



United Way of the Lower Mainland's

Family & Friend Caregivers
Information and Resource Handbook

2016

For seniors and boomers who are caring
for older family members and friends

FOREWORD

United Way of the Lower Mainland is pleased to place this *Metro Vancouver Family and Friend Caregivers Information and Resource Handbook – Second Edition*, in your hands. The handbook is United Way’s response to repeated calls for an accessible, up-to-date guide – in print form – to all the information that family and friend caregivers of the elderly need in their caregiving journeys.

Directed to family and friend caregivers, the handbook recognizes the crucial role that unpaid caregivers play in Metro Vancouver’s public health system. Just like doctors and nurses, they need comprehensive, up-to-date information in order to provide proper care to their loved ones.

The handbook is also a response to former B.C. Ombudsperson Kim Carter’s call for accessible, up-to-date and coordinated information about seniors’ services and health care across the public health authorities in B.C. so that seniors can secure *The Best of Care* (the title of Carter’s 2012 report). It can be seen, too, as part of the “regional health intelligence system” that UBC’s Dr. Jean Kozak envisioned in 2012. For family and friend caregivers and others at the community level, it knits together the two health authorities operating in the Metro Vancouver region in helpful ways.

This handbook is the work of Katherine Willett, a Lower Mainland-based gerontologist and elder-care consultant. Her extensive knowledge about caregivers and their needs is based on more than 18 years’ experience working closely with family and friend caregivers in the region. Katherine is also an information and referral specialist whose encyclopedic knowledge of caregivers and their needs has informed efforts to develop a provincial strategy for caregivers in B.C. She represents the interests of seniors and caregivers in several formal advisory capacities in our region’s public health and social service sectors.

She has also worked as the co-executive director of the Caregivers Association of B.C., led a popular, long-standing caregivers’ education program in Burnaby noted for its successful outreach to multicultural caregivers, and is currently a consultant and networking guru for Family Caregivers of British Columbia.

Please use the contact information provided on the preceding page to forward general comments, as well as new information, revisions and corrections. Your contributions are appreciated.

The *Metro Vancouver Family and Friend Caregivers Information and Resource Handbook* can also be found on United Way of the Lower Mainland website at www.uwlm.ca/resources/caregivers-information-and-resources-handbook

Beverley Pitman

Beverley Pitman, PhD

United Way of the Lower Mainland

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WELCOME

We hope you enjoy this second edition of the *Metro Vancouver Family & Friends Caregivers Information and Resource Handbook*.

As we grow older, the chance of developing complex health issues increases as does our need for assistance and care. If you are caring (unpaid) for an elderly family member or friend, this handbook was written for you! Caring for an elderly person with failing physical and/or cognitive health can provide challenges and significantly change your life. When you know what government services are available to you and your care recipient and tap into non-profit society and business resources, you can reduce strain, worry, and the risk of deterioration of your own health that can accompany the journey family and friend caregivers take when they care for an older person. As well, your care recipient can experience an improved quality of life by being connected to community resources. This handbook stresses three points:

1. TALK WITH THE PEOPLE YOU CARE FOR ABOUT PLANNING AHEAD AND THEIR WISHES FOR THEIR “OLD AGE” – PLEASE DON’T WAIT UNTIL A CRISIS OCCURS

Many transformations, big and small, come with aging, which is a normal part of the human life course. Growing old is not something to be denied or ashamed of. Have conversations about topics in this handbook as you all think about the future. Remember: decisions made during a crisis cannot be as well thought out as those made during a period of calm. Plus, the resources you might want to access during a crisis may not be available on demand. Many programs and services have wait lists.

2. CAREGIVING – DON’T TRY THIS ALONE! (Family Caregiver Alliance motto)

Get help. Tap into the services and expertise available to you so that you don’t become exhausted and will have time and energy to care for yourself. Getting help also gives you valuable time for just BEING with your care receiver as opposed to always DOING a task for that person.

3. PRACTICE SELF CARE

Protect your health. This means eat nutritiously, exercise, socialize, get enough sleep, and practice stress management. You do not have to sacrifice your life for your care recipient. Instead, find the balance between your needs and the needs of your care recipient. You can love yourself as much as you love your elderly frail family member. M. Allison Reeves, of Allison Reeves Counselling who works with Family Caregivers of British Columbia, reminds us: “Recognize your NEEDS come before another person’s WANTS. Your needs are like that of the person on the airplane who has to put on their own air mask first before attending to others they are looking after.” For example, your need for some assistance, takes priority over your care recipients’ want to have you do everything and not have outsiders helping out.

Katherine Willett Gerontologist, Eldercare Consulting & Planning

Coordinator, *Metro Vancouver Family & Friend Caregivers Information and Resource Handbook*

DEDICATION

This handbook is dedicated to all the family members and friends who lovingly provide unpaid care to those who struggle with the many changes aging can bring.

ARE YOU CONCERNED... WORRIED... STRESSED ABOUT AN ELDERLY FAMILY MEMBER OR FRIEND?

Are you a family caregiver?

Family caregivers provide unpaid care and assist loved ones who need support, at their home, in supportive housing (SH), assisted living (AL), or a residential care (RC) facility, because of age, injury, long-term chronic illness or disability. Caregivers simply think of themselves as spouses, adult children, siblings and friends. Seniors are caring for spouses, boomers are caring for aging parents, and young people are caring for adult siblings or parents with a disability.

What do family caregivers do?

Caregivers help with daily care activities such as bathing, dressing, feeding, grooming, medication management, toilet hygiene, and transferring (e.g. getting in and out of bed); these are called activities of daily living (ADLs). ADLs refer to functional status and are assigned high importance in health care. Carers also assist with instrumental activities of daily living (IADLs), which help seniors continue to live independently. These include such things as cooking, finances, housekeeping, oral hygiene, managing medical appointments, pet care, religious observances, selecting and supervising helpers, shopping, and transporting. And there is more: emotional support; exercise; foot care; grocery shopping; home repairs; hospital visits; housing; laundry; legal issues; making the home safe; socializing; and end-of-life care.

Why do family caregivers need to take good care of themselves?

Caregiving is a wonderful way to express love and to give back to family members and friends. The work caregivers do is a gift to the people being cared for, and to our communities. While caregivers help and honour their care recipient, they also experience stress given the numerous tasks they face. All these tasks can affect physical, financial, mental and emotional health. The stress and losses (the things caregivers have to give up) add up and can create caregiver stress. If you can no longer cope with the tasks of caregiving, your care recipient(s) also suffers.

CAREGIVERS – Please send us your comments about the usefulness of this handbook.

Your comments and suggestions for improving it will be taken into account in the next edition.

E: MetroVanCaregiversHandbook@yahoo.ca

Mail: Metro Vancouver Caregivers Handbook, c/o United Way of the Lower Mainland, 4543 Canada Way, Burnaby, B.C. V5G 4T4

This handbook can be found on the United Way of the Lower Mainland website at www.uwlm.ca/resources/caregivers-information-and-resources-handbook

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PART I. ABOUT THIS HANDBOOK

1. A HANDBOOK JUST FOR CAREGIVERS

When aging brings on complex challenges, family members and friends, along with services offered by government, non-profit societies and private businesses, can all assist. But it's not easy to find the help needed and sometimes we don't even know what questions to ask, let alone where to go.

The former B.C. Ombudsperson, Kim Carter, and the new B.C. Seniors Advocate, Isobel Mackenzie, recognize the struggle that seniors and their families undergo in the complex journey of caregiving, and how badly they need more accessible information. Right now, the information caregivers need is scattered, if it is publicly available at all.

It is our hope that this handbook will help family and friend (unpaid) caregivers as they take care of their loved ones. Caregivers are a genuinely vital part of the health-care system in Metro Vancouver. The handbook provides the best currently available information to understanding the range of services available, how services work, and ways to contact service providers.

2. METRO VANCOUVER CAREGIVERS HEALTH AUTHORITIES

This handbook covers 21 cities and villages in the Metro Vancouver area. These communities fall within the geographical areas served by the B.C. Ministry of Health's Fraser Health Authority (FH) and Vancouver Coastal Health Authority (VCH). The health authority (HA) responsible for the 21 cities and villages is noted below. This is helpful to know since local HAs provide important services to seniors and family caregivers. You will learn more about HA services and how to access them throughout this handbook.

- Bowen Island - VCH
- Burnaby - FH
- Delta - FH
- Langley: Langley City, Langley District - FH
- Lions Bay - VCH
- Maple Ridge - FH
- New Westminster - FH
- North Shore: North Vancouver City, North Vancouver District, West Vancouver - VCH
- Pitt Meadows - FH
- Tri-Cities: Coquitlam, Port Coquitlam, Port Moody plus Anmore and Belcarra - FH
- Richmond - VCH
- Surrey - FH
- Vancouver - VCH
- White Rock - FH

3. INFORMATION & REFERRAL (I&R) SERVICES

A lot of the services and programs mentioned in this handbook are available in many communities. Some might be unique to just one or two places.

To learn if a service you need is available for you, as caregiver, or where your elderly care recipient lives, you can contact the following I&R services to ask what is available in your community.

3a) bc211

www.bc211.ca

This free, confidential 24/7 service provides information specialists by simply dialing 2-1-1 to learn about community, social services and government programs. (bc211 does not refer to private business services.) Funded by United Way of the Lower Mainland, bc211 is the largest I&R agency in the Lower Mainland and its information database covers Metro Vancouver, Squamish-Lillooet, Sunshine Coast, and the Fraser Valley Regional District. Multilingual telephone assistance is available. Text telephone (TTY) for people who are deaf, hard of hearing or speech-impaired: call 604-875-0885.

You can also email questions to help@bc211.ca (expect up to 24 hours for a reply), or search its listings at its Red Book Online at <http://redbookonline.bc211.ca>.

3b) 8-1-1

www.healthlinkbc.ca/servicesresources/811

8-1-1 is a free, non-emergency health information phone line for all B.C. Just dial 8-1-1 to speak 24/7 to a health services representative who can help you find health information and services or connect you directly with a registered nurse (24/7), a registered dietitian (Monday to Friday; 9 a.m. - 5 p.m.), or a pharmacist (daily; 5 p.m. - 9 a.m.). Any one of these health-care professionals will help you get the information you need to manage health concerns. The 8-1-1 phone line is operated by HealthLinkBC, a Ministry of Health service. The multilingual service provides translation services on request in 130 languages. Text telephone (TTY) for people who are deaf, hard of hearing or speech-impaired: call 7-1-1. The HealthLinkBC website also contains a great deal of health information at www.healthlinkbc.ca.

Note: If you are dealing with a health emergency, call 9-1-1 for ambulance, fire and police service.

3c) LOCAL COMMUNITY INFORMATION AND REFERRAL SERVICES

Some communities have a free local I&R service. While limited by the number of hours they operate (typically standard weekday work hours), they sometimes know of small, unique community services not listed in large databases such as bc211 and HealthLinkBC. When problem-solving eldercare issues, it can be wise to use both a large and a small local I&R service so nothing is missed out. Dial 2-1-1 to learn about local I&R services.

3d) YOUR MUNICIPAL LIBRARY

Your library's reference service can provide reliable information. If you cannot go to your library, you can phone or email with your questions. If you are not computer savvy, the reference librarian can look up information for you, and if you are at the library, you can print out articles, forms, etc. for a small price per page.

ABBREVIATIONS USED IN THIS HANDBOOK

To ease readability, six abbreviations are used in this handbook.

For health authority matters: **HA** stands for health authority;

FH stands for Fraser Health Authority; **VCH** stands for Vancouver Coastal Health Authority.

For housing matters: **AL** stands for Assisted Living; **SH** stands for Supportive Housing; **RC** stands for Residential Care.

PART II. EDUCATION AND SUPPORT FOR FAMILY CAREGIVERS

Dr. Janice M. Keefe, PhD., Professor of Family Studies and Gerontology at Mount Saint Vincent University, in a Big Thinking talk called *Who Cares? Aging Boomers and Caregiving Policy in Canada* uses an analogy of caregivers as tree roots – hidden, invisible, underground, critical ingredients in the stability of the frail elderly care receivers, who, in this analogy, are the tree trunk that caregivers help hold up. Some roots are stronger than others; some caregivers are stronger with deeper roots/resources (physical, psychological, financial) than others. ALL caregivers need to know what supports are available; hence this part of the handbook addresses education and support programs specifically designed for family caregivers.

4. GENERAL EDUCATION AND SUPPORT PROGRAMS

Family caregiver education and support programs are for family and friend caregivers who provide unpaid care and assist loved ones who need support, at their home, in SH, AL, or a long-term care facility (RH), because of age, injury, long-term chronic illness, or disability.

Education programs help us gain knowledge about the problems we face. Caring is a journey that can develop slowly over time as with a diagnosis of dementia, or come on suddenly with a stroke. The journey can last many years, which is why caregiving is spoken of as “a marathon, not a sprint.”

Support groups help with the sense of being alone with a hard job to do, and painful feelings of loss related to seeing a loved one deteriorate. Support groups remind us we are not alone on the caregiver journey, and offer a friendly, open and informal atmosphere of understanding to share experiences.

The programs below can help you feel supported and pace yourself as you navigate the twists and turns of the caregiver road. These are all free unless otherwise mentioned.

4a) BURNABY

Burnaby Family Caregivers Support Group

604-291-2258 www.bsoss.org

This support group, run by the Burnaby Seniors Outreach Services Society offers:

- Meetings alternate Mondays, 2:30 - 4 p.m. for sharing emotions/experiences.
- Occasional educational speakers' series.
- Seventh Annual Caregiver Information & Speakers Expo, featuring a variety of speakers and exhibitors, Saturday, February 27, 2016, 10 a.m. - 3 p.m., at Holiday Inn Metrotown.
- E: bsoss@telus.net

4b) DELTA (SOUTH DELTA & LADNER)

South Delta Caregivers' Education & Support Network

604-943-3921 or 604-948-0660

Meeting space is contributed by the Delta Hospice Society. Services include:

- An eight-session education program once a week, \$50.
- A support group for those who have completed the eight-session education program meets the second Tuesday of each month, 12:30 - 2:30 p.m.
- E: info@deltahospice.org

4c) LANGLEY

Langley Caregivers Support Group

778-328-2302 2 www.lsr.ca

Offered by Langley Senior Centre, a support group meets Thursday from 1:15 - 2:30 p.m.

E: info@lsr.ca

4d) NORTH SHORE

Caregiver Support Program

604-985-7138 www.nscr.bc.ca/information/caregiver-families.html

Offered by North Shore Community Resources (NSCR), this program includes:

- Education on a wide variety of caregiving topics.
- Strategies to cope with stress, and to practice self-care and relaxation techniques.
- Telephone consultation and referral to additional services.
- Resource library including relaxation CDs, videos, books and articles.
- Bi-monthly newsletter and weekly blog posts for caregivers.
- Annual B.C. Family Caregivers Week Heart and Soul of Caregiving events honouring and celebrating caregivers, with a focus on self-care.
- Publishes *Resource Guide for Family Caregivers – North Shore Edition (2015)*. Available as a PDF or print copy. (This is the same guide published by the Family Caregivers' Network Society in Greater Victoria, but it has been updated and the resources listed in the North Shore edition are North Shore-specific.)
- Support/network groups to meet with other caregivers are a supportive place to share ideas and inspiration, and to be encouraged. The groups meet monthly. Choose from the second Wednesday, 10:30 a.m. - 12:30 p.m., or the first Thursday of each month, 7 - 9 p.m., at NSCR.
- E: karyn.davies@nscr.bc.ca or info@nscr.bc.ca

4e) RICHMOND

Caregivers Information & Referral Program

604-279-7020 www.rcrg.org

Offered by Richmond Cares, Richmond Gives (formerly known as Volunteer Richmond Information Services), services include information and referral to Richmond services that can assist caregivers.

E: info@rcrg.org

4f) RICHMOND

Caregivers Drop-In Group (604-271-3646) meets Fridays, 1 - 2 p.m. at Rosewood Manor.

