

# NCARE: Volunteer / Healthcare Provider Navigation

Supporting Older Adults Living with Advancing Chronic Illness

Summary Report August 2016



*“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 help us to understand a little more why they’re [healthcare] doing this or that. And oh, what a difference that makes.” (NCARE Participant)*

*“Cancer is not just the physical thing, it’s an emotional wound. She’s sort of like a placebo in that she’s not going to cure my cancer, but she makes it a lot more livable.” (NCARE Participant)*



## Summary

In this one-year intervention, volunteers were trained in navigation and provided navigation services to older adults in the home. Evaluation of the intervention was conducted at six-months and twelve-months.

## Reason for the Study

Older adults living with advancing chronic illness have unmet needs that result in poor quality of life. These needs include troubling symptoms, lack of social support, loneliness and isolation, lack of information, and an overwhelming number of decisions to make as they adjust to aging and chronic illness. There are few healthcare services available for this population that have been adapted to their special needs.

*“It showed us that other people have got the same problems, have the same feelings...it gives us an uplifting...if someone’s there just to put a hand on your shoulder we know we’re going through it with other people.” (NCARE Participant)*

## The Intervention

---

*She asked, ‘how are things going’ and then I opened up my mouth and we started to talk about what I felt we needed to talk about. It didn’t seem like she was on about this or that, or we must talk about this today. It was more fitting of my needs each time.” (NCARE Participant)*

---

Volunteers received training in navigation through a two day workshop. Each volunteer was partnered with two older adults and family. Volunteer navigators visited older adults in the home every two weeks over a one year period. Navigation services included assisting clients to determine their needs, connecting clients to supportive networks, finding available resources to meet needs, assisting with accessing resources, and promoting engagement with life. Volunteers were supported by a nurse navigator who screened clients and provided ongoing mentorship and support to volunteers. Volunteers conducted 193 visits (either in person or by phone), every 18 days (on average), over the year. The average in-home visit length was about 1.5 hours. Older adults cancelled 46 visits over the study period. Primary reasons for cancelling were feeling unwell or conflicting healthcare schedules. Volunteers and clients suggested that visits schedules could be more flexible depending upon client need.



## Participants

Seven volunteers took part in the project as Navigators. Six of the seven volunteers had backgrounds in healthcare and all volunteers had extensive volunteer experience. Eighteen older adults and three family members took part in the project as clients. Older adults were living with cancer and other life-limiting chronic illnesses. Volunteers were recruited through local hospice societies. Clients were recruited through healthcare providers and public advertising. No volunteers dropped out of the study; one older adult dropped out of the study at six months.

## Findings

Volunteers found the role satisfying and meaningful. They would do the role again and recommend it to others. It took time to learn how to navigate and volunteers were not always sure they were effective with older adults in this new role. However, data collected during study visits and from older adults show that volunteers were skilled and resourceful in meeting client needs. By study conclusion, volunteers were confident in most aspects of navigation. They suggested that continuing education and support were essential.

NCARE clients rated the service as highly important to their care. They experienced many troubling challenges related to getting older and living with an illness. NCARE helped them address those challenges. Volunteers were described as good listeners, caring, personable, outgoing, friendly, patient, positive, capable, conscientious, kind, non-intrusive, and diligent in finding out what they did not know. Clients described four primary benefits of being part of the NCARE service: making good decisions for both now and future, having a surrogate safety net, supporting engagement with life, and, ultimately, “making life more livable” in the presence of illness.

---

*I was surprised by how much it does help the minute she comes in. And later on I said to someone just the other day, ‘You know I did this and I didn’t realize I could still do it.’”(NCARE Participant)*

---

Clients had many decisions to make about things such as treatment, housing, and transportation. They often felt overwhelmed by these decisions. Volunteers acted as “sounding boards” and a “second sober opinion.” Once trust and rapport had been established, clients reported that volunteers provided a safe environment in which to get help with crises and explore challenging topics. This helped to alleviate anxiety. Clients also suggested that volunteers helped them re-engage with hobbies, social situations, and their illness management. This helped offset depression and supported feelings of well-being and productivity. Overall, clients suggested that having a volunteer navigator provided a degree of support that made life more “livable.”



## Lessons Learned

The results of this pilot of volunteer/healthcare provider navigation partnerships are promising. Volunteers found the role satisfying and meaningful, and would recommend to others. We learned that it is important to ensure that volunteers receive ongoing support and mentorship for this new role. Clients told us that being a part of the NCARE service improved their quality of life and met many needs that arose as a result of aging with an advancing chronic illness. We learned that a flexible visit schedule is important as clients' needs vary over time. In summary, we learned that volunteer navigator partnerships can enhance the quality of life of older adults and family living with advanced chronic illness while providing a satisfying and meaningful role for volunteers. We are now adapting, implementing, and evaluating the NCARE model in communities across Canada.

### For further information about this study, contact:

Dr. Barbara Pesut ([barb.pesut@ubc.ca](mailto:barb.pesut@ubc.ca))

Dr. Wendy Duggleby ([wendy.duggleby@ualberta.ca](mailto:wendy.duggleby@ualberta.ca))

Acknowledgements: We would like to acknowledge the funding agencies, volunteers, and clients who gave generously to make this study possible.

#### Investigative Team

Barbara Pesut, UBC

Wendy Duggleby, U of A

Grace Warner, Dalhousie

Konrad Fassbender, U of A

Carole Robinson, UBC

Suzanne Lehbauer, Castlegar Hospice

Marg Malcolm, Trail Hospice

Jane DiGiacomo, Nelson Hospice

#### Knowledge Partners

Brenda Hooper, Nurse Navigator

Elisabeth Antifeau, Interior Health

Lorraine Gerard, BCHPCA

Kathryn Downer, Pallium

Sharon Baxter, CHPCA

#### Additional Funding Partners

Canadian Hospice Palliative

Care Association

Pallium

Interior Health

University of Alberta, Faculty of Nursing

Canada Research Chairs Program

Canadian Patient Safety Institute

