their health and well-being. This negatively affects their quality of life.

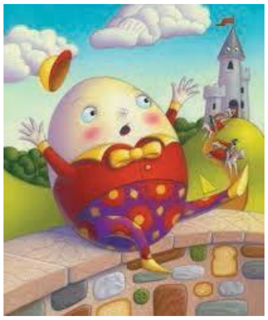
Volunteer navigators are uniquely positioned to help these individuals and their families with some of these needs throughout the trajectory of serious illness.

Common quality of life concerns

In a recent study in a rural area in British Columbia (Pesut, Hooper, Robinson, Bottorff & Sawatzky, 2015), a nurse navigator working with individuals living with serious illness found that this population struggled with:

1. Pain
2. Fatigue/exhaustion
3. Nausea/vomiting/constipation
4. Loss of appetite
5. Breathlessness

What is particularly important about these symptoms is that they often have a cascading effect on other aspects of client’s lives. Day to day activities become more difficult, energy diminishes, social contacts become less frequent, all of which can lead to isolation, loneliness, and diminished quality of life. Here is where the volunteer role becomes particularly important. Volunteer navigators play a key role in assisting clients to cope with the effects of living with a serious illness. Also, there are times when the navigator can help persons identify ways to talk to their healthcare professionals about getting better symptom relief.



Troubling symptoms come and go which leaves persons feeling like they are "Humpty Dumpty" sitting on a wall. They are balancing for the time being, but their symptoms can be so troubling they feel as if they will fall off the wall at any minute. This inconsistency can make it difficult for clients and family to know what to expect, both now and in future. As a result, family members may be completely surprised by a death, even when they have known about the illness for many years.

The course of a serious illness is up and down and highly unpredictable. This is why advance care planning is so important. Advance care planning will be discussed in more detail in a later module. Here we will introduce some important tips for having effective conversations to support the quality of life assessment process by volunteer navigators.

Conversations about quality of life concerns

The following are some general communication strategies taken from Susan M. Grover's publication entitled, "Shaping Effective Communication Skills and Therapeutic Relationships at Work" (2005), that volunteer navigators may find useful when building rapport with clients/family and encouraging conversations around quality of life issues.

- **Restatement:** In restatement, the listener simply repeats the individual's phrase or statement. This approach encourages the continuation of dialogue, particularly if the client is having a hard time focusing. It also helps to connect a statement with what is being experienced by the individual. For example, if a family member says, "I am trying to figure out how to get my father to be more socially active like he used to be," the volunteer navigator might say, "You are figuring out…" This type of response will give an opportunity for the family member to expand on their concerns.

- **Reflecting:** Reflecting is a strategy that emphasizes the emotional overtones of a message. Reflection is similar to restatement, however with reflection you are paying special attention to the feelings that have been shared in the conversation. For example, if a client says, "How can I do my errands if I keep having so much pain in my leg?" By using reflection, the volunteer navigator can say, "Sounds like you feel uncertain about…"

- **Open-Ended Questioning**: Open-ended questions are the type of questions that cannot be answered with a simple “yes” or “no”. They are phrased in a way that encourages a wide range of responses and information. Examples of open ended questions are: “How do you feel about not being able to keep up with your volunteer work?”; “What was that experience like for you?”; “What helped you deal with that situation in the past?”

- **Clarifying**: A clarifying question is another type of open-ended question. The goal is to encourage the individual to expand and give more detail about a particular piece of information that was shared. An example of a clarifying question is: “I appreciate how much you have shared with me about the time you were first diagnosed with your illness. How has the diagnosis impacted your day-to-day life since then?”

- **Paraphrasing:** Paraphrasing gives you the opportunity to check out your understanding of the meaning of something that was said by taking the original message, rephrasing it, and returning it back to the individual. For example, “It sounds like you have concerns about keeping up with the household chores as your health declines.”

While these strategies will be useful to keep in your communication toolbox, the key to having effective communication with clients and families, whether in terms of assessing for quality of life issues or relationship building, is to relax and be yourself. Some of the most meaningful conversations, according to Nav-CARE clients and volunteer navigators, have emerged from friendly visits over tea and cookies.

Distress

Quality of life concerns can quickly lead to stress and distress; therefore, it is important for volunteer navigators to be vigilant about noticing client changes or verbalizations of distress.

Stress, if not addressed, can lead to distress which is a term used to describe unpleasant feelings or emotions that impact a person's level of functioning. **Failure to address distress results in poor outcomes for individuals** (Blair, 2012) **and, a decreased quality of life.** When someone is distressed they may be showing **physical signs** (pain, disheveled appearance, rapid weight gain or loss) **emotional signs** (hopelessness, powerlessness, panic, and depression), **behavioural signs** (tearfulness, agitation, withdrawal) and/or **cognitive signs** (forgetfulness, disorientation).

Distress can be difficult to recognize because symptoms may not be clear. Also, distress, which is often thought of as an emotional reaction, may manifest in physical symptoms. The reality is that each person and family experience distress differently. It is important to be sensitive to indications of distress and to sensitively inquire about what you are seeing. If individuals identify that they are experiencing stress or distress, it is important for the volunteer to assist in seeking out appropriate strategies and resources to help.

Identification and treatment of distress in people with serious illness has been associated with increased quality of life, better outcomes, and a decreased incidence of suicide. Ways of reducing psychological distress and improving quality of life include improving social support, supporting problem-solving, being physically active, spending time outdoors and promoting health and mobility (Atkins, Naismith, Luscombe, & Hickie, 2013).

Emergencies

Although it is unlikely that volunteer navigators will encounter emergencies in their work with clients and families, you need to know how to identify when something is an emergency and what to do in an emergency situation.

During the first visit, it is recommended that the Nav-CARE volunteer navigator obtain consent from the client to record the name and contact information of the primary caregiver or family member that the volunteer navigator can contact in the event that the client cannot be reached or if there is an emergency.

Remember that volunteer navigators are not healthcare professionals. The volunteer navigator role is not to assess an individual or family in the event of an emergency, but simply to be aware of the possibility of an emergency and take action by notifying emergency services and the Nav-CARE agency coordinator.

What is an emergency?

Emergency situations can look different, depending on the type of emergency. Health emergencies include things like chest pain, excessive bleeding, falling, or a person's inability to get out of bed. Safety emergencies include things like fires, violence or criminal behaviour in the home, or gas leaks. If in doubt….treat it like an emergency.

If you discover an emergency, immediately **dial 911** and notify the volunteer coordinator at:

____

(Write number here)

Suicide

As adults struggle with serious illness, it is not uncommon for them to experience hopelessness and discouragement. This can lead to self-harm or suicide, so it is essential to screen for this potential and know what to do.

The potential for suicide is an emergency. Suicide affects individuals and families, with potentially long-lasting and devastating effects. About 4,000 Canadians die by suicide every year (Canadian Mental Health Association, n.d.). Adults living with serious illness may be at risk for suicide if their symptoms become particularly troubling or if their quality of life declines.

*The role of the volunteer navigator is **not** to perform a detailed suicide risk assessment.*

*The role of the navigator is **to be aware** of the warning signs that may indicate a person's risk for suicide, and to **communicate** any concerns to the coordinator at your organization.*

Volunteer navigators must be aware of the protective factors, warning signs and risk factors for suicide.

A person's risk for suicide is a bit like a balancing act. The risk increases if they have few protective factors and many strong risk factors and warning signs. Their risk for suicide decreases if they have more strong protective factors and fewer risk factors and warning signs.

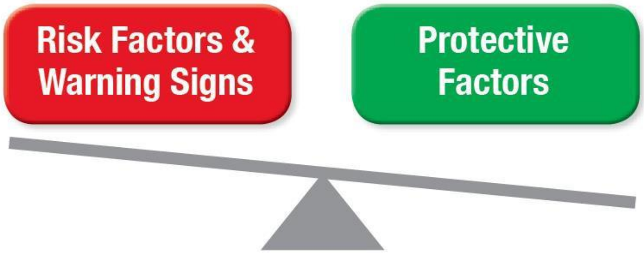
Protective factors

Protective factors are those things that lower a person’s risk of suicide. Identifying protective factors can help individuals realize their strengths and build resiliency and hope, which can act as a buffer against suicide (Perlman et al., 2011). People often consider protective factors the “reasons to live.”

Protective factors include:

- Strong family connections
- Community support
- Sense of belonging, sense of identity and positive self esteem
- Cultural, spiritual and religious connections and beliefs
- Enjoyable leisure activities
- Support through positive health care relationships
- Access to supportive health care (Perlman et al., 2011)

Volunteer navigators can help individuals to build strengths, hope and resiliency by noticing and reinforcing their protective factors.



Risk factors and warning signs

Risk factors are things that may cause a person to think about suicide but might not predict their actual risk of suicide. That is, an individual might have one or more risk factors but that does not always mean they are thinking about suicide. Common risk factors include serious illness and social isolation.

Warning signs are behaviours that indicate a person is at a higher risk of suicide. In combination with risk factors, an increase in warning signs may present a real suicide risk. It is important to be alert to the presence of warning signs.

Known risk factors for suicide include:

- A previous suicide attempt
- Family history of suicidal behavior
- A serious physical or mental illness
- Problems with drugs or alcohol
- A major loss, such as the death of a loved one, unemployment or divorce
- Major life changes or transitions, like those experienced by seniors
- Social isolation or lack of a support network
- Family violence
- Access to the means of suicide

The following are examples of warning signs, all of which can be signs that somebody is thinking about suicide. Of course, in most cases these situations do not lead to suicide. But, generally, the more signs a person displays, the higher the risk.

Warning signs of suicide spell: IS PATH WARM

I – **Ideation**: thinking about suicide

S – **Substance use**: problems with drugs or alcohol

P – **Purposelessness:** feeling like there is no purpose in life or reason for living

A – **Anxiety:** feeling intense anxiety or feeling overwhelmed and unable to cope

T –**Trapped:** feeling trapped or feeling like there is no way out of a situation

H – **Hopelessness or Helplessness:** feeling no hope for the future, feeling like things will never get better

W – **Withdrawal:** avoiding family, friends or activities

A – **Anger:** feeling unreasonable anger

R – **Recklessness:** engaging in risky or harmful activities normally avoided

M – **Mood change:** a significant change in mood

For more information on preventing suicide, including risk factors and warning signs, visit the Canadian Mental Health Association (CMHA) website at www.cmha.ca/mental_health/preventing-suicide

If a person displays warning signs, then the volunteer navigator must report the situation to the volunteer coordinator promptly.

Sometimes intuition is important as well. Even in the presence a few warning signs, if you feel uneasy about a situation, report it to your coordinator without delay.

What to do

When getting to know an individual, think about their protective factors and risk factors. Watch for warning signs by using the **IS PATH WARM** acronym.

Be aware of signs:

- Is this person socially isolated or withdrawn?
- Does this person have access to medications?
- Does this person talk about wanting to die or feeling trapped?
- Does this person say "I wish I were dead" or "I'm going to kill myself?"