4g) SURREY

Caregiver Workshops

604-501-5100 www.surrey.ca/seniors

This program offers some caregiver-oriented talks funded by the City of Surrey with the Seniors Advisory and Accessibility Committee.

4h) SURREY/DELTA

Caregivers Network Surrey/Delta

604-686-3793

Volunteer-led services include:

- One-on-one support.
- Information and referral linking to needed resources.
- Support groups:

- Delta: Northcrest Care Centre, third Wednesday of the month, 10 a.m. - noon.
- Delta (North): Kennedy Seniors Recreation, third Wednesday of month, 6:30 - 8 p.m.
- Surrey (Fleetwood): Fleetwood Villa, last Thursday of the month, 10 a.m. - noon.
- Surrey (Newton): Come Share Society Newton, last Monday of the month, 7 - 9 p.m.

4i) SURREY/WHITE ROCK

Caregiver Support Program for Those Caring for Family Members and Friends

604-531-9400 x 202 www.comeshare.ca

Seniors Come Share Society offers these services:

- Educational sessions.
- Caregiver workshops such as Caregiver Yoga, Expressive Arts, Learning How to Breathe, etc. These workshops provide an escape for an hour or two enabling caregivers to relax, focus on their needs and express themselves in a variety of ways, without much talking.
- Information and referral about community and health-care services. The society publishes a comprehensive 2015 resource guide valuable to family caregivers: *Seniors Resource Directory*.
- Direct one-on-one support for individuals and/or families.
- Outreach to groups and organizations within the community.
- Support groups – phone for information.
- E: caregivers@comeshare.ca

4j) TRI-CITIES (COQUITLAM, PORT COQUITLAM, PORT MOODY)

The Tri-Cities Seniors Caregiver Support Groups

778-789-1496 or 604-927-6098

Offered by Dogwood Pavilion Recreation Centre, services include support groups that meet monthly at Dogwood Pavilion and Maillardville Community Centre.

E: seniorcaregiverprogram@gmail.com

4k) VANCOUVER

Caregiver Support Groups

604-301-3876

Supported by VCH and Vancouver Community Volunteer Services, and led by their volunteers, services include a support group. There is one group, but it is full at the moment. If you would like to see more groups in Vancouver operated by VCH, let them know.

E: vcvolunteerprogram@vch.ca

In addition to the local groups above, there are other B.C. and Canada-wide caregiver groups.

4l) B.C. WIDE

Family Caregivers of British Columbia (FCBC – formerly called Family Caregivers' Network Society)

www.familycaregiversbc.ca

FCBC has supported family caregivers for 26 years and, in partnership with the Ministry of Health, now offers the following services for B.C. residents:

- Caregiver Support Line: 1-877-520-3267 toll free within B.C., weekdays; 8:30 a.m.- 4 p.m.
 - One-on-one phone support.
 - Information and referral to community resources.
 - Help navigating the health-care system.

- Caregiver coaching appointments for emotional support, problem solving and brief action planning. Call or email to make a phone appointment.
- Education for family caregivers and health professionals
 - Tele-workshops (phone only) and/or webinars (phone and/or computer) on topics such as Boundaries, Communication Tips, Guilt and Frustration: How Changing Your Expectations Leads to Emotional Wellness, Needs and Wants: You Both Have Them!, It's Time for Facility Placement: What Happens Now and How Do I Cope with the Process and My Changing Role, and more. Webinars are recorded and available for downloading.
 - Family Caregiver Support Group facilitator training for volunteers or staff to effectively set up and run support groups in your community.
- Online Caregiver Resource Centre: www.familycaregiversbc.ca available 24/7
 - A comprehensive listing of caregiver support groups in B.C. and links to other resources.
 - The *Network News* quarterly newsletter to stay informed and in touch.
 - Outreach to community groups with presentations on family caregiving.
 - What's new list of coming webinars, workshops and other events.
 - Blog, archived newsletters, informational handouts and articles.
 - *Toolkit for Employers: Resources for Supporting Family Caregivers*. For employers experiencing the impact of this growing social and economic issue (70 per cent of family caregivers are trying to juggle the demands of employment and caregiving), includes information and resources to help minimize the impact of caregiving on both the employee and the workplace. With the right information, support and education, employees can be healthier and more productive. Produced with the generous assistance of the Greater Victoria Savings Credit Union Legacy Foundation.
 - *Resource Guide for Family Caregivers 2nd Ed.* Each chapter supports the different stages of caregiving, the emotional and informational issues we face as things change, and suggestions for resources.
- Caregiver Engagement and Health Sector Collaboration
 - Including the voice of family caregivers in health system improvement efforts.
 - Collaborating at local, regional and provincial levels with condition-specific organizations to improve and coordinate programs, support and recognition for family caregivers.
 - Engagement in key Ministry of Health initiatives such as Patients as Partners, local HAs integrated community care transformation, as well as Doctors of B.C. (formerly called B.C. Medical Association), Divisions of Family Practice (community-based groups of family physicians working together to achieve common health-care goals), Self-Management B.C., UBC's interCultural Online health Network (iCON), Centre for Collaboration & Motivational Interviewing (CCMI) and more.
 - E: caregiversupport@fcns.ca

4m) CANADA – The Caregiver Network (TCN, formerly called Care-ring Voice Network)
 Toll free: 1-866-396-2433 <http://thecaregivernetwork.ca/> French: <http://lereseauaidant.ca/>
 Weekdays; 9 a.m.-5 p.m. EST. TNC offers free tele-learning conferences to Canadian caregivers; each conference can have five to 500 participants on the telephone. Facilitators ensure sessions flow smoothly, and all sessions are confidential. Examples of tele-learning conference topics include: Activities to Do with the Person with Dementia; Balancing Work and Eldercare Commitments;

Caring from Afar; Life with Aging Parents; Accompanying Your Loved Ones During Their Last Days; etc. Preregistration required. Call the Caregiver Network or register online. You can subscribe to its free newsletter. Past workshop recordings are on the website to listen to any time.

5. DISEASE-SPECIFIC EDUCATION AND SUPPORT PROGRAMS

Disease-specific programs exist for caregivers helping someone with a specific condition. In addition to being supported emotionally, you will learn a lot about a disease, treatments and progression.

5a) ALS SOCIETY OF BRITISH COLUMBIA

604-278-2257 www.alsbc.ca

The society offers a Care Connection program to aid your own group of caring family and friends to help their loved ones with ALS and their caregivers. Tasks that families need help with may include: walking the dog; cooking a meal; providing companionship or transportation; and other daily caregiver activities. By using a customized online web tool developed through a partnership between the ALS Society of B.C. and Lotsa Helping Hands, it is easier to stay in touch and let family and friends know what you need. One person is trained as the coordinator and organizes the Care Connection group. This person is usually close to, but not a member of, the immediate family. The primary purpose of a Care Connection is to lessen heavy caregiver responsibilities and reduce any worry the person with ALS has about their caregiver. By caring for the caregiver, the person with ALS is helped as well.

Inner feelings of caregivers have shown to be the biggest factor in determining their quality of life and their effectiveness in coping with ALS, so there is a free ALS Psychological Support Program.

Each autumn there is a Caregiver Day that offers a day of respite to carers of ALS patients.

5b) ALZHEIMER SOCIETY OF B.C. FAMILY CAREGIVER SUPPORT GROUPS

604-681-8651 www.alzheimer.ca/bc

5c) ALZHEIMER JAPANESE CAREGIVER SUPPORT GROUP

604-687-2172 <http://tonarigumi.ca/services/service-list/>

Tonari Gumi (Japanese Community Volunteers Association) takes place in Japanese the second Wednesday of the month, 1:30 - 3 p.m. in Vancouver.

5d) B.C. CANCER AGENCY CAREGIVERS WEBSITE

www.bccancer.bc.ca/our-services/services/library/recommended-websites/living-with-cancer-websites/caregivers-websites

This site contains links to many websites that specialize in information for those caring for someone with cancer. The list is compiled by B.C. Cancer Agency librarians.

5e) CANADIAN CANCER SOCIETY

604-253-8470

The society has a toll-free Cancer Information and Support Line (1-888-939-3333) for those with cancer and their caregivers, and website information at www.cancer.ca/en/cancer-information/cancer-journey/if-you-re-a-caregiver/?region=bc.

5f) HEART & STROKE FOUNDATION

778-372-8002 www.heartandstroke.bc.ca/livingwithstroke

A Guide for Stroke Caregivers can be found at <http://bit.ly/1P0zPEC>. Living with Stroke is a support and educational program for stroke survivors and their caregivers to gain confidence managing the challenges of living with stroke. The seven-week program develops new skills, and helps gain confidence in your ability to control your life. Program topics include: Understanding stroke; Physical changes and challenges; Swallowing and nutrition; Cognition, perception and communication; Emotions: Focusing on depression; Activities and relationships; Reducing the risk of stroke; and Moving forward.

Multicultural materials in Chinese, French, and Punjabi, as well as culturally sensitive resources for the First Nations, Inuit, and Métis people is at www.heartandstroke.bc.ca/site/c.kpIPKXOyFmG/b.3644335/k.8FED/Multicultural_Resource.htm.

5g) INSPIREHEALTH SUPPORTIVE CANCER CARE

604-734-7125 www.inspirehealth.ca

If you are providing care to someone living with cancer, InspireHealth offers free programs and services that can help you find simple and practical steps to support their health. InspireHealth integrates cancer patients and their friends, family and/or caregivers in its care model. Its program, partially funded by the Ministry of Health, begins with a short education session that explains its integrative cancer-care model which serves to complement (not replace) standard cancer treatments. Cancer patients work with their team of medical doctors, exercise therapists, clinical counsellors and nutritionists to optimize health and well-being. Its virtual centre also has a great deal of information.

5h) MULTIPLE SCLEROSIS SOCIETY OF CANADA

604-689-3144

Caregiver specific information: www.mssociety.ca/en/help/iAmaCaregiver.htm and a Caregiver Network.

French information: www.mssociety.ca/fr/aider/JeSuisLaidant_profil.htm.

5i) PARKINSON SOCIETY BRITISH COLUMBIA

604-662-3240 www.parkinson.bc.ca/Caregiving

The society offers education materials, support groups, and care partners' education events for family caregivers.

5j) STROKE RECOVERY ASSOCIATION OF B.C.

604-688-3603

The association has support groups across the province that include family caregivers:

<http://strokerecoverybc.ca/contact-us/branch-locations/>

There is a caregiver resources page at

<http://strokerecoverybc.ca/recovering-from-a-stroke/information-caregivers/caregiver-resources>.

Find *Recovering from a Stroke: Guide for Stroke Survivors, Families and Caregivers* at

<http://strokerecoverybc.ca/wp-content/uploads/Updated-2014-Stroke-Information-Booklet.pdf>.

6. CAREGIVER WEBSITES

These sites cover many caregiver topics. Some non-B.C. sites are listed because of their large variety of topics. Be careful when at a non-B.C. site as websites from other provinces and the U.S. will have some information that is not applicable to B.C. residents, e.g. legal information; names of housing types; medications; financial programs; government services; etc. Note many disease-specific groups

also have caregiver articles on their websites. Whether or not you have access to the Internet, remember that your local library and bookstore have books on family caregiving.

6a) American Association of Retired Persons (AARP), U.S.

www.aarp.org/home-family/caregiving

This link provides tools and resources to help.

6b) A PLACE FOR MOM, U.S.

See the *Caregiver Toolkit: Simplifying Your Senior Care Journey* at

www.aplaceformom.com/senior-care-resources/caregiver-toolkit.

6c) B.C. MINISTRY OF HEALTH

www2.gov.bc.ca/gov/content/family-social-supports/seniors/caring-for-seniors

The SeniorsBC website offers resources and tips for caregivers. The topics Daily Care Tips and Advice, Building a Care Guide, Caring for the Caregiver, and Training and Caregiver Role

Management Tools can be found at www2.gov.bc.ca/gov/content/family-social-supports/seniors/caring-for-seniors/daily-care-tips-and-advice. Under Building a Care Guide is *My Care Guide* (www2.gov.bc.ca/assets/gov/people/seniors/caring-for-seniors/pdf/mycareguide.pdf), a tool which provides an easy way to record and track medical information, including a list of:

- Diagnosis.
- Prior surgeries, procedures, lab tests (date, procedure, results).
- Medications (name, dose, time).
- Allergies.
- Names and contact information for family caregivers, paid caregivers, doctors, specialists, pharmacists and hospital.
- Assistive equipment/technology used (communication devices, home oxygen, insulin pump, orthotics, suction, walker, wheelchair).
- Important things to know about one's health condition.
- Important things to know in case of an emergency.
- Special instructions (organ donation, personal planning documents such as do not resuscitate orders, advance directives, representation agreements, enduring powers of attorney).

6d) CAREGIVER.COM, U.S.

www.caregiver.com

Thousands of articles; free weekly e-newsletter.

6e) CAREGIVER ACTION NETWORK, U.S. (formerly National Family Caregivers Association)

www.caregiveraction.org

This site has tip sheets and an electronic Family Caregiver Forum to post questions, receive support and communicate with others. Some tip sheets are available in Spanish.

6f) CAREGIVING.COM

This site has U.S. radio show podcasts that cover caregiving-related topics at

www.blogtalkradio.com/caregiving. Another radio program, Tools for Family Caregivers for Assessing Care Needs of their Family Members, is at www.voiceamerica.com/episode/69381/tools-for-family-caregivers-for-assessing-care-needs-of-their-family-members.

6g) CARING FOR FAMILY by Saint Elizabeth Homecare non-profit society

www.saintelizabeth.com/Caring-for-Family/Caregiver-Compass.aspx

The society offers a great deal of information including a free printed or online guide, *Caregiver Compass*, to help guide the caregiver taking on the responsibility of caring for someone. There is also www.Elizz.com dedicated to carers. Elizz also has caregiver coaching, nurse advisor and group support, offered online and by phone.

6h) DIAMOND GERIATRICS, B.C.

www.diamondgeriatrics.com

Lower Mainland geriatric social worker Peter Silin's site has a free monthly B.C.-relevant e-newsletter.

6i) FAMILY CAREGIVER ALLIANCE, U.S.

www.caregiver.org/caregiver-connect

The alliance has articles, including some in Chinese (Simplified and Traditional) and Spanish, plus free webinars.

6j) FAMILY CAREGIVERS OF BRITISH COLUMBIA (FCBC – formerly Family Caregivers' Network Society)

www.familycaregiversbc.ca

FCBC is a rich resource for B.C. information to support and educate those caring for family members and friends. Subscribe to its free bi-monthly newsletter.

6k) FH's *Handbook for Caregivers* (2005)

www.fraserhealth.ca/media/HandbookForCaregivers.pdf

The handbook covers: Being a Care-Receiver; Being a Caregiver; Managing the Caregiving; and Partners in Caring – You and the Home Health-Care Team.

6l) NATIONAL CAREGIVERS LIBRARY, U.S.

www.caregiverslibrary.org

This is one of the largest sources of information and tools for caregivers and seniors in the U.S.

6m) NORTH SHORE COMMUNITY RESOURCES CAREGIVER SUPPORT PROGRAM

www.nscr.bc.ca/information/caregiver.html

This site is filled with B.C.-relevant information, including a *Resource Guide for Family Caregivers – North Shore Edition*. It is the same guide as published by the Family Caregivers of British Columbia, but the resources listed are North Shore-specific.

6n) PLANNED LIFETIME ADVOCACY NETWORK (PLAN)

Toll free: 1-888-696-PLAN www.plan.ca

There are seniors who are caring for disabled adult children, and who worry about how their children will be cared for when they, the older parents, are gone. PLAN, a membership-based non-profit, was established by and for families committed to ensuring the safety, security and well-being of their relatives with disabilities. PLAN helps families build personal support networks that endure after the parents die.

