# First Link dementia support offered by the Alzheimer Society of BC

n estimated 70 000 British Columbians have dementia.1 Dementia has a deep impact on the lives of individuals with the diagnosis, but it also casts a large shadow over the lives of families, friends, and caregivers. It is often called "a family disease" because everyone experiences some stress watching the decline from dementia.<sup>2</sup> The many clinical impacts of the disease include changes in cognition, emotion, behavior, physical health, function, and social and financial well-being of individuals with dementia and of their loved ones.

The dementia journey is long and challenging. Caring for individuals with dementia means caring for both the patients and the caregivers. The care team extends from the patient and primary care provider to the primary health caregiver, family, friends, community teams, hospitals, long-term care, and palliative care. Another important resource is First Link dementia support, which is offered by the Alzheimer Society of BC.3

First Link referrals help physicians and other health care providers connect individuals with dementia and their caregivers to the Alzheimer Society of BC's programs and services, as well as to community resources. The goal is to help understand the diagnosis and to equip one to better cope with the changes to come. Education helps one to be prepared for the course of the disease, so that nobody

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## First Link resources

Referral information: https://alzheimer.ca/en/bc/We-can-help/About-First-Link-Referrals

**Referral form:** https://alzheimer.ca/sites/default/files/files/bc/generic\_formalrefform \_fillable\_2018-03-13.pdf

Dementia helpline: https://alzheimer.ca/en/bc/We-can-help/Resources/First-Link -dementia-helpline. English: 1 800 936-6033, Cantonese or Mandarin: 1 833 674-5007, Punjabi: 1 833 674-5003

Bulletins: https://alzheimer.ca/en/bc/News-and-Events/Newsletters-and-updates/First -Link-bulletins

walks the journey alone. First Link supports individuals with mild cognitive impairment and all dementia diagnoses.

In addition to general information about dementia, programs and services offered by First Link include:

- Individual support: Ongoing calls to help support and identify changing needs.
- Dementia education: In-person and online educational workshops on a wide variety of topics from diagnosis to end of life, including Getting to Know Dementia, Shaping the Journey, the Family Caregiver Series, and Grief and Loss.
- Support groups: In-person and telephone groups for people in the early stages of dementia and groups for caregivers.
- Minds in Motion: A social and fitness program for people with mild cognitive impairment in the early stages of dementia, to attend with a care partner.
- Information: Brochures, fact sheets, and videos, as well as quarterly newsletters including updates on events in the patient's
- Referrals to other community and health care services as necessary.

Throughout the progression of the disease, First Link clients receive regular, proactive contact from the Alzheimer Society of BC, and the society continues to provide relevant support as clients' needs change.

The First Link Dementia Helpline is a confidential, toll-free telephone contact with volunteers trained in dementia care. The helpline supports English, Punjabi, Mandarin, and Cantonese languages weekdays, 9 a.m. to 4 p.m.

When someone is referred to First Link by a health care provider, they will receive a call from a trained Alzheimer Society of BC staff member within a few weeks. Ongoing follow-up contact provides information about the disease, help planning for the future, tips for day-to-day living, and support services when needed. A First Link bulletin is distributed every 3 months to keep everyone informed about upcoming support and education programming, including Minds in Motion. The bulletin is regionally distributed for BC.

First Link referrals are associated with improved information on dementia and its progression, and improved access to community resources. A study has shown that people who

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established and agreed-upon referral patterns. The SCF reports large reductions in referrals outside their Nuka System of Care. The specialties closest to the SCF are shown on Figure 1B: podiatry, traditional healing, surgery, ENT, audiology, optometry, complementary services (acupuncture, chiropractic, oncology, and massage), dental, and cardiology. Cardiology provides its own referral resource of consultations for patients they have not seen. The SCF asserts that emergency room

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visits and hospital stays do not contribute to long-term health and are preferably avoided by continuous primary care.

# Lessons learned

The following are my main takeaways from learning about the SCF's gradual development of the Nuka approach (SCF's gradual approach to integrating specialty services with primary care):

- 1. The SCF innovated slowly, with careful measurement. Rushing to incorporate expensive innovations for theoretical reasons is not the Nuka way.
- 2. Choosing which services to integrate was guided primarily by asking customerowners what worked best for them and keeping track of outcomes (e.g., reductions in specialist visits and ER or hospital stays).
- 3. Migrating what were formerly specialist roles into primary care has paid for itself by saving costs associated with emergency room visits, specialist office visits, hospital stays, and an overall healthier population. ■

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were referred directly to First Link by health care professionals (direct referrals) received services 11 months sooner than clients who accessed the services themselves (through self-directed referrals). Early intervention helps individuals with dementia plan their own care while they can do so. The referral form is a fillable PDF document (except in the Firefox web browser).

Further information on First Link, referral documents, and helpline information is available on the First Link website [see box on page 24].

—Hetesh Ranchod, MD

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If you have questions or would like more information, contact gpsc.billing@doctors ofbc.ca or download the physician FAQ document posted at http://gpscbc.ca/what-we-do/longitudinal-care/incentive-pro gram/community-longitudinal-family-phy sician-payment.

—Shelley Ross, MD Co-chair, General Practice Services Committee

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