Watch for behaviours:

- Is this person frequently angry or withdrawn?
- Has this person recently begun to use alcohol or drugs excessively?

In the presence of risk factors and warning signs, ask questions. Though it can be difficult, many studies have shown that asking questions directly helps predict suicide risk (Perlman et al., 2011).

ASK…Do you have any plans to end your own life?

CRITICAL TO KNOW

Protective factors are important, but warning signs may be more important indicators of potential suicide.

***ALWAYS** contact the volunteer coordinator if an individual has any risk factors or warning signs for suicide.*

Self-reflection

Suicide is a difficult topic, and can sometimes trigger painful memories. Take a few minutes to rest your mind and be kind to yourself: sit with a cup of tea or coffee, or do your favourite activity. Remember it's important to take care of yourself too.

Identifying hope and joy

There are many different situations volunteers may face when talking with clients who have serious illness and their families. Although it may look like the focus in this module is on the negative aspects of life, it is important to also be looking for the positive aspects.

- What would give you hope in this moment?
- What gives you joy?

Helping people to see the positives in their lives is just as important as other types of assessing. The navigator also helps people to connect with resources that will enhance the positive parts of their lives.

There is an activity in the Changes Toolkit on page 27 (which will be discussed in more depth later in this module) that you may encourage clients and their families to try (Everyday Hope). The instructions are to:

- Think about what will give you hope today
- Think about one big or small thing you would like to do today (this maybe be something like choosing a song you want to listen to)

For more information about hope in older persons with serious illness view the film "Living with Hope" at www.nurs.ualberta.ca/livingwithhope

Self-reflection

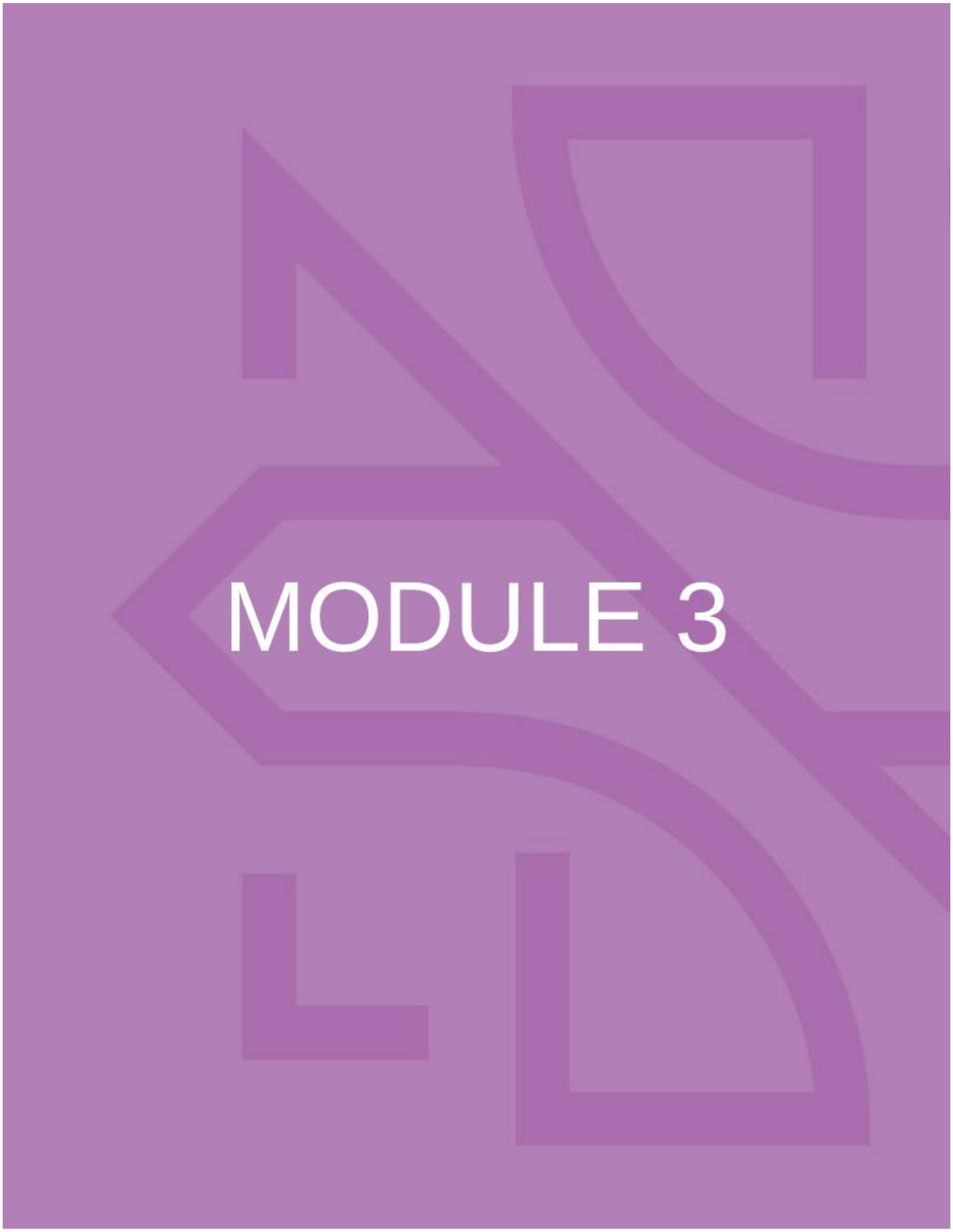
Hope is important to every one of us. Can you think of a situation where you had hope? Think about what will give you hope today.

A Nav-CARE story

June and Joe were both undergoing cancer treatment when they joined the Nav-CARE program. With both of them living with cancer they were faced with many decisions and losses. Often, they were fatigued and had little energy to do the many household tasks. Having a volunteer who listened to them and explored options with them helped them both enormously. The volunteer helped them to think through what was most important to them during this time and to focus their energies on that. When asked what Nav-CARE meant to them they stated, “It’s nice to have someone we could tell our whole situation to without feeling like we were burdening our friends and family.”

Moving forward

As the individual and family assessment happens, the work of advocating naturally follows. This will be the focus on the next module.



MODULE 3

MODULE 3

Advocating for Clients and Families

"I can't think of the word right now…someone who defends you. She was good at clearing the path for me. That took away some anxiety."

Nav-CARE Participant

Competencies

At the end of this module, volunteer navigators will be able to:

1. Identify client/family needs for resources
2. Assist family in making decisions
3. Identify barriers to needed resources
4. Advocate to meet client/family needs
5. Assist client/family to overcome access barriers
6. Advise client/family on negotiating for care and services
7. Facilitate strategies for self-navigation (e.g., Changes Toolkit and location of guide)

Learning Objectives

- Define what advocacy is and is not
- Describe how to be successful as an advocate
- Describe the importance of self-navigation for the client and family
- Learn about the Changes Toolkit as a tool for individuals and families so they may seek out their own supports

What is advocacy?

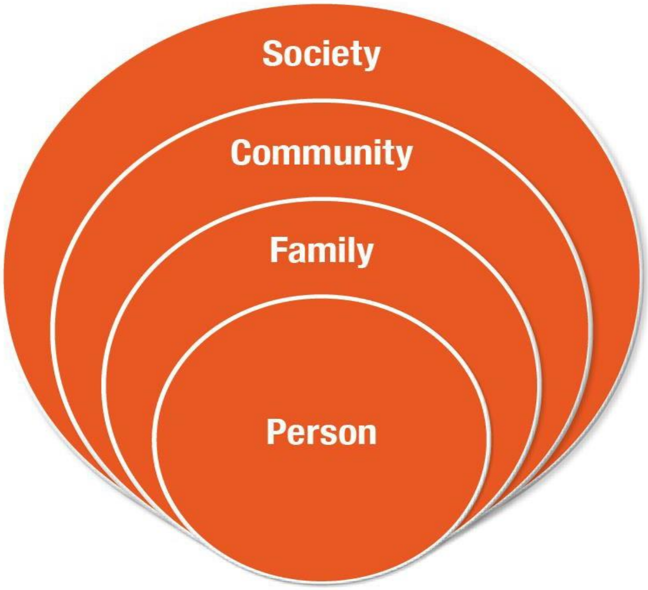
Advocacy IS:

- A process that involves seeing a need and finding a way to meet that need (Amidei, 2010)
- An advocate is a facilitator, someone who finds creative ways to accomplish something
- A complex skill requiring a mixture of strategic and creative problem-solving, commitment, influence and collaboration
- A collaborative, relational process, which involves working with people to affect change

Advocacy IS NOT:

- Something you do for someone else, rather it involves doing with others. Positive relationships are one of the keys to successful advocacy
- Confrontational or simply stating your :demands" to someone "in charge"

Advocacy can occur at many different layers such as self-advocacy or advocating on behalf of individuals, families, communities, or even for society at large (Shalof, 2013). See diagram below.



How to be an advocate

- Advocacy is a complex skill that improves with practice over time
- It involves engaging others and exercising your voice for the purpose of changing a situation
- Often, advocacy involves speaking out for those who cannot, or do not, speak out for themselves (Canadian Nurses Association, n.d.).

Volunteer navigators are advocates by supporting clients and families to:

- Express their concerns and views
- Access community services and information
- Explore options and choices
- Strategize and learn skills so that they take an active role in their own life

Steps to successful advocacy

(Canadian Hospice Palliative Care Association, n.d.)

1. Identify the goal
    - What are you hoping to accomplish?
    - What are some acceptable outcomes?

2. Know your **audience**
    - Does this person or organization have the authority to make changes? If not, who could you approach?
    - Consider the perspective of the party to whom you are advocating
    - Anticipate and understand their positions and their arguments: what might they say?
    - How might you counter those arguments?

3. Develop a **plan** or strategy
   - What facts and arguments support your position?
4. Be aware of **emotions** - on both sides
   - Sometimes emotions can get in the way, especially with sensitive issues. Your advocacy should be rational. It is important to avoid being led by emotion and to avoid making your advocacy personal
   - The other party may be led by emotion, so it is important they understand your advocacy is based on rational considerations and is not personal toward them
5. Create a clear **message**
   - Be clear about what you're asking for
   - Keep it simple and focused
   - Use positive language
6. **Deliver** your message
   - Communicate clearly to the right person

A navigation example:

The client you are working with has difficulty expressing her needs to her physician in the brief time allowed in the office visit. Together you craft an advocacy plan.

The Goal: The client will be able to communicate her needs to her family physician. **Audience:** The physician is most likely in a hurry and your client may have difficulty what is most important to her amidst so many challenges. She also may not be able to sort out what the physician can solve and what needs to be solved by other providers in her life.

The plan: Prior to each scheduled physician visit, you and the client will discuss and identify her most important needs.