6o) U.S. AREA AGENCY ON AGING

www.agingcarefl.org/the-four-stages-of-caregiving

Its *Four Stages of Caregiving* handbook has four chapters: When You First Become A Caregiver; When You Have Been A Caregiver For a While; When You Are a Heavy-Duty Caregiver; When You Are a Caregiver Who Has To Let Go.

6p) VCH's *Take Care: A Handbook for Family Caregivers (2013)*

This handbook has information applicable to all caregivers, up to page 52. Beware: the remaining pages refer to services in the VCH area and are not applicable to the area FH covers.

Available in English: <http://vch.eduhealth.ca/PDFs/EF/EF.625.T35.pdf>

In Simplified Chinese at: <http://vch.eduhealth.ca/PDFs/EF/EF.625.T35.CS.pdf>

In Traditional Chinese at: <http://vch.eduhealth.ca/PDFs/EF/EF.625.T35.CN.pdf>

7. DIVERSITY AND FAMILY CAREGIVER MATTERS

7a) FAMILY CAREGIVERS WHO ARE ALSO EMPLOYEES

Over one million people in B.C. provide unpaid care for an adult family member or friend; 70 per cent of them are also juggling the demands of employment. With the rapidly aging population and the fact we're also living longer, the responsibilities of carers who are also employed is quickly increasing. Many of these employees feel isolated, lacking in support, and some have financial strains related to their caregiving. They can benefit from flexible work schedules, access to caregiving information including brown bag lunch-and-learn sessions, emotional support including access to an Employee Assistance Program counsellor, and information about financial assistance programs such as those listed in item 10.

www.familycaregiversbc.ca/education/toolkit-for-employers

Adapted from Family Caregivers of British Columbia

Toolkit for Employers: Resources for Supporting Family Caregivers in the Workplace

The 2015 American Association of Retired Persons' guide book *Juggling Life, Work, and Caregiving* by Amy Goyer provides tips on dealing with the pressures of work and caregiving. You can download a free excerpt at www.aarp.org/entertainment/books/bookstore/home-family-caregiving/juggling-work-and-caregiving/. Please remember it is a U.S. book and so some resources won't apply to B.C., but there is still a great deal of helpful information in the publication.

7b) LONG-DISTANCE CAREGIVING

Caring for someone who lives far away from you adds to caregiver stress. The American Association of Retired Persons offers some tips for this unique group of caregivers:

- Collect important information before a crisis. Compile a list of addresses and phone numbers of your care recipient's contacts (e.g. friends, neighbours, doctors, faith leaders, etc.) who can be reached in the event of an emergency or who can assist with activities. Introduce yourself during a visit and consider giving a key to someone on this list if your care recipient consents. Give a copy of this list to your loved one and keep a copy for yourself. See Part XIII of this handbook for a good list of information to have on hand.
- Make visits productive. Visiting should be enjoyable but also include time to make necessary preparations: scheduling appointments; purchasing items that are needed; going through mail and old papers; checking the refrigerator and pantry to assess eating habits; and assessing the home for safety hazards (e.g. loose rugs, missing handrails or poor lighting). During your visit you may realize that your care recipient requires more help on a regular basis.
- Get help with managing the care. You can learn about different public and private assistance programs online for which your care recipient might be eligible. You can also call bc211, search the Yellow Pages or visit community centres and libraries for local services.
- Keep the lines of communication open. Listen to your loved one. They may find it difficult facing change and resist having strangers, such as caregivers, in their home. Maintain a positive and patient approach and take the time to explain to your care recipient how the services will work and that they are designed to help them remain independent. Consider having an objective third party, like a doctor, recommend the service(s).

- Don't forget your needs. Long-distance caregiving is straining; take the time to take care of yourself, eat right, exercise, and get enough sleep – and take credit for all of your hard work. Accept help from community services or your care recipient's contacts and consider a family meeting to divide care responsibilities or help resolve any issues.

Adapted from www.aarp.org

7c) SEXUAL AND GENDER IDENTITY

LGBTQ (lesbian, gay, bisexual, transgendered, queer) folks face unique challenges as they become frail elders, and these challenges also extend to their significant others, friends, families and allies (SOFFAs) who care for them. Older LGBTQ folks faced a great deal of discrimination, ridicule and violence in their lives and – if estranged from families (often through no choice of their own) – a great deal of isolation. Often childless, their social support system can be lacking as a result of feeling invisible and misunderstood, which makes it difficult to build a supportive care team.

The award-winning documentary film *Generation Silent* reveals some of these challenges as it follows the personal journeys of some LGBTQ seniors. A major theme uncovered is that the generation that fought hardest to “come out,” fears having to “go back in the closet” as they age and enter the health-care system needing medical care, home support, and seniors housing. There is concern that the service providers in these care systems are not always “safe” physically, psychologically, or spiritually for queer folk and will discriminate rather than welcome this community. It is important to remember that this is not simply an issue about sex, but rather about the unique LGBTQ culture which refers to a way of life, including beliefs, customs and language.

LGBTQ family caregiver resources include:

- Qmunity
604-684-8449 www.qmunity.ca/get-support/olderadults
B.C.'s Queer Resource Centre, has a two-year public education and policy development project, Aging Out Policy Dialogues, through its Generations program. The purpose of the dialogues is to create policy recommendations and competency training that effect positive change regarding the understanding of the needs and issues of LGBTQ seniors. The competency training is meant to ensure that proficient care is provided by medical, home support, and seniors housing staff, in a way that creates an inclusive environment. Those who have undergone competency-care training display the rainbow sticker on their property and in their materials. You can also ask what queer-competency training staff has received and if there are queer staff, or queer clients. The Qmunity Generations staff can assist.
- Rainbow Caregiver Support Group
604-675-5150
Offered by the Vancouver Resource Centre of the Alzheimer Society of B.C., this group gives family and friend caregivers caring for someone with dementia access to information and is open to queer family caregivers as well as non-queer people who are caring for a member of LGBTQ community.
- Choice in Supports for Independent Living (CSIL) program might be available if you are caring for someone with high-intensity care needs. This is a B.C. Ministry of Health self-managed care option for home support services where funds are provided to eligible clients to purchase and manage their own outside home support services, allowing for the hiring of queer friendly people. See item 8f for more CSIL information.
- LGBT End-of-Life Conversations
www.sfu.ca/lgbteol.html
This web project is funded by the Technology Evaluation in the Elderly Network. The name is deceiving as it provides information on many areas of LGBT aging, not just end-of-life.

This project believes there is a need to raise awareness about the unique challenges that the LGBTQ community faces as they get older. The website aims to share services, resources and tools to for aging LGBTQ persons to afford them the opportunity to take positive action in regards to end-of-life planning. It includes a resource inventory specific to B.C., articles addressing various LGBTQ aging issues, and online discussion forums.

- Plum Living

www.plumlivinghealth.com

This private home support service created with LGBTQ folk in mind provides inclusive services: housekeeping; cooking; shopping; companionship; health; maintenance; pet care; and transportation.

- LGBT Community Support: Caregiving for our Families and Friends

www.caregiver.org/support-groups

An online support group that is a safe place for lesbian, gay, bisexual and transgender caregivers to discuss the unique challenges that are faced when caring for their loved ones.

- FORGE's Transgender Aging Network (TAN)

www.forge-forward.org/aging/

A partner of the U.S. National Resource Center on LGBT Aging, this is a national advocacy organization for transgender people. Its website, designed for transgender people, is useful for informal (unpaid) as well as professional paid caregivers caring for all members of the LGBTQ community. The site includes a tip sheet, Quick Tips for Caregivers.

7d) TRANSLATED AND CULTURALLY SENSITIVE INFORMATION

Wherever possible we have indicated when information is available in multiple languages by underlining the languages available, and have also noted where translation is available as part of a service. There is a dearth of culturally sensitive family caregiver material.

In May 2015 a Summit on Asian Canadian Elder Care organized by S.U.C.C.E.S.S. and the Human Rights Committee of the National Association of Japanese Canadians called for many societal institutions, including health-care agencies and seniors housing, to implement policies and practices sensitive to the unique experiences and needs of Canada's diverse population, including family caregivers. There will be a follow-up committee of summit delegates to work to improve things.

If you are aware of any family caregiver translated or culturally sensitive material not listed in this handbook, please email to tell us: MetroVanCaregiversHandbook@yahoo.ca

8. HEALTH AUTHORITY HOME AND COMMUNITY CARE (HCC) SERVICES

Whether the person you care for lives in the areas served by Fraser Health or Vancouver Coastal Health, B.C. health authorities offer public (government-subsidized) home and community care services to assist both the care recipient and the family caregiver. Take note how the B.C. government explains these services at www2.gov.bc.ca/gov/content/family-social-supports/seniors/home-community-care: "These services are designed to complement and supplement, but not replace, your efforts to care for yourself with the assistance of your family, friends and community. Home and community care services can assist you on a short-term or long-term basis depending upon your care needs. Home and community care services are based on need, and depending on the service, may be subsidized according to income or provided at no cost. Publicly subsidized home and community care services provide a range of health-care and support services for people who have acute, chronic, palliative or rehabilitative health-care needs. "

To be eligible for subsidized home and community care services

General eligibility criteria - You must:

- Be a Canadian citizen (or have permanent resident status or have been issued a temporary resident permit by the federal minister for immigration).
- Be 19 years of age or older.
- Be a resident of British Columbia for at least three months.
(Please note: there are some exceptions to the three-month residency requirement and age requirement. Speak to your local Home and Community Care office for information about the exceptions to these requirements.)

AND you must also be unable to function independently because of chronic health-related problems or have health-care conditions that require care due to one or more of the following:

- You have recently been discharged from an acute-care hospital.
- You require care to prevent or reduce the need for hospital or emergency department services or admission to a RC facility.
- You have a life-limiting illness.

Adapted from www2.gov.bc.ca/gov/content/health/accessing-health-care/home-community-care/are-you-eligible

If the person you are caring for is eligible for the services described in this section of the handbook, call the Home and Community Care office (phone numbers below in 8a)) which corresponds to the HA area your care recipient lives in. Note that in addition to meeting the criteria described above, each service described below has its own needs-assessment criteria that must be met. Persons who do not meet the eligibility requirements for subsidized home and community care services are referred to other community resources (such as those mentioned in this handbook).

8a) HOME AND COMMUNITY CARE (HCC) OFFICES

Fraser Health (FH) www.fraserhealth.ca

1-855-412-2121 toll free, seven days a week, 8:30 a.m. - 4:30 p.m.

Vancouver Coastal Health (VCH) www.vch.ca

VCH - **North Shore** 604-983-6700 Mon-Fri, 8 a.m. - 4:30 p.m.
(After hours, leave a message)

VCH - **Richmond** 604-278-3361 Mon-Fri, 8:15 a.m. - 5 p.m.
(After hours, leave a message)

VCH – **Vancouver** 604-263-7377 Mon-Fri, 8:30 a.m. - 5:30 p.m.
(After hours, leave a message)

Services the HAs provide through Home and Community Care include the following.

8b) CASE MANAGEMENT

Access to publicly funded (government-subsidized) home and community care services is through case managers who provide detailed assessments of individual clients. The HA case managers coordinate care for people with complex health needs requiring extra ongoing support to live at home independently. Their goal is to help people live at home safely and avoid unnecessary or premature admission to a hospital or care facility.

Case managers work with the client and family to determine the priorities for care, provide education to the client and caregiver, identify the nature, intensity and duration of services that would best meet the client's needs, and arrange access to services as required. The case manager maintains contact with the client and family to make any necessary adjustments if the client's care needs change.

Case managers work with the Ministry of Health's Home is Best philosophy. That means there is a focus on enhancing home supports available for patients with complex chronic conditions, and seniors with complex care needs so they can maintain independence. To better support patients, case managers work so that care can be provided in one's home rather than hospital (acute care) or residential facility, if it is not necessary. The Home is Best philosophy also aims to avoid unnecessary trips to hospital emergency departments which can be very hard on frail elders.

For more about the philosophy that home, with appropriate supports, is the best place to recover from illness and injury when hospitalization is not required, manage chronic conditions, and live out final days, see www.fraserhealth.ca/your-care/home-and-community-care/home-is-best/home-is-best.

The case manager assigned to a client will assess needs, determine eligibility for services, and determine the costs for certain services, based on one's financial situation. Note that clients will be asked for their most recent notice of assessment from the Canada Revenue Agency and that information will be confirmed with the CRA; hence seniors need to file their income tax each year. The case manager will also plan, coordinate and monitor multiple care services, arrange relief (respite) for caregivers, and assess whether a client needs to move to a government-subsidized (public) assisted living or RC facility.

Adapted from www.fraserhealth.ca

Arranging for an assessment

If the person you are caring for is having difficulty managing their living situation, you can call the HA in the area where your care recipient lives (see the box with phone numbers on the previous page). A family member, friend, concerned neighbour, family doctor, hospital, or your care recipient can call and speak to someone in "Central Intake" who will ask a number of questions. If eligible for home health services, an appointment will be given for an assessment by a case manager. It might be several weeks from the time you phone until a case manager can visit to do the 60- to 90-minute assessment. Note: If it is determined the elder does not require home health services, you may be directed to other community resources that might meet your needs.

8c) HOME SUPPORT SERVICES

These services are designed to help clients remain independent and in their own home as long as possible. These services are for people with chronic illnesses, disabilities, progressive medical conditions, as well as those with short-term acute care or palliative care needs.

Home support provides personal assistance with activities of daily living including bathing, dressing, medication administration, as well as support and relief (also called respite) for the primary caregiver. If home support assistance is recommended by your case manager, they will determine the assistance that will best suit your needs and will make the necessary arrangements for services to be delivered. If your care recipient is in the hospital, note that home support services are often provided to people after they have been discharged from hospital and this is arranged by a hospital coordinator called a home health liaison or quick response case manager who understands how to match discharged patient needs to resources in the community.

Adapted from www.fraserhealth.ca

You can get the brochure *What is Home Support?* in English, Chinese, and Punjabi at www.vch.ca/your-health/health-topics/home-support/home-support.

Home health community health workers (CHWs) provide home support services. They are trained, screened and insured and their services meet established standards. Some clients have unique care needs for which a worker's gender, language or cultural awareness could make a significant difference. In such situations, efforts are made to consider those needs when scheduling a worker. Be certain to ask if an appropriate CHW is available for your loved one.

Your HA's Home Health Services does not provide banking, companions, driving to appointments, foot care, grocery shopping, house cleaning, laundry, meal preparation, or rehab equipment/aids, but intake staff or the case manager can assist in locating these types of services in your community. Some of those services are listed in Part IV of this handbook.

8d) ADULT DAY CENTRE PROGRAMS (ADPs)

These programs provide a break/respice during the day for the caregiver, as well as social recreational therapeutic activity, a hot meal, and some personal assistance for the care receiver. Access is through a home health case manager who must assess the client and determine their need for this program. Programs generally run from 10 a.m. - 2 p.m. and eligible seniors are usually assessed to attend one day a week. There is usually a nominal daily charge to supplement the cost of meals, supplies, and for transportation (if supplied by the program provider or HandyDART). If your loved one is assessed as being eligible for this program, expect to wait many months for a program opening in some areas.

8e) CAREGIVER RESPITE/RELIEF

A respite break can give the caregiver temporary relief from the emotional and physical demands of caring for a friend or family member. HA case managers can help you arrange three different kinds of respite:

1. Respite may be a few hours of service provided in the home of the senior while the caregiver takes a break to renew energy.
2. Adult Day Centre Programs (item 8d) also provide respite.
3. Short-term admission to a RC facility or hospice residence for a person with complex care needs is another respite service. This can give caregivers a temporary rest from between four and 30 days each year. Caregivers sometimes use this time to take a holiday; they even use this respite service to cover for them if they have to go into hospital. Caregivers wanting to use this respite service to cover their needs for vacation time are advised to give lots of notice to get the dates they need.

If you are in need of respite, speak to the case manager of your care recipient; if the person you are caring for doesn't have a case manager, contact the Home and Community Care office in the HA area where your care recipient lives.

8f) CHOICE IN SUPPORTS FOR INDEPENDENT LIVING (CSIL)

This B.C. Ministry of Health self-managed care option is for home support services where funds are provided to eligible clients to purchase and manage their own home support services. CSIL clients, or a designated representative or a client support group, receive funds directly for the purchase of home support services and assume full responsibility for arranging services, including recruiting, hiring, training, scheduling, disciplining, paying home support worker(s), and, if necessary, firing your own caregiver(s). You are the employer. You must follow Canada Revenue Agency,

WorkSafeBC, and the Employment Standards Regulation. To qualify for CSIL funding, clients must meet all of the following criteria:

- Be approved for home support services.
- Be living with physical disabilities and have high-intensity care needs requiring daily personal assistance.
- Be medically and functionally stable.
- Be able to direct all aspects of your care, or have an alternative decision maker to do this for you.
- Be able to direct and manage the CSIL contract obligations, or have an alternative decision maker to do this for you.

You must also complete an orientation before you sign a CSIL agreement, which outlines what you are required to do. The amount of funding you will get depends. Your case manager will work with you to determine the amount of money you will receive based on your personal-care needs. Funding is based on the current hourly CSIL rate and the number of hours of personal care you need. CSIL funds cover the costs of managing your home supports (such as wages, advertising, bookkeeping, etc.). You must submit regular financial reports to show how you have spent the funds.

If you think your care recipient might be eligible for this program, talk to your case manager and visit www2.gov.bc.ca/gov/content/health/accessing-health-care/home-community-care/care-options-and-cost/choice-in-supports-for-independent-living.

8g) ADVOCACY AND HOME SUPPORT SERVICES

The Office of the Seniors Advocate September 2015 report *Caregivers in Distress: More Respite Needed* expressed deep concern about the need for more home support hours and services to help relieve the strain on unpaid caregivers who enhance the ability of those they care for to continue to live in their homes. The report noted the level of carer distress rises with the number of hours of care they provide. The advocate emphasized that home support services have not kept pace with the rapidly growing seniors' population, and that family caregivers are becoming increasingly distressed. "If we cannot find a way to support these caregivers, especially those who are in distress, we will find that demand will increase on RC and acute care as seniors can no longer be supported at home."

There is also a call by the B.C. Seniors Advocate to have more than the typical one day a week adult day program (ADP) service available to clients, to have ADPs open on weekends, and also have a second shift, later in the day, for an additional group of clients. The advocate recommends ADPs be funded to support a second type of client with care needs that are more complex than the prevailing system allows. These changes, i.e. the provision of more ADP services to frail elders, would reduce the number of visits to hospital emergency departments and reduce hospital admissions.

The advocate is also calling for a simpler, less bureaucratic way to be able to use the CSIL option.

See item 102 for more on the work of the Office of the Seniors Advocate.

In November 2015, The Conference Board of Canada released *Future Care for Canadian Seniors: A Status Quo Forecast*. It predicted some pressing implications related to the rising number of Canadian seniors who will need paid and unpaid continuing care supports, and expressed concern that the reliance on unpaid caregivers to provide continuing care supports will grow dramatically. The forecast notes responding to these needs in an efficient and sustainable manner will require collaboration among the diverse mix of public and private stakeholders that make up the continuing care sector.

8h) PUBLIC (GOVERNMENT-SUBSIDIZED) AL AND RC

When independent living in the community is no longer possible, a senior might be eligible for publicly funded AL (a housing arrangement that consists of a private housing unit with a lockable door, hospitality services and personal-care services), or RC, also called long-term care, complex care, continuing care, facility care and nursing homes. RC refers to facilities that provide 24-hour professional nursing care and supervision in a protective, supportive environment for people who have complex care needs and can no longer be looked after in their homes.

See the housing sections of this handbook to learn about the three levels of care in seniors housing: SH; AL; and RC. You will also find an explanation of the three types of housing providers: public (government-subsidized); non-profit societies; and private businesses.

8i) END-OF-LIFE CARE

End-of-life care is supportive and compassionate care that improves the quality of life for people and their families who are facing the end stages of a terminal or chronic illness, or preparing for death. It addresses physical, psychological, and spiritual concerns and focuses on comfort, respect for decisions, and support for the family. It is provided wherever the client is living, whether in their home, a hospice, an AL residence or a RC facility. Note that end-of-life care is supportive and compassionate care provided during the remaining days, weeks or months of a person's life; it DOES NOT hasten death. To learn more about these services, and caring for a dying person, see Part XI of this handbook.

8j) NEW MODELS OF CARE FOR FRAIL ADULTS

Since we are living longer, the caregiving journey is lasting longer. The longer our care recipients live, the frailer they will likely become, and more services will be required to help them “age in place” and remain in their homes, as many wish to do. The B.C. Ministry of Health is working with the HAs to develop enhanced models of care to reposition health care for older adults. These new prototype models of care aim to improve integration of care with physicians and other health-care providers, and community organizations to realign services. This integrated primary and community care is meant to improve patient experience of care in community-based settings with timely access to quality hospital (acute) services when needed. The new models of care prototypes will slowly be introduced across B.C. beginning in 2016 with 13 communities. All should give some caregiver relief.

8k) OBTAINING SERVICES NOT PROVIDED BY THE HEALTH AUTHORITIES' HOME AND COMMUNITY CARE (HCC) SERVICES

If you want to add to the services offered by Home and Community Care, or are not eligible for those services, some home support services may be available from non-profit agencies in your area, including United Way's Better at Home program. You can also arrange for home support services from private business agencies.

See PART IV. Housing – Aging-in-Place at Home Using Community Services in this handbook for more about other services.

9. COUNSELLING

Caring can be very hard work and can even engender “dark” feelings and thoughts that are “not very nice.” *Searching for Normal Feelings* by Doug Manning reminds us such feelings and thoughts are normal and fine so long as we don’t act on them. We care for our care receiver, and as humans we also get tired, cranky, angry, etc. with those we care for. The \$2 monograph is available through Amazon.com.

9a) GUILT AND CAREGIVING

Caregiving can be difficult and guilt is a complicated emotion that often accompanies it. Guilt can stem from many things. We feel guilty because we think we're not doing a good enough job caregiving or think we should be doing more. Guilt may develop when we feel relieved having a break from our caregiving roles. It may also manifest itself when we start to feel frustrated, even resentful, of our caregiving duties, since they take away time from other parts our lives. We may wish we didn't have to carry the responsibility of handling the care needs of another. The guilt we feel in these instances sometimes has us questioning whether or not we are "good" people.

Acknowledge your guilt – don’t ignore it. It’s normal and understandable as we try to do the best possible. Be supportive of your contribution, rather than critical and judgmental of yourself in situations you cannot always control. Wanting to take care of yourself and needing help with your caregiving responsibilities is both reasonable and wise and are things this handbook stresses.

Remember: you are not a professional caregiver, and they too make mistakes, so forgive yourself for yours. Remember, too, you are part of a whole equation and your health and well-being are very important. Find what works for you and take time for yourself because your well-being is imperative to the care you are able to give. Share your stories and feelings with those in similar situations; people tend to find strength in numbers and caregiving is a role that requires a support system.

Contributed by Tasha Lorenzen-Ewing, M.A., Gerontology

9b) SENIOR PEER COUNSELLING (SPC)

Caregivers who are age 50-plus and feeling stressed might want to consider the free outreach SPC service available in some communities. Some seniors’ organizations offer free, confidential, one-to-one counselling services to those experiencing anxiety, frustration or difficulty because of life-altering changes in their later years, including the caregiver role itself. A peer counsellor is a trained volunteer who can provide some support and guidance through difficult times. These volunteers are selected for their personal qualities of warmth and compassion as well as their life experiences. They have received training in communications, listening and counselling skills in a course accredited by the Senior Peer Counselling of BC association. A senior peer counsellor will be nonjudgmental, assist you to find your own solutions to problems, help direct you to community services as needed, and will respect confidentiality. SPCs are also available to provide services to the senior you are caring for who might be struggling with the challenging changes of aging. Note that senior peer counsellors can come to you. The service is available in multiple languages at some centres.

9c) LOW-COST COUNSELLING

Some social service organizations offer low-cost counselling, often based on a sliding-fee scale. Expect wait lists. In Surrey, the DIVERSEcity Community Resources Society’s Counselling Services Department provides short-term, solution-focused counselling and support services to immigrants and refugees within their cultural value system in Arabic, English, Farsi, Hindi, Korean,

Mandarin, Punjabi, Spanish, Urdu, and Vietnamese. Staff are masters-level counsellors registered with the BC Association of Clinical Counsellors.

9d) PROFESSIONAL COUNSELLING

If emotional distress is overwhelming you, an experienced, trained professional (counsellor, psychologist or therapist) can offer the caring expert assistance that we often need during stressful times.

“Good indicators of when you should seek counseling are when you’re having difficulties at work, your ability to concentrate is diminished or when your level of pain becomes uncomfortable,” says Dr. Gail Robinson, past president of the American Counseling Association. “However, you don’t want to wait until the pain becomes unbearable or you’re at the end of your rope.”

“If someone is questioning if they should go into counseling that is probably the best indicator that they should,” says Dr. William King, a mental health counselor in private practice. “You should trust your instincts.”

Through counselling you examine the behaviours, thoughts and feelings that are causing difficulties in your life. You learn effective ways to deal with your problems by building upon personal strengths. A professional counsellor will encourage your personal growth and development in ways that foster your interest and welfare.

Adapted from www.counseling.org

If you are an employee, check to see if you have access to counselling through an employee assistance program at work. Otherwise, to find a professional counsellor, you can ask your doctor for a referral, ask friends if they can recommend anyone, or go to the B.C. Association of Clinical Counsellors (1-800-909-6303) or visit www.bc-counsellors.org and enter “find a counsellor” in the search box. Counselling B.C. (604-729-6059) also lists counsellors and psychologists in B.C. at www.counsellingbc.com.

10. FINANCIAL SUPPORT FOR CAREGIVERS

No B.C. program pays family caregivers for their caregiving work, but some assistance is available.

10a) B.C. EMPLOYMENT STANDARDS ACT, FAMILY RESPONSIBILITY LEAVE 2015
www.labour.gov.bc.ca/ESB/IGM/ESA-PART-6/IGM-ESA-S-52.HTM

Section 52 of the *Act* states: An employee is entitled to up to five days of unpaid leave during each employment year to meet responsibilities related to... (b) the care or health of any other member of the employee's immediate family.

10b) B.C. HARDSHIP-REDUCED RATES FOR PUBLIC LONG-TERM CARE

As explained in the Housing – RC part of this handbook, government-subsidized RC costs up to 80 per cent of an individual’s annual after-tax income, subject to a minimum and a maximum rate. This can be financially difficult for dependent spouses who, because they stayed home to raise children and care for family, had limited access to CPP and private pension plans, and relied on the pension of their spouse. The 80 per cent rate can severely limit household income for the spouse who continues to live independently in the community. In cases of financial hardship, be sure to speak with the social worker at the facility where your spouse is living about hardship-reduced rates.

10c) CANADA BEREAVEMENT LEAVE

An employee is entitled to up to three days of unpaid leave on the death of a member of the employee's immediate family. See item 97 for more information.

10d) CANADA EMPLOYMENT INSURANCE COMPASSIONATE CARE BENEFITS PROGRAM

Compassionate care benefits are employment insurance (EI) benefits paid to people who have to be away from work temporarily to provide care or support to a family member who is gravely ill and has a significant risk of death within 26 weeks (six months). See item 96 for more details.

10e) CANADA REVENUE AGENCY DISABILITY TAX CREDITS FOR CARE RECIPIENTS

Toll free: 1-800-959-8281

Caregivers should know their care recipients might be eligible for disability tax credits (DTCs), which are designed for those with severe and prolonged physical or mental disability. To be eligible, the person must be "markedly restricted" in terms of speaking, hearing, walking, eliminating (bowel or bladder), feeding, dressing or performing mental functions of daily life.

Guide RC4064 Medical and Disability – Related Information explains more, and is available on the CRA website or by phoning. Note that the guide no longer includes Form T2201, the Disability Tax Credit Certificate; you must now order it separately. This tax refund can be retroactive as far back as 10 years for some people who have lived with impairments for many years.

The process of applying for the DTC requires a qualified medical practitioner to complete the medical section of Form T2201, Disability Tax Credit Certificate for their patients. Many doctors charge a fee for this paperwork. Because the first application for the DTC is sometimes rejected by the CRA due to incompleteness, requiring one to redo the application and "try again," some private firms offer a service to help applicants through the process. However, in February 2011, a joint CBC News/Toronto Star investigation revealed the CRA believes some companies may be helping Canadians abuse the system, so if you hire a company to help you with the form, choose the firm very carefully. www.cbc.ca/news/canada/disability-tax-credits-under-investigation-1.1016518

10f) CANADA REVENUE AGENCY FAMILY CAREGIVER AMOUNT (FCA) TAX CREDIT,

Toll free: 1-800-959-8281

The FCA, a federal tax credit, provides an additional non-refundable tax credit that provides tax relief for some caregivers of dependant relatives who have a mental or physical impairment. This includes, for the first time, spouses, common-law partners, and minor children who are living with the family caregiver. The person you are caring for must have a low income. You must have a signed statement from a medical doctor showing when the impairment began and what the duration of the impairment is expected to be. You can claim the family caregiver amount for more than one eligible dependant. For more information and to view the CRA three-minute *Family Caregiver Tax Credit* video, see www.cra-arc.gc.ca/familycaregiver.

11. STRESS MANAGEMENT FOR FAMILY CAREGIVERS

In addition to tapping into resources such as caregiver education programs, support groups, information on websites, respite programs, counselling and financial support resources, these are some other ways to can reduce and manage stress.

11a) A LIST OF TECHNIQUES

Acceptance (some things cannot be changed); aromatherapy; art; avoiding people who drain you (energy vampires); bathing; breath; comedy; dancing; don't "should" on yourself; esthetic care (including hair care, nail care and spa treatments); eating out or ordering in; exercise; forgiveness; gardening; healthy nutrition; journaling/writing; massage; mindfulness meditation (using compassionate, non-judgmental awareness to notice your feelings and thoughts and see how transient they are – just observe/witness your mind without judgment to help gain perspective and distance; you can let difficult thoughts and feelings freely flow through you, without getting caught up in them or feeling pushed around by them, and without getting into a struggle with them); music; pet therapy; pick your battles carefully; prayer; reading; recreation programs at your local community centre or seniors centre; relaxation tapes; CDs and DVDs; time in nature, saying "no," sex; sleeping; socializing; stop striving for perfection (examine your standards); yoga....

Add your favourites here, and if you can't think of anything off hand, write down your biggest source(s) of stress and analyze it/them here:

11b) ACKNOWLEDGING THE RIGHT OF CARE RECIPIENTS TO LIVE AT RISK

One challenge we face is getting our loved one/care recipient to accept help. It's especially difficult when the caregiver is an adult child and the care recipient is the parent, although it can also be challenging with a spouse, sibling or friend. Remember that regardless of their frailty, our care recipients are autonomous adults who have the right to make their own decisions and the right to live at risk – providing they are not mentally incompetent or posing a direct threat to others.

This idea of having the right to live at risk is one of the most difficult ideas for caregivers to get their heads around as we never want to see our loved ones in danger or at risk. However, if we do not accept their rights, we cause ourselves unnecessary stress by trying to control their behaviour. Also, when we don't value another's autonomy and try to control their behaviour, we may unwittingly increase their level of dependence and loss of self-esteem prematurely. The Government of Canada National Advisory Council on Aging (since renamed the National Seniors Council) provides an article on this topic, *Rights and Limits to Risk*, at www.publications.gc.ca/collections/Collection/H71-4-1-9-2E.pdf.