The emotions: Your client is anxious about being more assertive about her healthcare needs. You discuss that and plan a strategy for how the client can think in that moment of anxiety (e.g., this is important and my life will be so much better once this is resolved).

Create a clear message: Write out and rehearse what needs to be said.

Deliver: Allow the client to try this and debrief with her on your next visit.

Points to remember

- Communication is key
- Planning is crucial
- Keep your message positive
- Relationships are important

Navigating conflicting needs

Once needs are identified, the volunteer navigator acts as coach to help met those needs. This can be challenging. There might be an agreement on the needs but not on how to meet it, resulting in conflict. It is important for volunteer navigators to recognize it is common for people to either choose not to meet their needs, or to do so in a way that is different than what others think is best.

Meeting needs requires three things: people must perceive a need; the need must be seen as important enough to address; and the importance has to be greater than the energy and resources required to meet the need.

In many cases, for those living with serious illness in particular, the energy to meet a need is so great they prefer to live with unmet needs. For example, an individual may have tried to get help with symptom relief, but the energy to get that help may have been so great that they have given up trying. Coping with the symptom takes less energy than coping with trying to find treatment. As a volunteer navigator, your job is to help individuals identify their needs and then help to remove the barriers to meeting those needs. This requires finding solutions that are manageable within the resource capacities of the client and family.

Further, individuals and families may have different ideas about how to meet needs. In a recent study with a rural nurse navigator (Pesut et al., 2015), some of the areas of conflict included:

- Where individuals wanted to receive their care (e.g. home or institution)
- Older adult capacities, such as the ability to drive
- Legal issues related to estate planning
- Ideas about who were important people to consider in the plan of care

Conflicts can arise around these competing needs, particularly in the midst of illness and declining health. Furthermore, individuals and family members may often be hesitant to open up conversations in the presence of heightened emotions and potential conflict. Other common emotions felt during these times are guilt, shame, regret, remorse, anger, fear and sadness. These can all affect communication. If the topic is not new, there may be fear of opening old scars (Lichtenthal & Kissane, 2008); however, there may be opportunities to heal and find reconciliation.

Through all of this, individuals and families feel the loss of control. Volunteers can provide support by assisting clients through the decision-making process while allowing them to control their decisions. A way of encouraging independence and a sense of control is through promoting self-navigation.

Self-navigation

An important part of advocacy is to help individuals and families to develop ways to find information and connect to resources by themselves. Just as you are learning how to be a navigator, people with serious illness and their families need to learn to be navigators too.

Self-navigation refers to the process of individuals and families identifying their goals and providing them with strategies to help them meet those goals. But it is more than simply making a list and completing a set of tasks. Self-navigation is focused on using individual assets and building on personal strengths. It is also about being committed to the goal the person wishes to achieve.

As a volunteer navigator, your role in the self-navigation is to help individuals and families identify goals and provide them with strategies to help them meet those goals. It is important to understand that their priorities and goals for their lives at a particular point in time take precedence over yours as a volunteer navigator. For example, a situation may arise when individuals and families make choices to not pursue or receive a type of support you think is necessary or important. It is essential to attempt to understand their way of thinking, provide all of the pertinent information so that they make educated and well- informed decisions, then respect what conclusions they reach. One tool that has been developed to help with this is the Changes Toolkit.

The Changes Toolkit was developed through several research studies to help older persons with serious illness identify their goals and connect with their communities (Duggleby et al., 2012). It is also an organizational tool that can be used to put information in. Take a moment and look at your own copy of the Changes Toolkit.

Below are some instructions for you when you give a person with serious illness and their family their own copy of the Changes Toolkit.

Changes Toolkit

The Changes Toolkit was developed through three years of research to help persons with serious illness and their families deal with the multiple significant changes they experience.

Although the Changes Toolkit was designed for individuals to work through on their own, there are sections where it would be appropriate for the client and volunteer navigator to work through the material together. There are instructions in the Toolkit about how to complete the different activities.

There is no need to go through the Changes Toolkit with the person unless you feel it is important. The most important instruction is that the Changes Toolkit is to be used however the client wants to use it. They can choose what they want to do.

Additional copies of the Changes Toolkit can be purchased by calling 780-492-9171 or emailing devpr@nurs.ualberta.ca. It can be accessed online at www.changestoolkit.ca.

Working as an advocacy team

The **client/family** role in advocacy:

- Is to identify their current needs, priorities and goals as well as possible future needs, priorities, and goals

The **volunteer navigator** role in advocacy:

- Is to assist clients and families in identifying barriers that create unmet needs and to thoughtfully consider creative solutions to help meet those needs

The **volunteer coordinator** role in advocacy:

- Is to support the volunteer navigator in their role, and provide guidance when difficult situations arise such as emotional crises as a result of the many possible barriers to services and resources

A Nav-CARE story

Aging, chronic illness, and caregiving had left Sylvia feeling invisible. It wasn't until she began participating in the Nav-CARE program that she started to feel encouraged again. "I've been helping others, ever since I was young that was a way of life, you helped people. And then I found myself in a position where I was asking for help but I didn't want to be dragging anyone down. Sylvia increasingly had difficulty communicating her multiple needs to her physician in the limited time available in the office appointment. This left her frustrated and overwhelmed as she tried to navigate both her and her husband's needs. While the volunteer was always able and willing to find her the information she needed, it was the compassionate, emotional support of the navigator that Sylvia valued the most. "It makes you feel important when someone comes to your home and takes the time to ask you how you feel, and you can answer the question honestly."

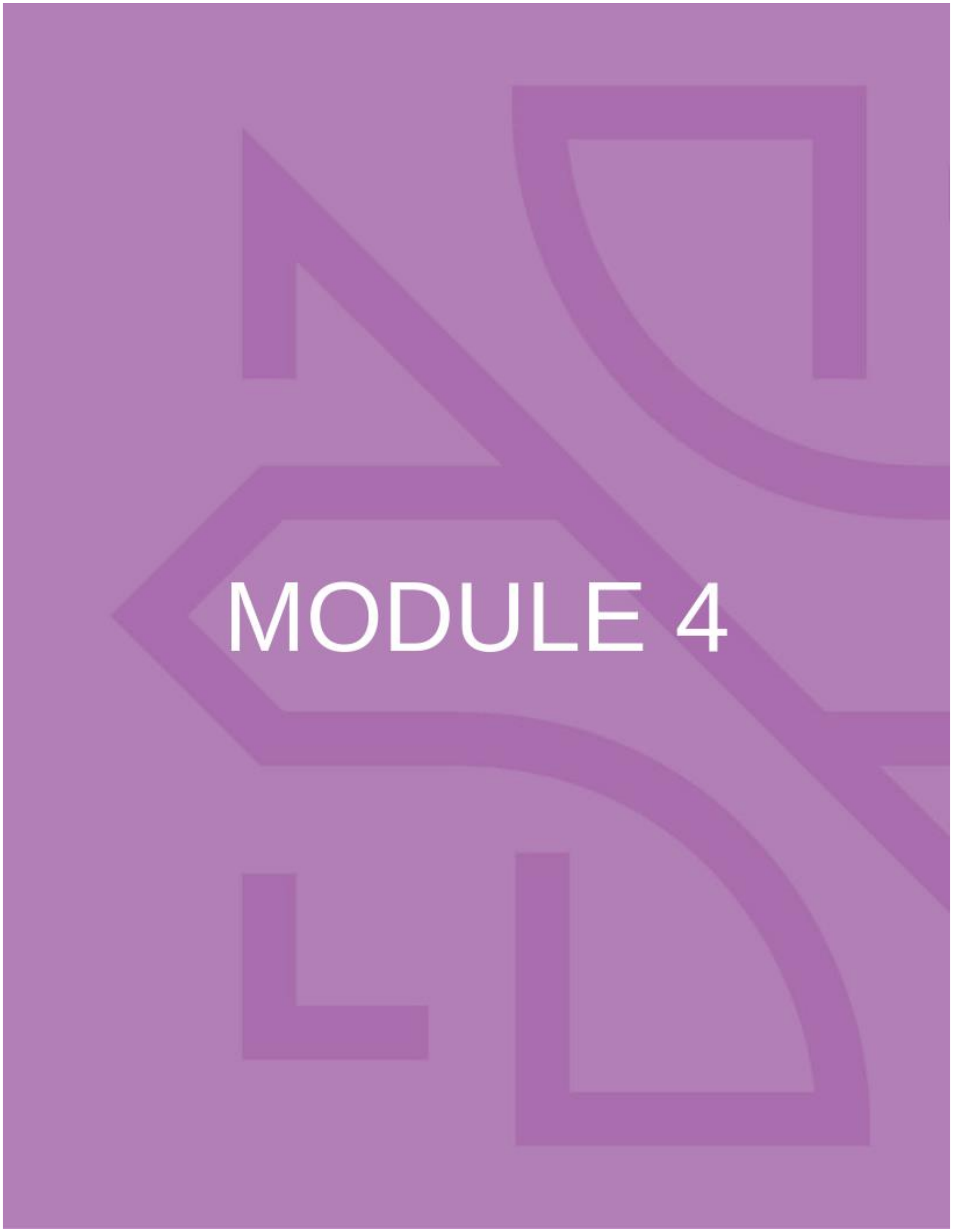
Moving forward

Once needs have been identified, the next step is helping clients and families discover appropriate resources within the community that can help to fulfill them. We now turn our attention to identifying community assets, resources, and services.

Advocates are people who work to make things better

"Never doubt that a small group of thoughtful committed citizens can change the world: Indeed it's the only thing that ever has."

Margaret Mead



MODULE 4

MODULE 4

Facilitating Community Connections

"You know someone is coming by and checking up on you, giving you a sense of community. He brings community to me."

Nav-CARE Participant

Competencies

At the end of this module, volunteer navigators will be able to:

1. Perform a windshield survey of what is available in the community
2. Identify community resources for client/family
3. Identify best-fit for client/family with community resources
4. Communicate to local leaders and/or professionals about community resource gaps
5. Assist client/family to build and connect, or reconnect with community networks/connections

Learning Objectives

- Explain the process of a windshield survey
- Define community assets
- Describe community sectors
- Define community resources by sector
- Identify individual or family needs that can be met by community resources
- Describe the characteristics of leaders and followers
- Describe ways to connect or reconnect client/family with networks

Getting to know your community

The windshield survey: Seeing your community in a new way

Volunteer navigators are often very familiar with their communities, but some community features, resources, and services may not be obvious. Despite the connected nature of many communities, very few people know all of the resources available within their community. In part, this is because what is available is often changing. This is an area where volunteer navigators can play a significant role. Volunteers become skilled at identifying resources that are available that are not part of healthcare services. For example, there might be a church or community organization that provides driving or house repair services. A good way to start is to step back and take a look around your community.

Conducting a windshield survey can help volunteer navigators to see their home community in a different way. A windshield survey is a method of community assessment that helps people to see the community from a wider perspective and often reveals hidden, or taken-for-granted, community features.