11c) BE MINDFUL OF THE CHALLENGES FACED BY THE PERSON YOU'RE CARING FOR

The following article acknowledges some of the stresses our loved ones are living with related to their frailty and helps remind us that they too are doing their best to cope with a lot of stress:

What does it mean to be a care recipient? Just as caregivers have mixed feelings about caregiving, the person receiving care is also likely going to be experiencing strong feelings. From a care receiver's perspective many things change as the need for care increases. Many of these changes are very difficult and may cause the care receiver to feel afraid, angry, ashamed, frustrated, helpless, lonely or depressed. Some of the issues that precipitate these feelings are:

- Threats to independence such as loss of a driver's licence, dependency on others, health problems that compromise senses and mobility, and so forth.
- Threats to dignity such as embarrassing health problems, lack of financial resources, having to ask for help with daily living activities, having to accept help, and being around others who do not respect elders.

- Personal safety within one's home, in public places and with one's caregiver.
- Worry, inconvenience, expenses, and losses associated with health problems.
- Financial management and concerns about having sufficient finances to get to the end of one's life.
- Social isolation due to immobility, lack of transportation, compromised senses, living far away from others, and loss of friends through death or illness.
- Grieving the loss of youth, health, life, friends, independence, meaningful work, and possibly preparing for one's own death.
- Loss of power in decision-making about matters related to one's own life.

These experiences and strong feelings can lead to behaviours that might be difficult for the care receiver and the caregiver. For example, some people may resist getting help, may refuse to admit they need help or become very demanding. This can be very upsetting for the whole family, but if you try to remember that it is a reaction to the fear of losing control and that some of the responses are the person's way of coping, it might be easier to deal with the behaviours. Also try to put yourself in their position and think about how you'd like to be treated.

Some ideas to help your loved one cope with the situation are:

- Involve the care receiver in all decisions related to their care, unless cognitive impairment is at a stage where this is not possible. Remember that it is their life.
- Try to set up a caregiving routine so everyone knows what to expect.
- Try to involve the care receiver in decisions related to the caregiving routine.
- Try not to over-help. You may be tempted to take over everything; however, try to encourage your loved one to do whatever they can for themselves.
- Listen! Reassure! Be respectful!

Reproduced with permission from *Family Resource Guide for Family Caregivers*
 Published by Family Caregivers Network Society
 Section adapted from *Our Aging Parents*
 Written by Clarissa P. Green, Consulting and Counselling, Vancouver, B.C.

11d) MOTHER & DAUGHTER: ALZHEIMER'S

This lovely piece of writing has been making its way around the Internet. It's written as a message an older mother with Alzheimer's disease has written to her adult daughter but it can be thought of as a message of all frail older people to their caregivers. Warning – it might bring tears to your eyes.

“My dear girl, the day you see I'm getting old, I ask you to please be patient, but most of all, try to understand what I'm going through. If when we talk, I repeat the same thing a thousand times, don't interrupt to say: “You said the same thing a minute ago...” Just listen, please. Try to remember the times when you were little and I would read the same story night after night until you would fall asleep.

When I don't want to take a bath, don't be mad and don't embarrass me. Remember when I had to run after you making excuses and trying to get you to take a shower when you were just a girl?

When you see how ignorant I am when it comes to new technology, give me the time to learn and don't look at me that way... remember, honey, I patiently taught you how to do many things like eating appropriately, getting dressed, combing your hair and dealing with life's issues every day... the day you see I'm getting old, I ask you to please be patient, but most of all, try to understand what I'm

going through.

If I occasionally lose track of what we're talking about, give me the time to remember, and if I can't, don't be nervous, impatient or arrogant. Just know in your heart that the most important thing for me is to be with you.

And when my old, tired legs don't let me move as quickly as before, give me your hand the same way that I offered mine to you when you first walked. When those days come, don't feel sad... just be with me, and understand me while I get to the end of my life with love. I'll cherish and thank you for the gift of time and joy we shared. With a big smile and the huge love I've always had for you, I just want to say, I love you ... my darling daughter.”

Original text in Spanish by Guillermo Peña; English translation by Sergio Cadena.

Posted on <https://plus.google.com/+AARP/posts/VYDvfv98GWo>

12. CRISIS LINES

12a) SENIORS' DISTRESS LINE (604-872-1234) and THE CRISIS LINE (604-872-3311)

www.crisiscentre.bc.ca

Both services provide confidential, free 24/7 highly trained listeners to support you when you find yourself in distress and cannot wait to speak to others at a caregivers' program office or support group. An interpreter service is available in over 100 languages.

12b) PROVINCIAL SUICIDE HELPLINE

Toll free: 1-800-784-2433 (SUICIDE)

This helpline offers 24/7 service.

12c) FH CRISIS LINE

604-951-8855

This crisis line offers 24/7 emotional support and resource information.

12d) S.U.C.C.E.S.S CHINESE HELP LINES

604-270-8233 (Cantonese); 604-270-8222 (Mandarin)

Volunteers provide caring support to those in distress. 10am - 10pm daily.

Remember the motto of the U.S. Family Caregivers Alliance:

CAREGIVING – DON'T TRY THIS ALONE!

PART III. HEALTH ISSUES OF YOUR CARE RECIPIENT

Aging is a normal part of the life course. It is not a disease, in spite of anti-aging product advertisements that ask: “Are you suffering from the disease called aging?” Normal aging is universal; it happens to all of us; it is also progressive, ultimately destructive to the body, and irreversible. With age, changes occur throughout our body systems. Body functions slow down; there is a higher risk of developing health problems; and the body has less ability to bounce back – it has less reserve. This information from the Area Agency on Aging (<http://agingcarefl.org/what-is-normal-aging/>) explains:

The changes aging individuals experience are not necessarily harmful. With age, hair thins and turns gray. Skin thins, becomes less elastic, and sags. There is a slowing down of functions which goes forward throughout adulthood – loss of function of bodily organs. In the gastrointestinal system, for example, production of digestive enzymes diminishes, reducing the body’s ability to break down and absorb the nutrition from food. Some of these losses may not be noticeable until later life.

Scientists theorize that aging likely results from a combination of many factors. Genes, lifestyle, and disease can all affect the rate of aging. Studies have indicated that people age at different rates and in different ways. Normal aging brings about the following changes:

- Eyesight – loss of peripheral vision and decreased ability to judge depth. Decreased clarity of colours (for example, pastels and blues).
- Hearing – loss of hearing acuity, especially sounds at the higher end of the spectrum. Also, decreasing ability to distinguish sounds when there is background noise.
- Taste – decreased taste buds and saliva.
- Touch and smell – decreased sensitivity to touch and ability to smell.
- Arteries – stiffen with age. Additionally, fatty deposits build up in your blood vessels over time, eventually causing arteriosclerosis (hardening of the arteries).
- Bladder – increased frequency in urination.
- Body fat – increases until middle age, stabilizes until later in life, then decreases. Distribution of fat shifts – moving from just beneath the skin to surround deeper organs.
- Bones – somewhere around age 35 bones lose minerals faster than they are replaced.
- Brain – loses some of the structures that connect nerve cells, and the function of the cells themselves is diminished. “Senior moments” increase.
- Heart – is a muscle that thickens with age. Maximum pumping rate and the body’s ability to extract oxygen from the blood both diminish with age.
- Kidneys – shrink and become less efficient.
- Lungs – somewhere around age 20 lung tissue begins to lose its elasticity, and rib cage muscles shrink progressively. Maximum breathing capacity diminishes with each decade.
- Metabolism – medicines and alcohol are not processed as quickly. Prescription medication requires adjustment. Reflexes are also slowed while driving; therefore, an individual might want to lengthen the distance between them and the car in front and drive more cautiously.
- Muscles – muscle mass decline, especially with lack of exercise.
- Skin – nails grow more slowly. Skin is more dry and wrinkled. It also heals more slowly.
- Sexual health – women have menopause, vaginal lubrication decreases and tissues atrophy. In men, sperm production decreases and the prostate enlarges. Hormone levels decrease.

The aging process also brings social and emotional change and loss into our lives. Inevitably, as we age, older relatives die, then some of our friends may grow frail and die, then the loss of a spouse affects many. Physical losses and social losses that can accompany aging may be very difficult emotionally. Grief and sadness are normal reactions to such situations, and we cannot stamp out these reactions in ourselves or our older relatives. Just as the physical losses of later life can be compensated for, so can the social and emotional losses be overcome. There are also financial changes to cope with.

It's understandable that Bette Davis said, "Old age is no place for sissies."

With advances in technology and medications, many incurable health problems that used to be fatal, e.g. cancer, congestive heart failure, dementia, diabetes, and stroke, are now chronic (lasting). Living longer can also mean living for a long time with multiple disease conditions. This is why it is said caregiving is more like a marathon than a sprint. Learning about the health issues of your care recipient can help you understand best care practices, and the expected course of an illness. This allows all the parties involved to begin preparing for expected changes.

13. DOCTORS

13a) TALKING WITH YOUR DOCTOR... AND OTHER HEALTH-CARE PROFESSIONALS

This booklet was written to help patients get the most out of their time with their doctor, given the notoriously short appointment times we have. The free PDF guide will help you prepare for visits, state your concerns clearly and honestly, provide a good description of your medical condition, ask clear questions about your illness, and explain any problems you have with medical treatments. Created by Dr. Don Segala, it recommends using the PACE system with health professionals: Presenting detailed information; Asking questions; Checking on your understanding of what is said to you; Expressing any concerns you have about the treatment. Google the title of the guide to get a copy.

13b) MEDICAL INTERVENTION DECISION-MAKING – PALLIATIVE AND THERAPEUTIC HARMONIZATION (PATH)

Frail elders have multiple chronic health issues, but our current model of care focuses on each individual health challenge, often failing to consider the overall frailty of a patient, which should be at the forefront of decisions. With humans living longer and facing more medical decisions because of advances in medicine, we also live with the risk of choosing interventions that leave us worse off rather than better.

Please note that this piece on medical intervention decision-making is NOT about saving dollars by cutting care to the frail. Rather, it is about making the time those living with frailties have left as good as possible.

A number of concerned physicians have addressed this issue with books such as *A Bitter Pill: How the Medical System is Failing the Elderly* by Vancouver's Dr. John Sloan. Best-seller *Being Mortal: Medicine and What Matters in the End* by Atul Gawande, a Harvard Medical School professor, wrestles with the downside of medical treatments that can be more harmful than helpful for those living with frailty. Dr. Dennis McCullough's *My Mother, Your Mother: Embracing "Slow Medicine," The Compassionate Approach to Caring for your Aging Loved Ones* expresses concern over treatments that may be inadvisable for those battling multiple ailments in their senior years.

One program addressing these misgivings is Palliative and Therapeutic Harmonization (PATH) – a process that helps older people make complex health-care decisions by looking at the big picture. It’s a new way of thinking about surgeries and other interventional therapies, considering frailty, i.e. “...the vulnerability that comes when people accumulate multiple health issues.”

All this is meant to optimize the decision-making of a frail elder, or, in the case of cognitive inability to make a complex health-care decision, to assist the substitute decision maker or legal representative in deciding on proposed treatments. It is not a quick process; it involves two or three visits with a PATH team to:

- Understand all aspects of your health and well-being.
- Communicate about your current health and what you can expect in the future.
- Plan. Once you understand everything about your health and what to expect in the future, the PATH process help frail elders and their family (or other care partners) prepare for making future health decisions.

As the PATH web page www.pathclinic.ca/getting_started explains, “There are times when it is appropriate to take all possible therapeutic measures to cure or delay the progression of illness. However, at other times this approach may cause more harm than good. As people develop more health problems they become frail. People who are frail may not be able to tolerate or benefit from the complex medical and surgical treatments that tend to benefit healthier people.... The goal of PATH is to help patients and families choose a blend of therapeutic and palliative measures that will best preserve an individual’s quality of life in their remaining time.”

Who is PATH for?

PATH is for older people with serious health conditions, including those who:

- Have one or more advanced or progressive illnesses.
- Have had multiple hospitalizations or uncontrolled symptoms.
- Have experienced a progressive decline in mobility, function (ability to carry out routine daily activities) or cognition (ability to remember, think or reason), or have questions about how to make health-care decisions that reflect individual values, how to manage symptoms, and how to anticipate what lies ahead.

Two Halifax physicians created the PATH program and the PATH clinic in Nova Scotia. They have been slowly training doctors across Canada to help them consider if, in the presence of frailty, medical interventions used with non-frail patients will help or harm their frail elder patients. The few B.C. physicians who have undergone some PATH training are looking at ways the PATH process can be used in B.C.

For more, including the short YouTube presentation *Introduction to the PATH Model*, visit the website.

Adapted from www.pathclinic.ca

Not all health issues are covered in this handbook as this is not a health resource guide, and space is limited. Following are some health issues that many family caregivers struggle with.

14. THE 3 Ds

The 3 Ds, also known as the Three Geriatric Giants, refer to delirium, depression, and dementia. These three medical conditions can resemble each other in older people because some of the symptoms overlap. It is vital to distinguish between the three. For example, a caregiver might assume

that sudden confusion is “just dementia,” when it is actually a reversible delirium which needs to be attended to immediately. None of the 3 Ds are a normal part of aging, but rather, are serious health threats in old age.

15. DEPRESSION

Depression is a serious illness that steals joy from life and, at its worst, leads to suicidal thoughts and actions. It is not a sign of weakness or personal defect. This term is used when feelings of unexplained intense sadness last for at least two weeks and when the symptoms such as sadness, negativity, loss of interest, pleasure and/or decline in functioning are of such intensity that they are out of the ordinary for that individual. It is much more than sadness. The exact diagnostic label is major depressive disorder.

While many older people are at risk of depression, remember that depression is NOT a normal part of aging, and like any health issue should be brought to the attention of a physician. Depression is treatable and treatment of late-life depression has benefits that extend to the family members on whom care recipients depend, i.e. the family caregivers.

12 Depression Busters for Seniors offers more insight and tips on depression and the elderly. See www.psychcentral.com/blog/archives/2012/08/28/12-depression-busters-for-seniors/.

Did you know that family caregivers are at more than double the risk of depression compared to the general population?

The U.S. Family Caregiver Alliance notes, “Caregiving does not cause depression, nor will everyone who provides care experience the negative feelings that go with depression. But in an effort to provide the best possible care for a family member or friend, caregivers often sacrifice their own physical and emotional needs and the emotional and physical experiences involved with providing care can strain even the most capable person. The resulting feelings of anger, anxiety, sadness, isolation, exhaustion – and then guilt for having these feelings – can exact a heavy toll. Unfortunately, feelings of depression are often seen as a sign of weakness rather than a sign that something is out of balance. Comments such as “snap out of it” or “it’s all in your head” are not helpful, and reflect a belief that mental health concerns are not real. Ignoring or denying your feelings will not make them go away.”

Antidepressant medications (approved by a medical practitioner), counselling, and exercise are cited as three good strategies used for managing depression – and even better when combined.

16. DELIRIUM

Delirium is a medical emergency and it can be deadly. It is characterized by an acute or sudden onset of confusion, disturbances in attention, disorganized thinking and/or decline in level of consciousness. There are a number of possible causes, including medical conditions such as infection, e.g. urinary tract infection or pneumonia, reaction to medication or surgical anesthetic, dehydration, malnutrition, and others (often referred to as bugs or drugs). Delirium comes on suddenly and is commonly reversible with treatment; hence the need to seek medical care quickly. See online: *Delirium in the Older Person: A Medical Emergency* by Vancouver Island HA

17. DEMENTIA

Dementia is an umbrella term which describes a serious irreversible progressive deterioration in brain mental functions such as memory, language, orientation, abstract thinking, and judgment. It is referred to as a cluster of symptoms or a syndrome, marked by gradual deterioration and it gets worse over time. Dementia is not a normal part of the aging process, it is not universal; not everyone who ages develops dementia.

Caregivers of individuals with memory disorders or dementia report that the challenges are not confined to the illness itself, but tied to the ambiguity and uncertainty it causes. It is difficult to care for someone who is here, but not here – here physically, but to differing degrees, gone mentally and psychologically. You feel alone, and in some ways, you are. For many caregivers, it's as if there's a stranger in the house. Adding to the stress is the unpredictable nature of memory loss that comes and goes – one moment here, the next moment gone. This roller coaster of absence and presence is a very stressful kind of loss, what author Pauline Boss calls “ambiguous loss.” Unlike death, there is no closure. Read more about Caregiving and Ambiguous Loss at www.caregiver.org/caregiving-and-ambiguous-loss.

From U.S. Family Caregiver Alliance website

17a) TYPES OF DEMENTIA

Just as there are different types of heart disease or cancer, there are different types of dementia. A variety of diseases cause dementia:

1. Alzheimer's disease is a progressive degenerative disease for which there is no known cause or cure. Brain cells shrink and are replaced by dense, irregularly-shaped spots called amyloid plaques. Threadlike neurofibrillary tangles also develop within healthy brain cells, and eventually destroy them. Alzheimer's is the most common type of dementia and almost 10 per cent of Canadians over the age of 65 have either Alzheimer's or another dementia. The older we become, the higher the incidence of the disease; 35 per cent of those over the age of 85 have dementia. N.B. early-onset Alzheimer's can strike people in their 40s and 50s.
2. Vascular dementia, the second most common form of dementia, is a broad term for dementia associated with problems of circulation of blood to the brain, and it includes multi-infarct dementia.
3. Other types of dementia include Lewy body disease, Fronto-temporal dementia including Pick's disease and frontal lobe dementia, dementias related to illnesses such as Parkinson's disease (dementia may develop late in the course of PD), Huntington's disease, Down syndrome, and HIV-related dementia.

Sometimes people have more than one form of dementia, a condition referred to as mixed dementia. Vascular dementia may co-exist with Alzheimer's disease, for example.

17b) GETTING A DIAGNOSIS

Doctors of B.C. (formerly the B.C. Medical Association) and the B.C. Ministry of Health created guidelines and protocols for MDs in 2007/8 called Cognitive Impairment in the Elderly – Recognition, Diagnosis and Management. They provide recommendations for recognizing, diagnosing and managing cognitive impairment and dementia in the elderly. The guidelines refer doctors to the key role of family caregivers as well.

The primary care objectives are to encourage early recognition and assessment of cognitive impairment and to support general practitioners in the development of a comprehensive care plan that includes the identification of community resources for people affected by dementia. Note that a

summary of the guidelines can serve as a worksheet to guide discussion in the physician's office. It may be necessary to complete the diagnostic evaluation over a few visits.

If you are concerned about the cognitive health of an elderly family member and are told there is nothing that can be done because the patient is old, you can ask if the physician follows the set of guidelines and protocols for diagnosing dementias.

The Alzheimer Society of B.C. gives the following helpful information about diagnosis, taken from www.alzheimer.ca/en/bc/About-dementia/Diagnosis/Getting-a-diagnosis :

Making the diagnosis

No single test can tell if a person has Alzheimer's disease. The diagnosis is made through a systematic assessment that eliminates other possible causes. Until there is a conclusive test, doctors may continue to use the words "probable Alzheimer's disease." Doctors making this diagnosis, however, are accurate 80 to 90 per cent of the time. Making the diagnosis can take time. The diagnosis can be made by a family doctor or a specialist. When making the diagnosis, the doctor may or may not refer you to other health-care professionals. These may include a psychologist, psychiatrist, neurologist, geriatrician, nurse, social worker or occupational therapist. They will look for problems with your memory, reasoning ability, language and judgment, and how these affect day-to-day function.

The process involves:

- Medical history. Both you and your family members or friends will be asked questions regarding your symptoms now and in the past. There will be questions about past illnesses and about family medical and psychiatric history.
- Mental status exam. This part of the process tests your sense of time and place as well as the ability to remember, express yourself and do simple calculations. It may involve exercises such as recalling words and objects, drawing and spelling, and questions such as "What year is it?"
- Physical exam. To help rule out other causes, a physical exam will be done. The doctor will look for heart, lung, liver, kidney or thyroid problems that may be causing the symptoms. To evaluate whether other nervous system disorders are causing the symptoms, the doctor will test muscle tone and strength, coordination, eye movement, speech and sensation.
- Laboratory tests. Detailed blood work will be ordered to help detect problems such as anemia, diabetes, thyroid problems or infections that might be contributing to the symptoms. Other tests such as X-rays and EEGs (electroencephalogram) may be used to determine the source of the problem. In some medical centres, scans may be used.

The following may be recommended, but are not always necessary for a diagnosis:

- CT (computerized tomography) scan and MRI (magnetic resonance imaging) take images of the brain.
- SPECT (single photon emission computed tomography) shows how blood is circulating to the brain.
- PET (positive electron tomography) shows how the different areas of the brain respond during certain activities such as reading and talking, but this scan is usually done after 45 minutes of rest.
- Psychiatric and psychological evaluations may be helpful in ruling out other illnesses such as depression, which can cause symptoms similar to Alzheimer's disease. Neuro-psychological testing can evaluate memory, reasoning and writing.

Why find out?

Symptoms of Alzheimer's disease can be similar to symptoms of other conditions such as depression, thyroid or heart disease, infections, drug interactions or alcohol abuse. Finding out the cause of the symptoms can help you: understand the source of the symptoms; get the proper care, treatment and support; and plan for the future. The earlier a treatment can be given, the better the result, and new treatments are on the way.

If the diagnosis is Alzheimer's disease, you may want to ask:

- What does the diagnosis mean?
- What can be expected over time?
- What care will be needed and is available now and in the future?
- What treatment is available? What are the risks and benefits?
- What resources are available in the community to help?
- Are there any experimental drug trials to participate in?
- When is the next appointment?

Specialty seniors' health clinics are another way to get a comprehensive assessment for cognitive health. See item 25 for a description of these clinics. Note these clinics specialize in assessing a number of health problems related to aging – not just dementia.

The Clinic for Alzheimer Disease and Related Disorders at UBC Hospital (604-822-7031) sees seniors from all over B.C. The clinic provides assessment and diagnosis of Alzheimer's disease and related disorders for patients including care and support for the affected individual and their family by team members from geriatrics, neuropsychology, neurology, social work, geriatric psychiatry, genetic counselling, and neuropathology. Patients can only be referred to the clinic by their family physician or other medical specialists. The appointment wait list is at least six months.

Regardless of where the diagnosis is made, a dementia diagnosis can be horribly shocking. The Alzheimer Society of Canada reminds us:

People with dementia can live meaningful and productive lives for many years after an early diagnosis. Dementia diagnosed early helps both the person and family members to learn about the disease, set realistic expectations and plan for their future together. There are many benefits to an early diagnosis. Here are our top 10:

1. Getting an accurate diagnosis. Conditions such as depression, thyroid disease, infections or drug interactions sometimes produce symptoms similar to those of dementia. A thorough medical assessment can lead to an accurate diagnosis so that appropriate treatment can begin.
2. Being actively involved in health-care and personal decisions. Earlier in the process, the person is able to participate more actively in their own health-care decisions and future plans.
3. Using medications effectively. Treatment of Alzheimer's disease and other dementias is typically most effective when started early in the disease process.
4. Focusing on what's important. An early diagnosis allows the person to set priorities based on what is important to them, such as travelling, pursuing new goals, or deciding when to stop working.
5. Making choices is empowering. An early diagnosis allows the person with dementia to make informed decisions about legal, financial and care matters and make their wishes known to their family and friends.
6. Taking advantage of resources. The person and their family can benefit from local Alzheimer Society information, support and education programs to learn how to live well with dementia.

7. Supporting families. Families who understand the disease and the challenges that come with its progression are better able to support the person with dementia and get the help that's right for them.
8. Advocating. People with dementia can make their voices heard to raise awareness about the disease, the need for quality care and increased funding for research.
9. Advancing research. People with dementia can participate in clinical trials and other research to help improve diagnosis and enhance care.
10. Reducing stigma. People with dementia can continue to live life to the fullest. Sharing experiences of living with dementia can be very helpful in reducing the stigma of the disease and in encouraging others to reach out for support.

Copied from www.alzheimer.ca/en/bc/About-dementia/Diagnosis/Getting-a-diagnosis

17c) DEMENTIA MEDICATIONS

There is no cure for dementia, but there are medications that help some people with symptoms for a period of time, though not indefinitely. Not all medications work for all people. When they do work, they help improve quality of life for the person with dementia, and this lessens the load a little on the caregiver(s).

Commonly prescribed medications for individuals diagnosed to be in the mild to moderate stages of Alzheimer's disease include a group of drugs called cholinesterase inhibitors. They include Aricept® (donepezil), Exelon® (rivastigmine), and Reminyl® (galantamine).

Aricept (donepezil) is also used for the treatment of moderate to severe Alzheimer's disease, as is Ebixa® (memantine hydrochloride). Memantine is one of a group of drugs called NMDA which targets a different neurotransmitter system from the cholinesterase (ChE) inhibitors.

All drugs have side effects. Discuss these with the doctor and the pharmacist and report any to the doctor.

17d) DEMENTIA INFORMATION AND SUPPORT

604-681-8651 (Lower Mainland) www.alzheimerbc.org

The Alzheimer Society of B.C. provides information and support for those living with Alzheimer's and other dementias, and for their family caregivers. Programs and services include:

- Alzheimer resource centres throughout B.C. offer information, educational opportunities, support groups and the ability to talk directly with a knowledgeable team member. Resource centres also offer information packages with brochures and fact sheets, individual support by appointment and referrals to community resources.
- A Dementia Helpline, 604-681-8651 (Lower Mainland) or 1-800-936-6033 (toll free) weekdays; 9 a.m. - 4 p.m., provides information about diagnosis, disease progression, planning for the future, maintaining independence, providing care and support, and local resources including support groups and education programs.
- Caregiver support groups.
- Dementia education talks:
 - Heads Up: An Introduction to Brain Health encourages people to actively engage in protecting and maintaining their brain.
 - Getting to know Dementia is an introductory session for the person with dementia, as well as their care partners, and family members.

- Shaping the Journey: living with dementia™ is a six-session education series for people with dementia and their care partners to explore the journey ahead in a positive, informative and supportive environment.
- Family Caregiver Series is a five-session series for family members who are caring for a person with dementia. Learn about dementia, practical coping strategies and early planning
- Tele-workshops are one-hour telephone workshops for family caregivers on topics such as Activities to do with the Person with Dementia, Driving and Dementia: Strategies for Caregivers, Helping with Memory Loss, Long Distance Caregiving, TYZE Personal Networks, Understanding Communication, and more. Workshops include a live web video of the presentation, making it easy to follow along on your computer while you listen on the phone, or you can just listen on the phone. The telephone and web workshops are archived so they are available anytime to listen to at www.alzheimerbc.org. Enter “tele-workshops” in the search button.
- First Link®, is an early-intervention service designed to connect individuals and families affected by Alzheimer’s disease or another dementia with services and support as soon as possible after diagnosis. First Link individuals/families receive an information package, connection to education programs and support groups, and referrals to other community and health-care services. They also receive follow-up contact every three to six months to ensure families receive information about the disease, plan for the future, and get tips for day-to-day living, and services when needed. A bi-monthly First Link bulletin keeps everyone informed about coming education and support programs.
- Minds in Motion® is a fitness and social program designed for people diagnosed with Alzheimer’s disease or another dementia, and a friend, family member or care partner. The program includes 45 minutes of gentle exercise led by a certified fitness instructor. After that, enjoy social time in a relaxed atmosphere with games and other activities, or just conversation and light refreshments.
- Early-stage support groups for people in early stages of dementia.
- MedicAlert® Safely Home® (toll free: 1-855-581-3794) is a nationwide partnership with the Alzheimer Society of Canada and the Canadian MedicAlert Foundation to help identify a person who is lost and assist in their safe return home. "Wandering" refers to a variety of behaviours that may result in people with dementia becoming lost or having their safety at risk. It happens because even if a place is familiar, dementia can cause a person to become disoriented and unable to find their way home. MedicAlert Safely Home members receive engraved identification (e.g. a bracelet, necklace, watch), which allows police and emergency responders to quickly identify the person who has wandered and bring the family back together.

It is important to remember that no one thing is going to ensure the safety of a person with dementia. Multiple strategies are recommended. The Alzheimer Society of B.C. can assist people with dementia and their families to explore a variety of practical strategies to minimize the risk of wandering and to be prepared if wandering does occur.

- Information bulletins. Two regular publications to connect and inform caregivers (*In Touch*) and people with dementia (*Insight*).

- Rainbow Caregiver Support Group (604-675-5150) offered by the Vancouver Resource Centre of the Alzheimer Society of B.C. gives family and friend caregivers caring for someone with dementia access to information and is open to queer family caregivers as well as non-queer people who are caring for a member of LGBTQ community.
- Chinese resource centres (604-687-8299) in Vancouver and Richmond to speak with someone in Chinese.
- Individual support in person is available by appointment at your local Alzheimer resource centre.
- Information on dementia and services in Chinese, Farsi, French, Japanese, Korean, and Punjabi at www.alzheimer.ca/en/bc/We-can-help/Resources/Non-English-resources

Multilingual information on dementia can also be found at Alzheimer’s Disease International www.alz.co.uk/other-languages (50 languages).

Alzheimer's Caregiving is a free e-newsletter for caregivers of people with dementia. It’s created by the U.S. Mayo Clinic. Subscribe at <https://newslettersignup.mayoclinic.com/?FN=203>.

Geriatric eldercare consultant and author Peter Silin reminds us of how we can unintentionally de-personalize people living with dementia in his newsletter article Don't Bury the Living: Dementia and Dignity. We need to examine our assumptions about the abilities of those with dementia and focus on what they can do, not just what they can’t do. Read the April 2014 article at www.diamondgeriatrics.com/newsletter/newsletter-directory.html.

17e) DEMENTIA ADVOCACY

The Alzheimer Society of Canada is proposing a Canadian solution to curb the soaring economic, social and personal impact of Alzheimer’s disease and other dementias. They recommend a Canadian Alzheimer’s disease and dementia partnership be created as a government-funded arms-length entity that would facilitate the development and implementation of a fully comprehensive national dementia strategy.

The B.C. Ministry of Health published its *Provincial Dementia Action Plan for British Columbians: Priorities and Actions for Health System and Service Redesign (2012)*: www.health.gov.bc.ca/library/publications/year/2012/dementia-action-plan.pdf.

In 2013, the United Way of the Lower Mainland, Alzheimer Society of B.C., City of Vancouver, FH, Simon Fraser University, Social Planning and Research Council of B.C., UBC, and VCH began collaborating on the project Creating Dementia-friendly Communities in the Region – A Call to Action. Reports of their June 2013 dementia-friendly workshop are on the United Way of the Lower Mainland website: www.uwlm.ca/wp-content/uploads/2015/06/Dementia-now-and-in-the-future-Fung1.pdf and www.uwlm.ca/wp-content/uploads/2015/07/Overview-of-Dementia-Friendly-Communities-Metcalf.pdf.

The dementia-friendly communities’ work continues and “...the initiative is an important opportunity to reduce stigma, as well as social and physical barriers that have a real impact on the quality of life of the people in our communities who are living with dementia,” said B.C. Health Minister Terry Lake. The Alzheimer Society of B.C. is now leading the work “...because ensuring that people with dementia have opportunities for involvement and social interaction is critical as

people with dementia may face challenges when shopping, banking, using transportation or visiting the post office.” However, with information, compassion and community engagement, there’s an opportunity to change this. For more about dementia-friendly communities’ work to better support people with dementia in B.C. municipalities, and those who live and work in them, visit alzbc.org/dementia-friendly-communities and www.alzheimer.ca/en/bc/Feature-stories/Dementia_Friendly_Communities_Toolkit_unveiled_at_UBCM_Convention.