It is called a windshield survey because it involves driving around and looking at the community through the windshield, making note of important features. However, keep in mind that, although it is called a windshield survey, it can also involve walking to get a closer look at some things and places.

How to do a windshield survey

According to The Community Tool Box (KU Work Group for Community Health and Development, 2015), there are many factors to notice about your community. We have selected the ones that have the most impact for persons living with serious illness:

- How far do people generally live from the centre of town? What sorts of businesses are in the area? Is there a mix of large and small businesses?
- Are there public parks and spaces? Do they have seating areas, trees or plants? Are they welcoming? Who uses these spaces? Who doesn't use these spaces?
- Are community spaces, parks and buildings accessible to people with disabilities?

- Are there people in the streets at most times of the day? In the evening? How late are people out and about? Do people interact with each other on the sidewalks or in stores?

- Are there young families with children? Older adults? A mixture of young and old? Is the use of mobility devices obvious in the community? Would they be easy to use in the community?
- How heavy is the traffic in the community? Are there times of day in which traffic is heavier? Does traffic consist mostly of cars or are there bicycles? What about heavy trucks or farm equipment? Do semis drive through town?
- What about parking lots? Are they easy to find and to park in? Is parking free?
- What about public transportation? Is there a public transit system? Is it well-used? Who uses it? Who doesn't use it? Does it allow easy access to all parts of the community? Is it reliable? How easy is it to navigate and use? How much does it cost? Are subsidies available?
- What about religious institutions? What kinds of churches are there in the community? Does one particular religion or sect dominate the area? Are religious institutions well attended? Are they accessible to persons with mobility challenges?
- What about health services? Are there hospitals, clinics, nursing homes? How big are they? Are they easy to get to? Is parking easy to use? Is parking expensive?
- Finally, what's your overall "feeling" of the community?

When doing a windshield survey, remember that what you ***don't*** see is just as important as what you ***do*** see.

What’s in YOUR community?

The Windshield Survey can give you a rough guide to the overall feel of your community. However, it is also important to know the specific resources and services available to those living with serious illness. To help you accomplish that, we have created a **Nav-CARE Community Resource Guide** template (a copy is included with your training materials). This template of common resources can be adapted to specify what is available in your community. It is important to take some time to seek out what is available and to add things to your guide as you become aware of them. This guide also includes internet resources that would be considered high quality. You can further learn about locally available resources through the website of your health region. This Resource Guide is meant to be a living document. You should add to it each time you identify a resource and share it with others in your organization.

What are community assets?

Just as individuals and families have assets, so do communities. Community assets can be anything that improves the quality of the community life.

A community asset can be:

- An individual, such as someone who organizes “coffee and tea” gatherings for adults in the community
- A place or a building, such as a favourite meeting place or park
- A community service that helps make life better for people living in the community, such as public transit or Meals On Wheels
- A business that provides jobs and supports the local economy
- Everyone living in the community has the potential to shape the community in a positive way
- Identifying community assets is an important part of your role as a volunteer navigator. The more assets you’re familiar with, the more able you will be to link clients and families with their community

Best fit and best practice

As a volunteer navigator you want to help individuals with serious illness and their families to connect to resources in their communities. When a person is part of a community they interact and shape their community. Every person is different and so is every community. The idea of “best fit” means that people need to find what works best for them within their community (Keating et al., 2013). A resource that works well for one person may not be the “best fit” for another person because we are all so different.

Best fit asks **“What is best for this person at this particular time?”** and is heavily influenced by personal preferences and by the unique circumstances and context in which people live. For example, we all thrive when we are connected socially. But how individuals choose to connect will vary. Some like to be in groups and attend seniors’ centres. Others prefer one on one conversations.

In a role where community connections, independence, and quality of life are the priorities, best practice becomes finding the best fit for the client and family. It may take time, practice, and an open mind to learn to set aside health care priorities and ways of thinking and doing things. “Best fit” may or may not be in line with best practice in health care, but instead will reflect and respect individual and family priorities. The volunteer navigator tries to find solutions that bridge the two, and in this way best practice becomes finding the best fit for the individual and family. Take for example, the concept of living at risk. For many seniors staying at home is so important to their quality of life that they are willing to take risks to be there. Healthcare may not be easily accessible or the property may not be age friendly. But, these concerns must always be balanced by what individuals feel is most important to them.

The idea of “best fit” really is important to volunteer navigators, as they need to work with the client and their families to find what works for them. Finding the best fit requires a balance of skills: it takes problem solving and creativity on the part of the volunteer navigator. Volunteer navigators must learn to lead and to also follow the lead of the client and family. It is important that you become aware of your tendencies and to be sensitive of the needs of those you are supporting. Remember, what you think is the ideal plan of action, or what the evidence suggests is the ideal plan of action, may not be what the individual thinks is the ideal plan of action. While as the leader you will work collaboratively with clients to bring change, you will also need to follow their lead and appreciate their perspective. Therefore, both leadership skills and followership skills are important to the volunteer role.

Self-reflection

Have you ever chosen a path that others disagreed with but you felt was right for you? What did it feel like to have others disapprove of your choices? What happens to people when we try to force them into making certain choices?

Communicating to local leaders and/or professionals about community resource gaps

Inevitably as you seek to connect clients to resources you will find important resources that are missing in your community. An important role for Nav-CARE volunteers and coordinators is helping communities identify what is missing in their community so that they can advocate for change. For example, one of our volunteer navigators identified that there were no legal services in the community that were accessible by wheelchair. She advocated for change and made a difference in her community.

Advocacy for change is most successful when you have relationships with those in the community who can enact change. Therefore, we recommend that you get to know the local leaders and change-makers and that they get to know you. As a volunteer navigator you will develop expert knowledge about the assets and gaps in your community. You will be perfectly positioned to make these needs known to those who are in a position to create change. You may want to have a strategy in your organization for how to connect with local leaders in your community.

Here are some tips for your organization:

1. Think how best to approach local leaders, professionals and other resources
2. Purposely find ways to meet local leaders, professionals and other useful contacts, through local gatherings or more formally by making appointments
3. Introduce the Nav-CARE program
4. Let them know why it is important that they know what you are doing. Your own community connections will make it easier for you to connect others

Connecting and reconnecting with the community

Volunteer navigators not only connect people with the resources they need, they also work to connect or reconnect them with family, friends and neighbours. Older persons with serious illness and their families have described feeling isolated from their communities (Duggleby et al., 2011). Loneliness is a major issue with persons living with serious illness and can put them at risk for more health problems. Loneliness is different from solitude. A person can be lonely while in a crowd.

> *"The most terrible poverty is loneliness..."*
>
> Mother Theresa

Being connected to the community is very important to adults with serious illness and their families. Below is a quote from a person with cancer to illustrate this point:

"I am part of the community but I feel alone. Family and friends come to visit me, but I feel isolated as they are unable to understand what is happening to me and my wife. They are unable to care for me…. Yet this is my home." (Duggleby et al., 2011, p. 2)

Some ways to connect or reconnect people with serious illness and their families with the community may be to:

1. Have the client and their family describe what they participated in previously
2. Have them identify people in the community who are important to them
3. Identify the barriers to connecting with others
4. Increasing their social support (encourage friends and family to visit)
5. Increase their opportunities for social interaction (discuss ways that the can attend community events)
6. Identify ways they can reconnect with others and their community

Potential ways to decrease social isolation and loneliness may be to:

1. Encourage the client and family members to contact people they wish to reconnect with through the use of technology (text messaging, Skype), telephone, or letter
2. Help family, friends and neighbours understand the experiences of people and families living with serious illness
3. If transportation issues are causing the disconnection, consider asking community members for help with transportation needs or using adaptive transportation and mobility aids

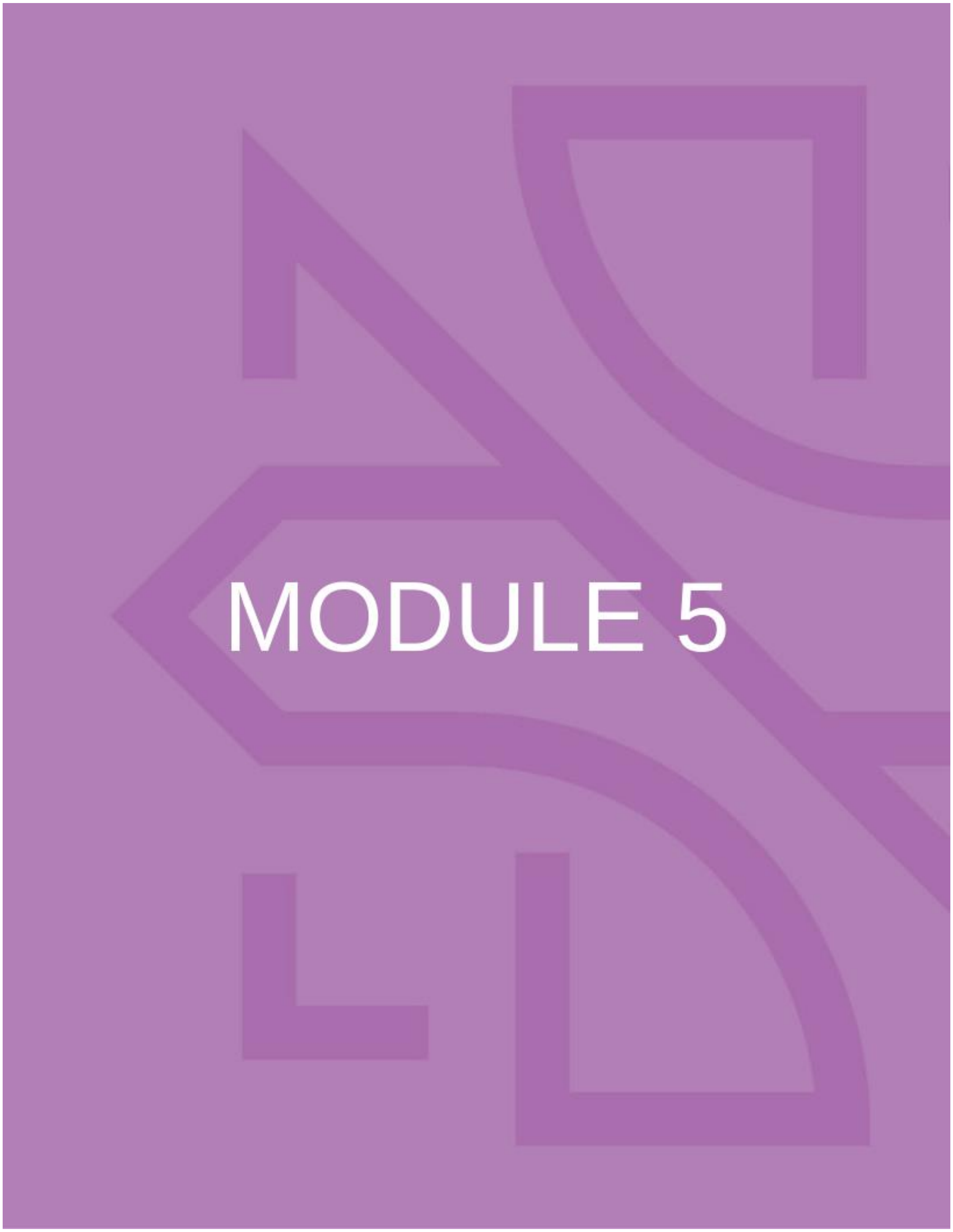
There may be multiple ways that as a volunteer navigator you may need to help clients and their families connect or reconnect with their community.