18. HEARING LOSS

One out of three people will experience hearing loss at the age of 65 and it is the third most common physical condition after arthritis and heart disease. Hearing loss can be caused by a number of things including a life-long exposure to loud noises due to one’s profession, age, illness, genetics, and even some medications.

Hearing is a significant component of communication and socialization so older adults who suffer from hearing loss may become withdrawn and isolated, which can lead to the potential loss of support networks and the risk of depression. Since hearing loss is an invisible condition, its effects may be wrongfully attributed to confusion, personality changes or conditions such as dementia, even when it is an unrelated outcome.

Adapted from www.chs.ca & www.hearingloss.org

Hearing assistance, such as a hearing aid, can vastly improve the quality of life for those with hearing loss. Private audiology and hearing aid companies can be found in the Yellow Pages. Be sure to use audiologists and hearing instrument practitioners who are licensed and regulated through [The College of Speech and Hearing Professionals in B.C.](http://www.collegeofspeechandhearing.com). Some make home visits.

The Western Institute for the Deaf and Hard of Hearing (WIDHH) (604-736-7391; www.widhh.com) is a non-profit agency that offers a number of services for the deaf and hard of hearing. The WIDHH clinicians are dually registered as audiologists and hearing instrument practitioners under the College of Speech and Hearing Health Professionals of B.C.. They provide hearing assessments and hearing aids from all major brands, recycled hearing aids and a hearing-aid loaner program. Other services include hearing clinics, employment services, interpreting services, communication devices, and community presentations. WIDHH has been the largest provider of sign language interpreting services in Western Canada and offers both medical interpreting services (MIS) and community interpreting services (CIS).

Contributed by Tasha Lorenzen-Ewing, M.A., Gerontology

19. INCONTINENCE

The following description of the prevalence and types of incontinence as well as the ways caregivers can help was written for this handbook by Marcia Carr (RN, BN, MS, GNC(C), NCA), clinical nurse specialist with Fraser Health.

Incontinence – Not able to get to the toilet in time

Incontinence may be the "straw that breaks the camel's back" for the home caregiver. It is important that the caregiver know what resources are available to help them, know what they can do, and how they can do it. First of all is for the caregiver to acquire the correct information of why the incontinence is happening.

One in four women and one in eight men will experience bladder (pee, urine), bowel (stool, feces) or both bladder and bowel incontinence, especially as they age. For women it is often related to losing the strength and tone in the pelvic floor muscle (the sling-like muscle that is between the legs that holds up the bladder, uterus, and rectum). One way to know that the pelvic floor muscle needs to be stronger is when the person laughs, coughs, sneezes suddenly, causing urine or bowel leakage. This is called "stress" incontinence. Factors that may lead to this type of incontinence are childbirth, straining due to constipation or any activity that consistently pushes down on the pelvic floor muscle.

"Urge" incontinence is when the person is unable to hold on to the urine or bowel movement when they feel the need to pee (void, urinate) or have a bowel movement as they have little to no time to make it to the toilet in time.

"Functional" incontinence happens when the person has lost the ability to get to or use the toilet. Some examples are because of poor mobility, loss of hand control/strength to remove clothing and inability to recognize where the toilet is.

"Overflow" incontinence is when the person is frequently emptying only small amounts of pee or stool. This can be compared to a dam overflowing its walls. This is often caused by an obstacle (e.g. hard stool, enlarged prostate gland, dropped uterus or bladder) that prevents the bladder or bowel from fully emptying.

The good news is that there are ways to help both the caregiver and the person with incontinence.

The following are a few practical tips on what may help decrease the burden of incontinence:

- Drinks six to eight glasses of fluids a day, preferably water. Concentrated urine is very irritating to the bladder so diluting it often will decrease the number of times that the person feels the urge to pee.
- If possible stop all beverages with caffeine (e.g. coffee, tea) or drinks that are carbonated as they irritate the bladder.
- Have a high fibre and fluid diet to prevent constipation.
- After the person eats, try going for a short walk or do leg exercises to stimulate the bowels and then use the toilet afterwards.
- Ensure that the person is sitting correctly on the toilet (feet are flat on the floor and, if not, provide a step stool to put their feet on).
- Schedule regular times (every two hours) to visit the toilet.
- Make sure that the toilet is safe and accessible. An occupational therapist can help with this.
- If the person has a change in their peeing (urine smells bad, going more often with smaller amounts, has pain, blood), they may have an infection so it is important to take them to the doctor.
- If the person has a change in their stool (very hard or very loose, blood, slimy, green), they need to be seen by their doctor.

There are many different types of disposable products to contain the urine. It is very important that the product fit correctly. The padded part must be held closely and firmly against the body parts where the pee or stool is being evacuated. Do not use female menstrual products.

In B.C. there are increasingly more nurse continence advisors (NCAs). The NCA is a registered nurse who has completed a specialized program in order to diagnose the type of incontinence and to provide a conservative treatment plan. VCH, Providence Health Care, FH, Vancouver Island HA and

Interior HA have NCAs available as a resource that you can contact to help you. The Canadian Continence Foundation (www.canadiancontinence.ca) and Canadian Nurse Continence Advisor Association (www.cnca.ca) are excellent online resources to look at. Physiotherapists who specialize in the pelvic floor muscle are another excellent resource.

20. MENTAL HEALTH

Mental illness (a brain ailment) can happen to anyone – nobody asks to have it; it is an illness of a body organ, the brain, just as diabetes is a disorder of the pancreas. It does not mean a person is weak. Unfortunately, mental illness isn't well understood, and it can sometimes be looked down upon or feared because it is something people don't understand. In an effort to try and prevent our family member from being stigmatized, we might decide to keep their mental illness a secret but this can make it harder to reach out for support and get help. Different mental illnesses affect people differently; stereotypes are not effective, but people can improve with treatment.

20a) HA GERIATRIC MENTAL HEALTH SERVICES

In the FH area, Geriatric Psychiatry Services offer a specialized outreach service for seniors affected by dementia, major affective disorders, or other severe mental illnesses. Multidisciplinary in nature, the program consists of psychiatry, social work and nursing. Clients may live in their own home, in SH, or in RC. The teams operate out of local mental health centres which are listed at www.fraserhealth.ca/find-us/services/our-services?program_id=10674.

FH After Hours Emergency Mental Health Program (toll free: 1-877-384-8062) offers professional mental health staff available via phone weekdays, 4:30 - 11 p.m., and 1 - 11 p.m. on weekends. There is also a Mental Health Support Line: 310-6789 (no area code needed), for emotional support, and mental health resources.

VCH Older Adult Mental Health Program - North Shore (604-904-3540), Richmond (604-675-3975), Vancouver (604-709-6785) - has mental health teams for seniors who have recently developed a mental health problem such as depression or bipolar illness, have high-risk behaviours related to advancing dementia, or have medical problems related to aging that complicate the treatment of a mental illness. Services include specialized assessment and consultation, treatment/case management, and rehabilitation. Most seniors are seen in their own homes.

VCH's PDF booklet *Community Supports for Families Supporting a Loved One Living with Mental Illness and/or Addiction - Counselling, Support Groups, and Education (December 2013)* lists community services, support groups, counselling options, and other education resources, and includes contact information, email addresses, and web links. Google the title to obtain a copy.

In Vancouver, VCH offers a Family Support Group For Families and Friends of people with Mental Illness and/or Addiction which includes an embedded library technician to research and provide up-to-date information for your specific needs. The group is facilitated by VCH's family support and involvement coordinators and meets two evenings each month. Call 604-313-1918 for details.

20b) CANADIAN MENTAL HEALTH ASSOCIATION (CMHA) - B.C. DIVISION 604-688-3234

CMHA works to support the resilience and recovery of people experiencing mental illness through advocacy, education, community-based research, and a number of programs and services:

- Bounce Back: Reclaim Your Health is a program designed to help adults experiencing symptoms of depression and anxiety that may arise from stress or other life circumstances. Bounce Back offers two forms of help. First, a DVD providing practical tips on managing mood and healthy living is available in English, Cantonese and Mandarin. The second form of Bounce Back help is a guided self-help program with telephone support that teaches problem solving strategies. Available in English and Cantonese. The free Bounce Back program requires your doctor's referral.
- Education and support groups for family caregivers are available.
- Chinese Mental Health Services Resource List is available for the Chinese community

Adapted from www.vancouver-burnaby.cmha.bc.ca

20c) MOOD DISORDERS ASSOCIATION OF B.C. (MDABC)

604-873-0103 www.heretohelp.bc.ca/sites/default/files/family-self-care-and-recovery.pdf

MDABC provides support and education in English, Cantonese, Mandarin and Punjabi for those living with a mood disorder or other mental illness. MDABC recognizes that mental illness can be as challenging for family members as it is for the person experiencing mental health symptoms, so they offer a support group for caregivers. It is vital that family members take time to learn how to best help someone experiencing mental health issues to not only ensure that the support they provide is more beneficial to the person receiving it, but also to be able to maintain their own health. MDABC, with B.C. Partners for Mental Health and Addictions, have a 91-page resource manual, *Family Self-Care and Recovery From Mental Illness*, which offers a wealth of practical guidance for families dealing with mental illness. There is also an information manual available in Punjabi:

www.heretohelp.bc.ca/sites/default/files/punjabi_full.pdf.

Adapted from www.mdabc.net

21. STROKE

Stroke is a medical emergency; it involves a sudden loss of brain function, caused by the interruption of flow of blood to the brain (ischemic stroke) or the rupture of blood vessels in the brain (hemorrhagic stroke). The interruption of blood flow or the rupture of blood vessels causes brain cells (neurons) in the affected area to die, which can lead to stroke-induced dementia. The effects of a stroke depend on where the brain was injured, as well as how much damage occurred. A stroke can impact any number of skills including the ability to move, see, remember, speak, swallow, reason and read and write.

In Canada, someone has a stroke every 10 minutes. Recognizing and responding immediately to the warning signs of stroke by calling 9-1-1 or your local emergency number can significantly improve the chances of survival and recovery because “time equals brain.” If a person is diagnosed with a stroke caused by a blood clot, doctors can administer a clot-busting drug available only at a hospital, and only within a few crucial hours after symptoms begin (“lose time, lose brain”). A stroke can destroy up to two million brain cells per minute. That is why it we need to recognize these five warning signs of stroke and immediately call 9-1-1:

1. Weakness – Sudden loss of strength or sudden numbness in the face, arm or leg, even if temporary.
2. Trouble speaking – Sudden difficulty speaking or understanding or sudden confusion, even if temporary.
3. Vision problems – Sudden trouble with vision, even if temporary.
4. Headache – Sudden severe and unusual headache.
5. Dizziness – Sudden loss of balance, especially with any of the above signs.

Information about stroke and heart disease is available in [Chinese](#), [English](#), [Farsi](#), [French](#), [Hindi](#), [Ojibwe](#), [Oji-Cree](#), [Punjabi](#), [Tamil](#), and [Urdu](#) at www.heartandstroke.com.

The Stroke Recovery Association of BC (604-688-3603) offers B.C.-wide education and support groups for caregivers and people recovering from stroke. Caregivers information for can be found at <http://strokerecoverybc.ca/recovering-from-a-stroke/information-caregivers/>. There is also a guide, *Recovering from a Stroke: Guide for Stroke Survivors, Families and Caregivers (revised version)*, at <http://strokerecoverybc.ca/wp-content/uploads/Updated-2014-Stroke-Information-Booklet.pdf> It is also available in [Traditional Chinese](#) and [Simplified Chinese](#) at <http://strokerecoverybc.ca/recovering-from-a-stroke/information-caregivers/caregiver-resources/>

22. SUBSTANCE ABUSE

22a) AL-ANON FAMILY GROUPS

604-688-1716

These support and education groups are for those who are affected by the excessive drinking of someone close, including family caregivers who understand the frustration, worry, fear, financial problems, and loneliness that often results from caring for someone who drinks inappropriately. Al-Anon is an anonymous program. One of the main principles of Al-Anon is that what is said there is held in strict confidence. There are no dues or fees.

Based on the 12 steps used in Alcoholics Anonymous (AA), Al-Anon groups meet throughout North America. Phone for meetings in your area, or search online “Al-Anon and B.C.” Al-Anon can also refer you to 12-step groups for friends and families of people who abuse drugs (prescriptions, over-the-counter, and street drugs).

22b) OLDER ADULT ADDICTION SERVICES

FH Older Adult Outpatient/Outreach Services (604-777-6870) is an older adult/senior-specific program that provides outreach support to seniors. Clients are 65 years and older or under 65 with mobility and cognitive problems that preclude attending regular adult clinics. They may have challenges with alcohol, drugs or prescribed medications as well as cognitive decline attributed to aging. The team also provides support to family members or caregivers of older adults who are affected by substance misuse. The approach focuses on reducing the harm that alcohol or drugs are causing the senior and improving their overall health. This service is free and confidential.

For VCH older adult addiction services, contact VCH (604-736-2033). In Vancouver, VCH offers a family support group for families and friends of people with mental illness and/or addiction which includes an embedded library technician to research and provide up-to-date information to your specific needs. The group is facilitated by VCH’s family support and involvement coordinators, and meets two evenings each month. Call 604-290-3817 for details.

23. MEDICATION ISSUES

Regardless of the health issues of the family member or friend you care for, medication management is important. As we age the number of medical conditions we deal with rises, and that tends to increase the number of medications we take. Seniors make up 14 per cent of the Canadian population but take over 30 per cent of prescription drugs. Older bodies do not handle meds as easily as younger ones because of reduced liver and kidney function, and polypharmacy (the use of many, i.e. four or

more medications) puts older people even more at risk. “High pill burden” can decrease the probability that medications are taken correctly, increase the possibility of adverse side effects as every medication has possible negative side effects, and raise the possibility of negative drug interactions. This can result in delirium – a medical emergency – other illnesses, and increase the risk of hospitalization. Over 20 per cent of all elderly patient admissions to hospital are related to adverse drug reactions or incorrect drug use.

Is Your Mom on Drugs? tells a Vancouver story about the dangers some medications can pose for older people: www.isyourmomondrugs.com.

23a) B.C. MEDICATION REVIEW SERVICES PROGRAM

Pharmacists can perform free medication reviews every six months; not many people know about this beneficial service, designed to increase communication between patient and pharmacist to promote safe medication use and improve health.

The review is carried out during an in-person appointment with a pharmacist. Eligible patients are B.C. residents with a personal health number (PHN) who require at least one medication that is entered in PharmaNet, and who give informed consent to receive the service. In a standard review the pharmacist meets with the patient to go over their medications and prepare a best possible medication history (a list of current medications). The purpose is to improve the patient’s understanding of their medications, including what medications they are taking, why they are being taken, how best to take them, and more. Speak to your pharmacist to learn more.

23b) MEDICATION REMINDERS

If your care recipient finds it challenging to manage medications, pharmacists have different ways to package medications (e.g. blister packs) that increase the probability of compliance with doctor instructions.

23c) MEDICATIONS LIST

Having an up-to-date list of medications taken (over-the-counter, prescription, herbal, tonics, immunizations, etc.) can be useful for visits to doctors and extremely useful in the event of emergencies where medical personnel might ask, “What medications are you taking?” A helpful list of medications will include: name; dosage and reason for taking; when and how it is taken; date it was started (and if use stopped, note end date); notes on any side effects; who it was prescribed by; and the pharmacy name. See item Part XIII, page 118.

24. HEAT-RELATED ILLNESS IN SENIORS

Heat-related illnesses include heat stroke, heat exhaustion, heat fainting, heat edema (swelling of hands, feet and ankles), heat rash and heat cramps (muscle cramps). Heat illnesses can affect you quickly and are mainly caused by over-exposure to heat or over-exertion in the heat. Heat illness can be fatal.

Anyone caring for an older person needs to be mindful that older adults are more vulnerable to heat illness because of chronic illnesses, reduced ability to sweat, reduced fitness levels overall, medications, reduced sense of thirst, dehydration, and isolation (no one may be monitoring them on a hot day). Heat illness can also impair judgment, e.g. the senior may not think they need to cool down.