A Nav-CARE story

Ralph was increasingly struggling with mobility. It was all he could do to take a short walk outside to get his mail each day. But then his mailbox was relocated several blocks away and Ralph could no longer walk to get his mail. Ralph's volunteer navigator noticed that his neighbour walked by each day to get his mail. Together Ralph and the volunteer navigator decided to approach the neighbour to see if he would pick up Ralph's mail when he picked up his own. The neighbour was happy to do so. Now Ralph and his neighbour touch base each day for a moment over the mail. Ralph is connected to his community in a new way.

Moving forward

The next module, Supporting Access to Services and Resources, will build on what has been learned so far and take it one step further by beginning to formulate plans on how to act on some of the connections that have now been made to address quality of life needs and gaps.



MODULE 5

MODULE 5

Supporting Access to Services and Resources

"It's taken a load off of my mind in getting some things done. It's been a big weight off of my shoulder, so I'm able to relax and not worry about things for the future."

"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 it helps us to understand a little more about what is happening. ***And oh, what a difference that makes****."*

Nav-CARE Participants

Competencies

At the end of this module, volunteer navigators will be able to:

1. Identify client/family needs and concerns
2. Access client/family need for support
3. Develop plans reflective of client/family needs and concerns
4. Provide family with caregiving and support resources
5. Coordinate access to needed services
6. Assess client/family service usage
7. Facilitate beginning discussion with client/family regarding advance care planning (ACP) and goals of care
8. Assist client/family with access to services for loss, grief and bereavement support

Learning Objectives

- Identify client/family concerns and/or needs
- Explain the steps required to set priorities
- Develop an action plan
- Describe the importance of open communication

- Describe the process of advance care planning (ACP)
- Describe ways in which to engage in discussions about ACP
- Describe ways to respond to inquiries about Medical Assistance in Dying
- Recognize the importance of bereavement care

In the previous modules, you learned about how to identify quality of life needs for clients and families, what advocacy means, and strategies for how to get to know your community and build connections. In this module you will learn about setting goals, making plans, and using tools that can help you to focus on specific needs, including practical needs and advance care planning.

Individuals living with serious illness and their families face significant challenges and may have many diverse needs.

Individuals and families may have needs for:

Information

Individuals and families have described their need for information as very important to their quality of life (Michael et al., 2014a/b). Individuals and their family may require information about their illness, what to expect in the future and what services or organizations exist in their community (Robinson, Pesut, & Bottorff, 2012). Giving people information can help to inform their decision-making and reduce anxiety.

However, there are several important things to consider when giving information:

- It is very important that the information be given by trusted experts or from a trusted source (Duggleby et al., 2010)
- It needs to be accurate
- Information is not always helpful, as it depends upon the needs of the person with serious illness and their families

- Volunteer navigators need to be aware that there may be times when a person does not want information
- It must also be in a format that is readable, acceptable and easily understood

There is a wealth of information available on how to live with serious illness in the community and online. Those living with serious illness also get an overwhelming amount of information (and sometimes conflicting information) from the different healthcare professionals involved in their care. Individuals often need assistance with getting access to, interpreting, and making decisions around all this information. One of the most valuable roles of the volunteer navigator is facilitating the abilities of clients to access and use this information for self- navigation. This facilitates independence and quality of life.

Support

People may require emotional or spiritual support, as well as practical support with daily activities such as housework, transportation and personal care. Often what is most needed are things that can "fill in the gaps" and provide "an extra pair of hands" to allow the person to live "normally" at home (Robinson, Pesut, & Bottorff, 2012). Providing emotional, spiritual, or practical support can help improve quality of life.

Resources

People may require external resources, such as community services, to meet their physical, emotional or practical needs. Linking clients and families with services that can meet their needs and improve their quality of life is a key component of the volunteer navigator role.

Priorities, goals, and action plans

Setting priorities, formulating goals and developing plans are multi-step processes that involve making decisions based on resources, limitations and alternatives (Forest & Mulcahy, 1976). Alternatives or possibilities are critical to the decision-making process, for without alternatives, there can be no choice. Remember that individuals are only free to choose within their limitations, alternatives and available resources.

As a volunteer navigator, you can help individuals to overcome their limitations, see viable alternatives and coordinate resources.

Making decisions and setting priorities involves:

- Identifying the priority
- Formulating a goal
- Considering alternatives
- Considering consequences to the alternatives
- Identifying values to the decision-maker of these consequences

For volunteer navigators, this process occurs in collaboration with clients and families; it is an open and transparent process, focused on what will work best for the client and family to meet their identified needs.

How to develop plans with a client/family

Establish priority needs

In Module 2, we explored quality of life needs. Priority needs are those needs that are most important to individuals and families. Remember that determining a priority need is subjective; therefore the client or family is best suited to identify his or her own priorities.

Priority setting is a specific kind of decision making with two dimensions, *value* and *time*. Setting priorities involves not only deciding what to do (what is most valuable and important), but what to do *first* (what is most important now).

When individuals set a priority, they judge one possibility to be more important, urgent, or valuable than another at this time.

Priority setting, then, is:

- Deciding what needs doing most
- Deciding what needs doing ***first***

To determine needs and help to establish priorities, ask:

- What is most important in your life right now?
- Please tell me the top three things that you feel would make your life better

Set goals

Priority needs and goals are not the same thing. Replacing the word “need” with the words “will have” can help to identify the relationship between priority needs and goals.

For example:

1. **Priority need: “I need transportation to and from the grocery store”**
2. **Goal: “I will have transportation to and from the grocery store”**

Goals are what we hope to achieve. They may be general or specific. Often specific goals are aimed at fulfilling broader, general goals (Forest & Mulcahy, 1976). A broad goal, for example, is to improve the quality of life of individuals and families with serious illness. Within that broad goal are other, smaller goals, each of which contributes to the larger goal. Improving a client’s appetite or facilitating access to transportation for example, may contribute to the larger goal of improving client’s quality of life.

Plan actions

Goals are achieved through actions. Making an action plan involves answering the follow questions:

- What are your priority needs?
- What results do you hope to get?
- What must we do to achieve that end?
- How are we going to do it?

When planning actions, remember the preferred solution is always the one chosen by the client/family.

Unfortunately, achieving goals in reality is rarely as straightforward as it seems. Adapting to many changes in a short period of time can be extremely difficult. It is important to explore with clients and families some of the reasons that make it difficult for them to adjust to changes. Volunteer navigators should explore some of the barriers that may prevent individuals with serious illness and their families from achieving their goals, including reasons why they may not use services. Knowing what the barriers are is another way of helping people to identify their needs, as barriers often create needs. Knowing what the barriers are can also help volunteer navigators to identify how best to address them.

Remember, discussing options may not always lead to an immediate decision and that is okay. Often persons have been in process around some of the bigger decisions for many years (e.g., selling a rural property to move into town). When the transition comes that forces a decision, individuals will be more likely to make a decision in accordance with their values if they have had sufficient time to anticipate and weight the options. Research with Nav-CARE clients has indicated that this process in which volunteers help them to reflect on decisions is one of the most valuable aspects of the program.

What are some of the things that prevent people from using community services?

The Federal/Provincial/Territorial Ministers Responsible for Seniors, (2007) and Gallagher & Truglio-Londrigan (2004) have identified several barriers that prevent adults from using resources, including:

- Transportation problems, including lack of public transit and parking difficulties
- Geographical and/or social isolation
- Lack of knowledge of available resources
- Lack of facilities or resources
- Complexity of the system
- Superficial or ‘cookie cutter’ connections not adapted to individual needs
- Costs
- Vision and/or reading-related difficulties
- Lack of access to a computer and/or internet
- Lack of knowledge of computers
- Complicated automated telephone systems
- Lack of access to cable TV or radio

When setting priorities with individuals and families, ask them specific questions about barriers. To help clients form a plan or identify barriers, ask:

- What do you think you will need to achieve this choice?
- What do you think might be the issues that would prevent this choice? (McCall & Rice, 2005)

Once the client has identified some of the barriers, you can work together to set goals for how to overcome them, make a plan, and take action!

CRITICAL TO REMEMBER

The role of the Nav-CARE volunteer navigator is to facilitate priority setting and to follow the lead of clients and families. The navigator does not make decisions for people; instead, navigators collaborate with people, working with them to support the decisions they make to enhance their quality of life.

Supporting access to community services and resources to assist with practical needs is a large part of the volunteer navigator's role. Research has shown that many individuals and families struggle to balance practical needs with other increasingly important needs (Robinson, Pesut, & Bottorff, 2012). Finding ways to assist clients and families with practical needs is an important component of improving their quality of life.

Examples of Coordinating Access

- Helping with technology needed to access services
- Facilitating access to road tests prior to renewing driver's license
- Assisting with researching healthcare professionals and making appointments

To help identify practical needs, you may want to use the following tool, in collaboration with an individual or family:

Task	Did you need help in the past 3 months?	Were you able to get the help you needed?	Do you need help now?	Do you think you may need help in the future?
Filling out forms	**YES / NO**	**YES / NO**	**YES / NO**	**YES / NO**
Housecleaning	**YES / NO**	**YES / NO**	**YES / NO**	**YES / NO**
Income Tax preparation	**YES / NO**	**YES / NO**	**YES / NO**	**YES / NO**
Yard care	**YES / NO**	**YES / NO**	**YES / NO**	**YES / NO**
Gardening	**YES / NO**	**YES / NO**	**YES / NO**	**YES / NO**
Grocery shopping	**YES / NO**	**YES / NO**	**YES / NO**	**YES / NO**
Personal transportation to or from events	**YES / NO**	**YES / NO**	**YES / NO**	**YES / NO**
Home repair or maintenance	**YES / NO**	**YES / NO**	**YES / NO**	**YES / NO**
Meal preparation	**YES / NO**	**YES / NO**	**YES / NO**	**YES / NO**
Snow removal	**YES / NO**	**YES / NO**	**YES / NO**	**YES / NO**
Delivery service	**YES / NO**	**YES / NO**	**YES / NO**	**YES / NO**
Garbage removal	**YES / NO**	**YES / NO**	**YES / NO**	**YES / NO**
Mail	**YES / NO**	**YES / NO**	**YES / NO**	**YES / NO**
Banking	**YES / NO**	**YES / NO**	**YES / NO**	**YES / NO**
Taking medications	**YES / NO**	**YES / NO**	**YES / NO**	**YES / NO**
Picking up medications from the pharmacy	**YES / NO**	**YES / NO**	**YES / NO**	**YES / NO**
Other	**YES / NO**	**YES / NO**	**YES / NO**	**YES / NO**

(Adapted from "Aging Well in Haliburton County" Questionnaire available at afc.uwaterloo)

Communicating with service providers

Individuals living with serious illness often see many different health and social service providers. It can be exhausting and exasperating having to explain the same situation repeatedly to different people. Assisting clients to communicate with others, such as healthcare professionals, can be an important part of the volunteer navigator role. For example, volunteers might assist clients with communication strategies such as identifying their priority problems, bringing up sensitive medical issues, communicating their wishes, understanding physician communication, or acting as a second set of ears at appointments.

Generally, volunteer navigators would not communicate directly with healthcare professionals except in exceptional circumstances where the client is incapable. **It should only happen with permission of the client and their family**. A volunteer navigator should never share any information without the person's permission. The only exception would be communication with the volunteer coordinator.

Individuals and families have identified communication with their various providers as an important factor for those living with serious illness (Robinson, Pesut, & Bottorff, 2012; Duggleby et al., 2014). Ensuring clear communication with doctors, nurses, pharmacists, etc. can avoid causing undue strain on individuals and families. As well it helps to ensure everyone is working toward the same goals for each individual and/or family. One way to facilitate communication is to encourage clients and their families to use the Changes Toolkit health information activity.

The following are some communication tips for volunteer navigators:

- Clarify with the volunteer coordinator a schedule for regular updates, either in person or by telephone
- Share concerns about clients or families immediately with the volunteer coordinator
- Do not email information about clients and families; many email servers are not secure
- Do not use your mobile phone to text information about clients or families to anyone

Self-reflection

Have you ever had difficulty talking to a healthcare provider? If so, can you identify why you had difficulty? Can you imagine the difficulties seniors with complex illness might have in talking to their healthcare providers? Have you learned any strategies that you could share with them to make communication under difficult circumstances easier?

Advance care planning

According to "Speak Up" (n.d.), the Advance Care Planning (ACP) in Canada Initiative, advance care planning (ACP) is a process of reflection and communication, a time for an individual to reflect on their values and wishes, and to let others know about their future health and personal care preferences in the event that they become incapable of consenting to or refusing treatment or other care. Advance care planning means having discussions with family and friends. It may also include writing down wishes, and may even involve talking with healthcare professionals and financial and legal professionals. For more information visit www.advancecareplanning.ca.

As a volunteer navigator, you may find it difficult to bring up the topic with clients and families. You are not alone. Many people, including healthcare professionals, find it difficult to initiate conversations about ACP. Although difficult, it is essential that individuals have the opportunity to discuss their goals and plans for the end of their life. In fact, individuals in studies have said discussions about ACP should be part of a routine and "normal" process, but that **advance care planning should be introduced gently and gradually** (Michael, 2014a).

The volunteer navigator's role in advance care planning is to encourage and support clients and families to think about and write down their goals and wishes for the end of life.

The Changes Toolkit has a specific activity on page 19 that can help begin this discussion: "My Goals of Care." The instructions are:

- Write your thoughts about the goals of the care you wish to receive
- Think about changes you may experience
- Think about whether others need to care for you
- What type of care would you want?
- What do you value that would influence your care?
- Discuss this with others

Short, frequent and casual conversations about ACP are generally more effective than one long interview or information session (Michael, 2014 a/b). ACP may be a difficult process for individuals; they need time to reflect and consider their beliefs, values, and wishes.

Timing

Timing is important when discussing ACP. Studies show individuals may be more willing to talk about end of life decisions late in the course of their illness (Brom et al., 2014). On the other hand, waiting too long to discuss ACP may mean the individual is too ill to make decisions. So it is important to get the timing right (Say, Murtagh, & Thomson, 2006). It is also important to give people enough time to make decisions and think about things for a while.

Canadian resources, such as "Speak Up", the national ACP booklet as well as provincial ACP kits and documents are effective tools to use as they give individuals the opportunity to read and think about their desires on their own time.

Living with serious illness makes ACP a priority, yet research shows people's desired level of involvement in ACP varies. Some people want to be involved and make decisions for themselves, whereas others avoid the topic completely (Braun et al., 2014). Furthermore, this kind of decision-making can be very different depending on cultural background. Culture may refer to people of different ethnic backgrounds, persons with disabilities, people sharing the same disease, people living in rural/remote communities, etc. As a result, individual circumstances based on one's beliefs, values and goals may impact their ACP.

Messaging

Volunteers can perform an important role in advance care planning. However, it is important to get the message right.

- Advance care planning is a process that helps you to think and talk about your goals for future health care should you be unable to speak for yourself
- Advance care planning helps you to create and put into place plans to describe the type of care you want
- Advance care planning is a gift you give to others. If you are sick or injured and you are unable to speak, there is a lot less stress for your family, friends and healthcare professionals when they know what care you want and don’t have to guess
- Advance care planning is for every adult, not just people with health issues
- It is best to do advance care planning when you are feeling able rather than during a crisis
- No one can make you do advance care planning. We can only give you information, answer your questions, and help you with the process. It is something you choose to do
- Over time, revisit your goals for care to make sure they still reflect your wishes. Nothing is set in stone. You can change your wishes whenever you want

Who speaks for you when you can’t?

A benefit of advance care planning is that you are an active participant in your health care, even if you are not able to speak. Some people are able to guide their care right up to their passing, whereas others are unable to speak, possibly because they are unconscious, in a coma, have suffered a stroke or are in the advanced stages of Alzheimer’s. In situations like these, it is best to have healthcare plans in place to allow someone else to speak for you so your voice is heard.

In the Changes Toolkit there is an exercise on page 23 to help people think about choosing a person to speak for them to their family, friends and/or healthcare professionals when they can’t.

The instructions are:

- Write below their name, or names, and their phone numbers so others will know
- Tell them what you want shared with others
- Tell them what you want them to tell the doctors, nurses, and other healthcare professionals
- Let this person, or persons, know when they are to speak for you

For advanced care planning and for identifying someone to speak for you, it is important to find out what provincial laws are in place to make this formal.

Self-reflection

Take a few moments and think about what it might be like to be asked to prepare an advance care plan. How might that make you feel? If you’re comfortable doing so, now might be the time to consider talking to your family and close friends about your own advance care planning.

Medical Assistance in Dying (MAiD)

On June 17, 2016 amendments to the Canadian Criminal Code came into effect making Medical Assistance in Dying (MAiD) legal everywhere in Canada provided certain conditions are met. The service can only be legally provided by physicians and nurse practitioners (depending on the province or territory where you live).

There are two types of MAiD available to Canadians. They include where a physician or nurse practitioner:

1. Directly administers a substance that causes death, such as an injection of a drug. This is commonly referred to as clinician-assisted death.
2. Gives or prescribes a drug that is self-administered to cause death. This is commonly known as patient-assisted death. To date, this is rare in Canada.

MAiD may be topic raised when you are working with people with serious illness and their families. A research review (Monforte-Royo, Villavicencio-Chavez, Tomas-Sabado, Mahtani-Chugani, & Balaguer, 2012) summarized the evidence regarding why patients wished for a hastened death and concluded the reasons were:

- Suffering (physical, psychological and spiritual)
- Sense of loss of self, dignity, meaning in life and hope
- Fear of the dying process and imminent death
- A cry for help expressing a desire to live in a better way
- To maintain control over one’s life, “ace up one’s sleeve just in case”

As you can see from the results of this review, people living with serious illness can experience a range of complex concerns, feelings and emotions. Although many individuals may want to talk about MAiD as an option, research from other countries where this practice has been legal for some time shows that only a small number of people actually ask for assistance to end their life and even fewer make the final decision to die this way.

“Too often we underestimate the power of a touch, a smile, a kind word, a listening ear, an honest compliment, or the smallest act of caring, all of which have the potential to turn life around.”

Leo Buscaglia

Having Conversations

Anyone who has worked with persons who are suffering deeply know that is it not uncommon for individuals to express a wish to die. Asking about MAiD may be a way for individuals to introduce the conversation about their suffering. It does not necessarily mean they want MAiD; they may walk to talk about the things that are making them think about MAiD.

Research in this area suggests that these conversations are vital to helping individuals think through their decisions. In some situations, just having the conversations over time with others about their suffering has resulted in persons changing their mind about wanting MAiD. However, having these conversations require a high level of skill. As a volunteer your best approach is to listen, listen, and listen some more.

If a person wishes to discuss MAiD with you as a volunteer navigator:

- Listen
- Do not express your own opinion about the topic
- Encourage them to talk to their primary care physician or nurse practitioner
- Contact the coordinator from your agency following the conversation

Boundaries of the Volunteer Role

It is important to remember that you must never introduce the concept of MAiD, even if a client talks about wanting to die. You should ensure that they are asking specifically about MAiD before you a respond to a request. It remains a criminal offense to counsel someone to die by suicide and so you want to ensure that your conversation cannot be misrepresented.

In the situation where your client wants to discuss the possibility of MAiD your main responsibility is to encourage them to talk to their primary care physician or nurse practitioner. Even if their primary care physician is a conscientious objector, they have an obligation to inform their patients about the access lines available within each health regions. MAiD is only an option for those who meet specific criteria. As such, volunteers should never put themselves in the role of navigating in relation to MAiD, except to encourage them to talk with their health care provider.

The volunteer navigator has the responsibility to respect and respond to the concerns of these individuals while still respecting their own values. People will only share their thoughts with people who they trust and respect. It is possible that by talking about this with you, it will help them a great deal**. However, remember that it is outside of the volunteer navigator role to do anything beyond listening to clients as it relates to MAiD and helping them to access their health care provider.**

Self-reflection

What do you think about Medical Assistance in Dying? How might this influence your ability to be with others who are considering assisted death?

Supporting access to bereavement care

In the event that your client continues down the serious illness trajectory to death, you will need to think about bereavement care. Because palliative care is believed to encompass the whole family, it does not end with the death of the palliative individual. Care for the family continues as they walk through stages of grief and bereavement. Some say bereavement needs are to be assessed through indicators of risk that suggest who is need of more support (Melliar-Smith, 2002).

Suggested indicators of difficult bereavement according to the Bereavement Risk Assessment Tool (Allen, Haley, Small, Schonwetter, & McMillan, 2013) include:

- Mode of death – was it sudden or traumatic?
- Nature of the relationship – was the relationship strained or tense?
- Received support – do they have support around them or are they alone?
- Anticipatory grieving – were they in denial prior to the death?
- Concurrent life and death – stresses in life complicating death?
- Previous losses – multiple or building bereavement?
- Medical history – are they experiencing their own health challenges?

Many experts believe that bereavement services should be offered and available to anyone, not just those determined to be at risk of complicated grief (Relf, Machin, Archer, & Payne, 2009). One of the reasons for this is that the most positive results come from people who have self-referred as opposed to being assessed and referred (Relf et al., 2009).

Whichever way you arrive at the offering of bereavement support, an important tool that can be given to the bereaved is information (Relf, Machin, Archer, & Payne, 2009).

This information can include resources and services for bereavement support, for example, local hospice organizations, and/ or grief support groups, or specific grief and bereavement counselors.

A Nav-CARE Story

Clara’s quality of life was impacted when her health took a turn for the worse. Chronic debilitating pain left Clara with many unmet needs. Unable to find the energy even to make phone calls, Clara described the assistance of the volunteer navigator as crucial at a time when she felt increasingly frustrated trying to connect to local resources. “The volunteer navigator helped me through some problems when I was really running out of steam. She was able to handle people on the phone for me. I just wasn’t capable of it anymore especially when people don’t have the time to listen to, or hear, what I have to say.”

Moving forward

The ultimate purpose of this curriculum is to help you as a volunteer navigator help adults living at home with serious illness make stronger connections with their community, and promote independence to improve their quality of life.

The modules so far have focused on assessing for assets and strengths of individuals, families, and communities, and establishing connections to fill needs by making these relationships stronger. The next and final module builds on everything presented so far by promoting active engagement of clients in their own quality of life priorities.

MODULE 6

MODULE 6

Promoting Active Engagement Competencies

"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 I could still do it.'"

Nav-Care Participant

Competencies:

At the end of the module, volunteer navigators will be able to:

1. Determine effective and appropriate ways to meet client wishes
2. Identify level of desired client/family involvement in self-navigation
3. Build capacity with client/family towards their desired level of independence
4. Promote desired engagement in decision-making and self-navigation by client/family
5. Develop opportunities for engagement in activities meaningful to client and family

Learning Objectives

- Explain the purpose of building capacity
- Describe the components of active engagement
- Explain the benefits of social, cognitive, physical and spiritual engagement
- Explain the importance of continuous evaluation
- Describe the "Plan Do Check Act" cycle

In the previous modules, you learned about how to identify needs, set priorities, identify community resources and make plans to support the quality of life for individuals and families living with serious illness in your community. In this module, you will learn how to pull everything together by building capacity and promoting active engagement.

Building capacity

Building capacity means assisting individuals to develop the knowledge, skills and support to bring about positive changes in their lives. For volunteer navigators, this can mean sharing information with people (building knowledge), helping them learn new skills, such as how to use a computer, and providing emotional or practical support. Together, these actions can help to empower individuals and families, making them feel more in control of their lives.

Promoting active engagement

Promoting active engagement comes from capacity-building and is based on the belief that people should have, and want to have, a say in the decisions that affect their lives (Sheedy, 2008). People are actively engaged when their values, beliefs and decisions guide the process. As a navigator, your role is not to drive but to discover routes along a pathway set by the individuals and families with whom you connect.

Promoting active engagement depends on a commitment to a family-centric, collaborative process.

Engagement is a five-step process that includes the following:

- **Inform:** Explain your role to the clients and families with whom you work. Let them know what you can do and that you're there to help. Provide them with information.
- **Consult:** Listen to and acknowledge clients' concerns, identify their needs.
- **Involve:** Remember that they identify their own needs and goals.
- **Collaborate:** Partner with clients and families; don't direct them.
- **Empower:** Remember that clients and families are in control. Remind them that you will only do what they want you to do. (International Association for Public Participation, n.d.)

How to promote active engagement:

- Honour the values and beliefs of clients and families
- Listen to what is important to them
- Design creative strategies so they can stay involved in what's important
- Ask them what would help them most
- Partner with clients to overcome barriers
- Remember decisions are always in the hands of the clients and families with whom you work
- Follow through on your commitments
- Whenever possible, give clients and families the opportunity to participate and to self-navigate

Examples of Promoting Active Engagement

- **Sounding board to assist clients with making decisions about their lives and transitions**
- **Advance care planning (e.g., funeral home visits, writing out things clients want healthcare professionals to know**
- **Options of how to modify hobbies so they are achievable (e.g., camping, berry picking)**
- **Design walking routes and an activity plan**

Contribute to capacity

Adults living with serious illness are often active, have lives full of meaning, and are fully engaged in their world. They bring capacities of knowledge, experience, ability, interests, and a desire to be productive (Thanakwang & Isaramalai, 2013). But, those living with serious illness often experience barriers that threaten to reduce this capacity to live a fully engaged life.

Learning to recognize capacity for engagement, barriers to active engagement, and strategies to overcome them is a way volunteer navigators can tangibly contribute to individual, family, and community overall quality of life.

There are many different ways adults engage in their own capacity building in health and quality of life. We have grouped them into four different themes: social, cognitive, physical, and spiritual engagement.

Social engagement

Social engagement includes activities such as participating in volunteer or paid work (Morrow-Howell, Lee, McCrary, & McBride, 2014); caregiving (Stay, Hallenen, Lane, & Arbensman, 2012); participating in social networks (Stay, Hallenen, Lane & Arbensman, 2012), civic, or cultural engagements (Kobayashi, Wardle, & von Wagner, 2015); and taking part in community art projects (Phinney, Moody, & Small, 2014). Social activities such as working, volunteering, or caregiving are also referred to as "productive engagement" (Thanakwang & Isaramlai, 2013).

It is important to recognize the capacity of those living with serious illness to contribute to their own improved overall health, well-being, and quality of life through social engagement. Table 1 summarizes the outcomes of social engagement.

Table 1: Summary of the Outcomes of Social Engagement

Social engagement may ***decrease**:*	Social engagement may ***increase**:*
• Morbidity (Thanakwang & Isaramlai, 2013; Morrow- Howell et al., 2014)	• Physical, cognitive and mental health (Morrow-Howell et al., 2014; Stav et al., 2012)
• Mortality (Thanakwang & Isaramlai, 2013; Stav et al., 2012)	• Happiness (Thanakwang & Isaramlai, 2013)
• Depression (Thanakwang & Isaramlai, 2013; Stav et al., 2012)	• Life satisfaction (Thanakwang & Isaramlai, 2013; Stav et al., 2012)
• Cognitive health decline (Stav et al., 2012)	• Independence with activities of daily living (Stav et al., 2012)
• Health literacy decline (Kobayashi, Wardle, & von Wagner, 2015)	• Morale (Thanakwang & Isaramlai, 2013)
	• Psychological well-being (Thanakwang & Isaramlai, 2013)

Beyond improved health and well-being of the individual, social engagement also has the potential to affect family and community. Increased personal social engagement leads to increased society strength and improved intergenerational relationships (Morrow-Howell et al., 2014).

Although evidence suggests social engagement is beneficial for the health and well-being of adults, it is not always easy; at times, barriers can make it difficult.

Barriers to social engagement

Many of the same things that hinder your own social engagement may also hinder social engagement for those living with serious illness. If they are in a caregiving role, it may be difficult for them to find the time. If serious illness is taking its toll, they may not have the energy. Serious illness may also be decreasing their cognitive or physical ability to function the way they used to, causing them to feel like they cannot be a productive part of society. This can lead to feelings of depression and sadness, further decreasing their desire to engage socially.

Self-reflection

What keeps you from social activities? Not enough time? Not enough energy?

Strategies to overcome barriers to social engagement

The following strategies have been recommended for increasing social engagement (Stav et al., 2012). Encourage clients to:

- Maintain regular contact with friends
- Attend social gatherings outside of the house
- Consider healthy communication strategies
- Play games
- Go on outings if physical health allows
- Participate in clubs
- Continue to pursue hobbies with friends, such as gardening
- Participate in cognitive leisure activities, such as attending museums

Cognitive engagement

Social and cognitive engagement appears to be closely linked. An increased capacity in either social or cognitive engagement may positively affect the other. Therefore, there is potential for increasing overall quality of life for adults by encouraging their continued engagement in cognitive activities. Cognitive engagement includes leisure activities such as playing games, completing crossword puzzles, reading, taking a museum trip (Stav, Hallenen, Lane, & Arbesman, 2012) and use of the internet (Kobayashi, Wardle, & von Wagner, 2015). Table 2 summarizes the literature on the benefits of cognitive engagement.

Table 2: Summary of the Literature on Benefits of Cognitive Engagement

Cognitive Engagement may ***decrease****:*	Cognitive engagement may ***increase****:*
• Mortality (Stav et al., 2012)	• Cognitive and mental health (Stav et al., 2012)
• Depression (Stav et al., 2012)	• Independence with activities of daily living (Stav et al., 2012)
• Risk of dementia (Stav et al., 2012)	• Greater life satisfaction (Stav et al., 2012)
• Health literacy decline (Kobayashi, Wardle, & von Wagner, 2015)	• Morale (Stav et al., 2012)
	• Psychological well-being (Stav et al., 2012)
	• Ability to contribute to health care decision-making “(Kumar, Maskara, & Chiang, 2014)

Barriers to cognitive engagement

Much of the engagement in health for adults living with serious illness revolves around adapting to changes and making healthcare decisions. Some barriers affecting how comfortable adults will be adapting to change and making these decisions include:

- Lack of education (Kumaret al., 2014)
- Decreased attention span (Hess, 2014)
- Lack of interest in making change (Hess, 2014)
- Increased distractibility (Hess, 2014)
- Fear of technology (Kumar et al., 2014)

Strategies to overcome barriers to cognitive engagement

- Engage clients in making decisions by presenting information in alternative ways, for example using humor, public forums, support groups, free training, games, social events, and consultants (Kumaret et al., 2014)
- Present information in such a way that makes it relevant (Hess, 2014)
- Avoid too much information, which can be distracting (Hess, 2014)
- Present benefits to engagement clearly (Hess, 2014)
- Help clients access and understand what they see on the internet (Kobayashi et al., 2015)

Simple cognitive engagement strategies, such as playing a game or recovering an old skill, can improve quality of life and feelings of productivity.

Physical engagement

Physical engagement includes activities such as general exercise, walking, gardening, home maintenance, meal preparation, shopping, dancing, and swimming (Stav et al., 2012). Physical engagement is particularly at risk for those living with serious illness because of symptoms that often make it painful or difficult to move about.

Being physically engaged has the ability to increase overall health and well-being (Stav et al., 2012). Table 3 below summarizes the effects of physical engagement.

Table 3: Effects of Physical Engagement

Physical Engagement may ***decrease****:*	Physical engagement may ***increase****:*
• Mortality (Stav et al., 2012)	• Performance of activities of daily living (Stav et al., 2012)
• Function limitations (Stav et al., 2012)	• Instrumental activities of daily living (Stav et al., 2012)
• Disease severity (Stav et al., 2012)	
• Progression of disability (Stav et al., 2012)	

Barriers to physical engagement

There are many different barriers to physical engagement people may encounter that result in a potential hindrance to their quality of life. Some examples include:

- Environmental factors affecting the use of motorized scooter/ electric wheelchairs including harsh weather conditions, difficult terrain (narrow, uneven sidewalks), stairs, curbs, narrow doorways, and aisles.
- Social factors influencing the use of mobility aids. For example, persons who live in communities of young families may be reluctant to use scooters, wheelchairs, etc.

- Physical factors such as residential arrangements and community infrastructure; for example, suburban living arrangements may have less transportation options for adults when compared to more urban living arrangements. Apartment buildings may also make informal helping networks easier to maintain (Morrow-Howell & Wang, 2013).
- Beliefs suggesting older persons or those living with serious illness should be less physically engaged. For example, a care provider who holds ageist beliefs can hold back an older adult from finding their full potential to thrive and experience health.

Strategies to overcome barriers to physical engagement

As a volunteer navigator, you can inform clients about resources in your community that have made physical adaptations to their environment to accommodate then. A bank with appropriate wheelchair access, or a different route through town that has better quality sidewalks, are good resources to know about. You can keep an eye out for these things when doing your windshield survey, and add them to your Nav-CARE Community Resource Guide, so you can make recommendations to people who need them.

Simply encouraging general exercise or other physical activity can also be beneficial to physical engagement, even if progress is slow. You may want to do some physical activity together, like go for a walk, during your volunteer navigator visits.

Spiritual engagement

Spiritual engagement includes activities such as attending religious services, or private religious or spiritual practices (Stav, Hallenen, Lane, & Arbesman, 2012). Table 4 below summarizes the effects of a decrease or increase in spiritual engagement.

Table 4: Effects of Spiritual Engagement

Spiritual Engagement may ***decrease****:*	Spiritual engagement may ***increase****:*
Depression (Stav et al., 2012)	Mental health (Stav et al., 2012)
Functional problems (Stav et al., 2012)	Independence with activities of daily living (Stav et al., 2012)
Cognitive decline (Stav et al., 2012)	Social connectedness (Stav et al., 2012)

Barriers to spiritual engagement

One of the major barriers to spiritual engagement may be mobility issues, particularly if the client has been involved in attending a spiritual community. Other barriers may be related to the loss and grief that often accompanies living with a serious illness. It can be difficult for clients to make sense of their circumstances or to maintain enthusiasm for spiritual practices amidst great suffering. Spiritual barriers may present as unmet spiritual needs. For example, this may include not finding meaning and purpose in life; an inability to build healthy relationships with self, others, God, or nature; or, a sense of not fulfilling the “image of God” within (Taylor, 2007).

Strategies to overcome barriers to spiritual engagement

Ways of combating spiritual barriers do not need to be as intimidating as many people believe. Once we remove ourselves from the idea of needing to solve spiritual problems, we free ourselves to be available to be present and listen to people wrestle with their questions. Taylor (2007) puts it like this:

> Solving others’ spiritual problems, correcting or eliminating their spiritual suffering and converting individuals to your way of believing are inappropriate and unrealistic goals. Not only are these an unethical approach to caring, but they reflect what may be an unhelpful view of spiritual “problems.” Spiritual problems are not things to solve, but opportunities for finding God (however God is experienced) (p.55).

Taylor goes on to say we cannot solve others' spiritual pain and we cannot push them to solve it either. The answer lies in each person's capacity to sort through their own thinking and this begins with self-awareness. By being present, listening with empathy, and responding in ways that encourage self-reflection, we can provide spiritual support.

Dr. Marsha Fowler, and ethicist and theologian, suggests important safety considerations related to spiritual care. She likens the spiritual dimension of a person to an onion. At the surface of the onion are things such as whether individuals consider themselves spiritual or religious, whether they have spiritual practices, or whether they are involved in faith communities. However, spiritual care also has deeper dimensions that touch on the inner lives of individuals where there may be brokenness and pain. She suggests that persons who do not have formal training in spiritual care should not enter these deeper dimensions with those they are caring for. She likens it to a non-swimmer jumping in to save a drowning person. In these cases of deeper angst, referrals should be made to a spiritual care provider (Pesut, Fowler, Reimer-Kirkham, Johnston Taylor, & Sawatzky, 2009). Ways for individuals to experience an increased sense of spirituality are dependent on the person's beliefs and views on what constitutes spirituality. For example, Stav et al.'s (2012) review discusses going to religious services, spending time praying, and participating in other religious traditions.

Some general guidelines when it comes to helping people with spiritual pain are as follows (Taylor, 2007):

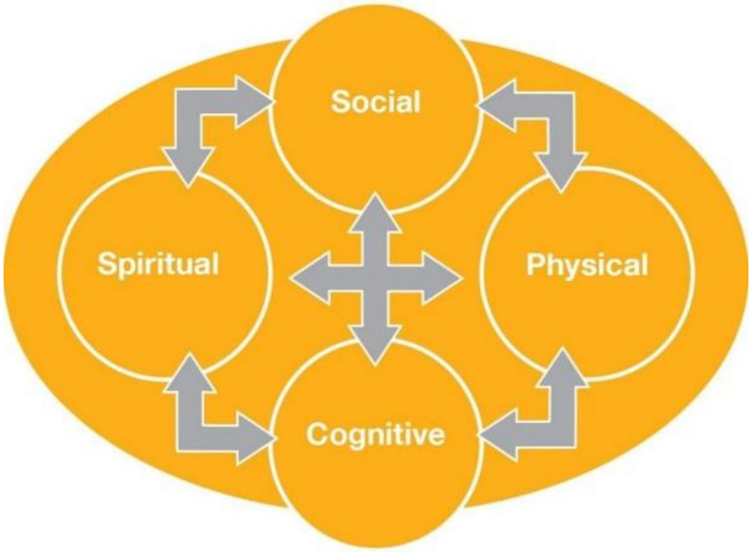
- Be nondirective as a helper, and allow the solutions and answers to come from the client
- Keep the conversation ball in the client's court as much as possible; only speak when silence is not being helpful
- Do not ask questions the client is not already asking
- While listening, ask yourself "what is at the core of what the client is saying? What is the main thought they are feeling?"
- Focus on the client's feelings, not the pathology, the relatives, religious beliefs, or practices
- Focus on the present; although the past informs the present, focus on how the present will affect the future

Holistic engagement of those living with serious illness

The different areas of engagement (social, cognitive, physical, and spiritual) are all interconnected. If an adult living with serious illness is struggling to engage in one area, it will ultimately affect the others. Conversely, if time and energy are devoted to improving engagement in one area, the benefits of this will also be felt in other areas.

As a volunteer navigator, you may help a client to engage socially by attending a community walking group. This will have positive effects on their physical health by increasing their exercise tolerance, but it may also have positive effects on their spiritual health by reconnecting them with others and nature, and it may have positive effects on their cognitive health by increasing conversations with other people.

The potential for building capacity and contributing to life change and increased quality of life are significant.



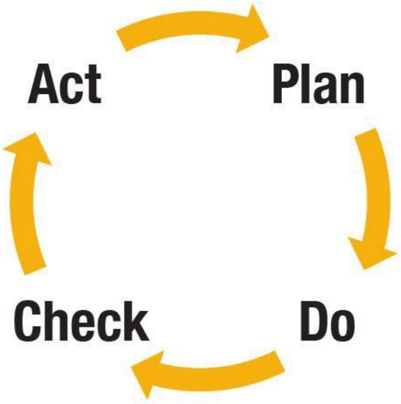
Evaluation

Continuous evaluation is an important facet of the volunteer navigator role. Evaluation must be built into all of your navigation activities as part of a cycle. This evaluation cycle is known as the “PDCA” or Plan, Do, Check, Act cycle (Mind Tools, n.d.).

The PDCA is not a complex process. In fact, we do it frequently in our everyday lives. It is a simple mechanism for checking to make sure everything is working out well and, if not, developing new plans and continuing to try until you succeed. The key to the PDCA is that it be an **ongoing** and **continuous** process.

As a volunteer navigator, you will use the PDCA cycle to ensure the information, support, or resources you provide for individuals and families really are the best fit.

Here’s how it works:



1. **Plan:** After establishing priority needs with individuals and families, set goals and make a plan to achieve those goals.
2. **Do:** Enact the plan.
3. **Check:** At each meeting, ask clients and families how the resources or services are working for them. Based on their answers, you may need to explore the need or problem again. Remember the goal is to establish a “best fit” with resources and services for people, so it’s important to know if the fit really is “the best.” Are they using the resource or service? If so, is it meeting their goals? Is it improving their quality of life?

If the current plan is not working well for people, explore some of the reasons why not. Ask the individual or family for guidance to learn in what ways the plan is not working? What would they most like to change? Are there other ways to meet this goal?

4. **Act:** With the individual and family, begin the planning process again.
5. **Repeat:** Continue this process until the goals have been successfully met.

Helping people with serious illness to be actively engaged in decision-making and directing their care has been discussed in every module in this learning manual. It is an important goal for your work as a volunteer navigator.

A Nav-CARE story

Harvey's eyesight and hearing were becoming increasingly poor as he aged. As a result, he felt disconnected from the things he loved such as talking to his family on the phone and reading. His volunteer worked with him to find assistive devices for his telephone so that he could speak with his family. She discovered his reading tastes and brought audio-books from the library. Harvey found that once again he could enjoy the things that were most important to his quality of life.

Notes:

As you begin your journey…

You are now at the conclusion of the manual. Congratulations! You have been introduced to many new ideas, but this is just the beginning. You will learn much more as you engage in this new role with the Nav-CARE program. Volunteers who have gone before you have found that working as a volunteer navigator has been highly satisfying because of the relationships they build with clients. They have also found it a meaningful role as they make a difference in clients' quality of life. But, they have also told us that the role requires a great deal of self-care.

How do you care for yourself as you care for others?

Here are some strategies to think about.

1. Take time for yourself and engage in those activities that restore you. Perhaps this is walking in nature, engaging in a favourite sport, or reading a good book. The important thing is that when you do it you experience a sense of restoration.
2. Stay engaged with other volunteers in your community. Talk to one another about the work you do and what you are learning. Ongoing learning is a significant source of inspiration.
3. Take time to reflect. Everyone does this differently and reflects on different things. How are you experiencing yourself in relationship? What do you aspire to do or be? What might you do differently? What are you learning about the world and the meaning of living in the world? You may want to journal or to express these reflections through the arts.
4. Know your boundaries and limitations. You will experience many challenges in the role – you may not be able to solve problems or get people what they need. Think carefully about how much you can give to the relationship and set boundaries around that. Think carefully about what is in your power to change and what is not. Then let go of those things that you cannot change.
5. Be thoughtful about the good work you are doing – celebrate it. You are making the world a better place, one relationship at a time.

   Clients have told us that having a volunteer navigator has made a significant positive difference by making their illness experience more ‘livable’. We trust that you will find the same satisfaction and meaning as you start on your journey. All the best in your new role!

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