Things you can do to help prevent your care recipient from getting heat-related illnesses include making sure the person: stays cool using air conditioning or fans, or spends time in a cool place such as a community centre, mall, or big box store; keeps hydrated (because of a reduced sense of thirst, seniors need to drink BEFORE they get thirsty); wears loose, breathable fabrics such as cotton and linen; has a cool shower or bath; blocks out the sun in the house; and eats food with a high water content. Please check on your family member or friend a few times a day (once is not enough when very hot).

Find more information on preventing heat-related illness in seniors at Health Canada www.hc-sc.gc.ca/ewh-semt/pubs/climat/heat-adults-chaleur/index-eng.php in French at www.hc-sc.gc.ca/ewh-semt/pubs/climat/heat-adults-chaleur/index-fra.php and in multiple languages at the Toronto Public Health website www.toronto.ca/health

25. WHEN UNCERTAIN ABOUT WHAT AILS YOUR CARE RECIPIENT

If your care recipient's physician has difficulty diagnosing or treating the health challenges of your aging family member or friend, you can request a referral to a specialized geriatric program, also known as specialty seniors' health clinics. Some are located in hospital buildings; others are separate standalone clinics. In FH, these clinics are called Specialized Geriatric Clinics; in VCH, they are given various names depending on the location. They can provide help with a clinic social worker, e.g. when a caregiver is overwhelmed with providing care to a loved one, and help seniors with:

- chronic disease (dementia, depression, etc.)
- disruptive behaviour
- risk of falls, or history of falls
- incontinence
- difficulty managing medications
- changes in the ability to live independently
- failure to thrive

The clinics provide comprehensive screening, assessment, treatment, care planning, and education to seniors and their families, as well as mentoring support to professional caregivers. The clinic staff – geriatricians, geriatric nurses, occupational therapists, social workers, and more – have specialized skills and knowledge to treat a variety of geriatric health problems.

To get an appointment at your local specialty seniors' health clinic, ask your care recipient's doctor for a referral. Expect a wait. If you are able to transport your loved one to a clinic farther away than the one closest to your community, you can ask for a referral to another clinic with a shorter wait list. Expect your first visit to be 1.5 to two hours long, and include a head-to-toe examination of your care recipient. Be sure to get connected also to the social worker on the team for support related to your caregiver concerns; remember: you have needs too.

26. THE HOSPITAL JOURNEY

The hospital journey can be alarming for both care recipients and family caregivers. The older a person is, the higher the use of hospital services, and seniors are likely to have longer hospital stays. As explained in the FH publication, *Code Plus: Physical Design Components for an Elder Friendly Hospital* by Belinda Parke and Kathleen Friesen, “not only must the care provided respond to an acute health-care crisis, it also must recognize the developmental phenomena associated with aging, and the likelihood that chronic illnesses are present, and compounding, both diagnosis and treatment. In the face of a rapidly growing aging population, a new approach to hospital care is imperative –

one that takes into account the special considerations of being old in a system of care focused on acute illness episodes.”

When admitted to a hospital, ask for the hospital pamphlet; not all hospitals have one, but if they do, it can help you understand how some things work and where things such as the cafeteria, Internet service, quiet chapel room, etc. are located. There are also a number of hospital-based elder-friendly programs for frail seniors, but not every hospital has all programs.

Dorothy’s Story – Seniors, Families and Professional Partners in Care is an eight-minute video resource to support older patients and their loved ones during a hospital stay. It emphasizes the need to proactively participate in hospital care. Created by VCH’s Community Engagement Advisory Network (CEAN), it reminds us that frail elderly people in the hospital need to ask questions, express themselves, be vocal about changes, be aware of medications, get adequate liquid and food, and to move and be as active as possible. *Dorothy’s Story* can be found on YouTube; enter the video title.

26a) GERIATRIC EMERGENCY NURSE CLINICIANS (GENC)

In the emergency room these nurses have specialized knowledge and skills in managing the care of older adults. Generally, the GENC, when available, assesses patients who are 75 years of age or older who present with: an acute illness; a number of medical problems; a sudden or recent change in function; or a loss in ability to maintain their usual daily activities. The GENC can assist patients with the following concerns: functional decline; changes in mobility; falls; pain management; continence issues; nutritional and medication concerns; caregiver stress; behaviour; and memory changes. The GENC works with the patient and care partners to develop an individualized plan of care for patients who present with complex needs. This role includes: assessing and identifying care needs; providing patient and family education; and providing information regarding health services and community resources.

26b) 48/6 MODEL OF CARE

This model addresses six care areas of functioning through patient screening and assessment within the first 48 hours of hospital admission. By addressing these essential needs early in a patient’s admission, 48/6, which is mandated in all B.C. hospitals by the B.C. Ministry of Health, can reduce the risk of functional decline in hospital and proactively support independence:

1. Bowel and bladder management.
2. Cognitive functioning which refers to the mental processes including memory, thinking, judgement, calculation, and visuospatial skills. Attention will also be paid to the possibility of delirium, depression, dementia, and mild cognitive impairment.
3. Functional mobility, i.e. a person’s ability to stand, walk, and transfer from bed to a chair. N.B. Bed rest inhibits a person’s capability to perform these functions as it contributes to muscle atrophy and reduced endurance.
4. Medication management which involves reviewing each person’s medication list, dosages (dose and dose interval), potential medication interactions and balancing the benefits versus the risks of medications.
5. Nutrition and hydration to assess for adequate amount and type(s) of food and liquid consumed, assessing for any swallowing difficulties and/or food allergies.
6. Pain management, i.e. the use of medications and other interventions (such as massage, exercise, or physiotherapy) to prevent, reduce, or stop acute or chronic pain.

This screening and/or assessments are then supported by the development of an individualized care plan to address key areas of health for the senior. Care plans must be developed within 48 hours of

the decision to admit and are further supported by a discharge (see 26f for more on discharge) and/or transition plan to ensure the senior can return to home safely with established access to the health resources in the community they require.

Adapted from www.48-6.ca

26c) ACUTE CARE OF THE ELDERLY (ACE) UNITS

ACE is a unit in some hospitals that provides specialty care to admitted seniors who have a number of serious medical problems, and are at risk of losing their ability to function independently. The medical unit provides comprehensive care for frail geriatric patients who typically are 75 years or older, have complex medical issues, and are experiencing recent changes in their physical, cognitive or functional abilities. The care provided in an ACE unit is uniquely designed to help seniors get well quickly so they can return home, and to prevent or delay their admission to RC.

The interdisciplinary ACE team, which includes dedicated health providers directed by a geriatrician, is specially educated in the care of seniors. They treat problems common in the older population such as dehydration, falls, pain, confusion, drug-related illnesses, delirium and dementia. The ACE team involves families, community providers and other local health services, such as home and community care, to help patients maintain or improve their physical, social and functional abilities, and to plan for a successful return home. Elderly patients admitted to hospitals with ACE units are assessed for their physical, cognitive, psychosocial and functional status to determine whether or not they are a candidate for ACE care.

26d) KEEPING PATIENT ROOMS SAFE FROM GERMS

Reducing the incidence of hospital-acquired infections is a hospital priority. Keeping hospital rooms clutter free and ensuring staff and visitors keep their hands clean are two important goals. Hospital rooms can harbour germs (bacteria, fungi, and viruses) that can cause serious infections, especially for elderly patients, those with weakened immune systems and those who have undergone surgery or who have catheters or tubes inserted in the body.

Patients play an important role in reducing the risk of infection transmission by keeping their hospital bed space clutter free. Please limit personal items and keep them inside the bedside table as much as possible. Keeping personal items off the floor and away from waste containers reduces the harbouring and spreading of germs and reducing clutter also simplifies the critical job of the cleaning staff.

Watch staff to make sure they wash or sanitize their hands with waterless sanitizer before providing care, and remind them if they forget. Don't be shy to ask, "Doctor, have you just washed your hands?"

To keep your environment as clean as possible, visitors should not sit on your bed or handle your equipment. Ask visitors to sanitize their hands when entering and leaving your room to avoid bringing in and carrying out germs. And remember, patient bathrooms are just for patients. Visitors should use common bathrooms in the lobby or hallways. Visitors should stay home if they feel sick or have a fever. This will help protect everyone in the hospital. Remember, what may seem like just a little cold to others can be a big problem for someone in the hospital.

Adapted from: *Keeping Your Hospital Room Clean - Association for Professionals in Infection Control* www.apic.org/For-Consumers/Monthly-alerts-for-consumers/Article?id=keeping-your-hospital-room-clean

26e) PATIENT AND FAMILY EDUCATION CENTRES

Many hospitals have centres where patients and family caregivers can get information about health-related topics and HA services. They can also have time-limited access to onsite computers offering Internet and email connections to fill out online government forms and research needs. Be sure to ask the information staff or volunteers to assist with health-related inquiries.

26f) DISCHARGE (ALSO REFERRED TO AS RELEASED FROM HOSPITAL CARE) PLANS

When an acute (urgent) episodic illness occurs in addition to normal aging changes and chronic (ongoing) medical conditions, then a potential crisis exists. The episodic illness or event can diminish whatever independent function exists.

Evidence shows leaving the hospital as soon as possible and recuperating at home with home supports and community services is better than waiting to fully recover in hospital. Hospital environments can be very disruptive: new routines can cause confusion (as can some pain medications) making it difficult to think as clearly as one does at home in a familiar environment; mobility is severely restricted causing rapid loss of general muscle tone (known as de-conditioning; one day in bed leads to loss of one to five per cent muscle strength, or seven to 20 per cent per week); loss of joint articulation flexibility (one day in bed requires one week to regain); medication errors can occur; noise makes sleeping difficult; falls (which can be devastating) occur more often in unfamiliar settings; food is “strange;” and immune systems weakened by age make seniors more vulnerable to bacterial and viral infections. (Adapted from a 2012 public presentation *Top Ten Reasons Home is Best* delivered by Dr. Cheryl Nagle, Richmond, B.C.) These and other possible unfavourable responses from the activity of a health-care provider (e.g. diagnostic and or treatment procedures) or institution are referred to as “iatrogenic disorders” and they can cause deterioration in health status of a senior.

B.C. hospitals have discharge processes intended to set frail elderly patients up with the support they need to be independent back at home for as long as possible when hospital care is no longer needed. Some patients need further health care such as home-care nursing, or rehabilitation services. Your health-care team will work with you to help plan your discharge and any additional care that is required. This is based on the B.C. Ministry of Health philosophy that home is best as the place to recover from illness and injury, and manage chronic conditions as long as one is safely able to do so with appropriate supports in place, and home is the best place to recover from illness once hospital care is no longer needed. A discharge goal is to support high-needs clients to live in their homes while waiting for RC if that is required, to avoid RC if possible, to avoid emergency room visits and hospitalization if not appropriate, and for end-of-life clients to allow for a supported home death if possible. This supports the wish to remain in their homes for the rest of their lives expressed by many seniors.

The case manager should be monitoring to ensure the patient is managing safely at home. If care needs can no longer be safely met in one’s home, patients are assessed for alternative living arrangements, such as AL or RC.

If you are concerned about how a loved one who is recuperating will manage at home after leaving the hospital, speak to a member of the health-care team on your ward and they will relay your concerns to a hospital coordinator called a home health liaison or quick response case manager who understands how to match patient needs to resources in the community.

At VCH hospitals, care teams give patients a two-page document, *My Discharge Plan*, which summarizes their hospital stay, any follow-up tests or appointments, medication information, and

contact information for community health providers. Providence Health Care hospitals in Vancouver and FH hospitals give some discharge documentation also. Make sure the elder you care for does not leave the hospital without a written discharge plan.

Let's Get You Home is a pamphlet that addresses the needs of hospital patients and their loved ones who are exploring home-care support options: www.fraserhealth.ca/media/LetsGetYouHome.pdf.

Getting Home Safely: A Hospital Discharge Guide for Older Adults & their Families addresses the importance of leaving the hospital as soon as medical problems have been treated due to the risks of being in hospital longer than necessary. It also provides a long list of questions you might ask to start the discussion of the transition home such as:

- Why was I in hospital?
- What are my main health concerns?
- What do I need to do to manage my health at home?
- Is there anything I need to learn to do to follow the recommendations made by the team?
- What supports or service will I need?
- What information should I get before going home?

Google the title of the nine-page guide to download a copy.

A Checklist: Preparing to Go Home poses some questions to ask before going home:

- Have you arranged transportation to get home?
- Do you have your keys?
- Do you have clothing and shoes to get home in?
- Is there food in the house?
- Do you need someone to help you get groceries or provide meals?
- Have meal services been ordered?
- Will you need someone you know or a community health worker to help when you return home?
- Will you need some help to get new medications?
- Do you require a follow-up visit with your doctor, a physiotherapist, or other health-care professionals?

Checklist adapted from *Discharge Planning Resource Guide*, Lions Gate Hospital

Depending on the reason for hospitalization, you may receive some health-specific information. For example, for those treated for a hip fracture, HAs along with some hip health organizations have produced *FReSH START Toolkit Fracture Recovery for Seniors at Home: A hip fracture recovery guide for patients & families* available by emailing freshstart@hiphealth.ca. The FReSH START video *So the journey begins: Recovery after Hip Fracture* is available at www.vimeo.com/hiphealth/recovery.

26g) LANGUAGE SERVICES

This service provides interpretation or written translation in over 60 different languages and dialects. Sign language interpreters are also available for deaf, deaf-blind, and hard-of-hearing persons. There is a free interpretation or written translation service provided through a provincial program to ensure patients understand their health issues, how the hospital can help, and what patients need to do to maintain their health after they leave the hospital. If you require the use of language services, please inform the hospital; it will do its best to provide a trained interpreter.

27. HEALTHLINKBC / 8-1-1

Want to know about health services like the ones in this handbook available in your community? Just dial 8-1-1. This free 24/7 non-emergency health information line operated by HealthLinkBC, a Ministry of Health service, provides trusted health information with just a free phone call. A health services representative can help you find health information and services or connect you directly with a:

- Registered nurse about your symptoms (daily, 24/7).
- Registered dietitian - formerly known as Dial-A-Dietitian service (Monday to Thursday; 8 a.m. - 8 p.m.; Friday; 8 a.m. - 5 p.m.)
- Pharmacist when your community pharmacist may not be available to answer your medication-related questions (daily, 5 p.m. - 9 a.m.)

Translation services are available in over 130 languages on request. For deaf and hearing-impaired text telephone (TTY) assistance, call 7-1-1.

The website www.HealthLinkBC.ca provides medically approved information on more than 5,000 health topics, symptoms, and over-the-counter and prescription drugs and offers tips for maintaining a healthy lifestyle. It also offers information on more than 6,100 health services to help British Columbians find services close to their home communities.

A free *B.C. HealthGuide Handbook* is available from your pharmacist in Chinese, English, French and Punjabi. Chapter 3: Healthy Aging even has a section called Caregiver Tips in the Chinese, English and Punjabi editions. The [B.C. First Nations Health Handbook](#), an online companion document to the B.C. HealthGuide, is also available at the HealthLinkBC website or by phoning 8-1-1.

HealthLinkBC Files (fact sheets on public health and safety topics) are available on the web. Some are available in Chinese, Farsi, French, Punjabi, Spanish, and Vietnamese.

PART IV. HOUSING – AGING IN PLACE AT HOME USING COMMUNITY SERVICES

When considering housing options available to seniors as they get older, some prefer to “age in place,” i.e. stay at home in their communities and use locally available public (government-subsidized), non-profit, and/or private business services. There are a wide range of programs and products that can assist with health and home maintenance challenges to maintain independence as much as possible. Some leave their larger homes and downsize to smaller homes or condos. As needs change, seniors can tap into community services such as health care, home cleaning, meal and transportation services. Some even hire live-in care aides.

Signs that may indicate an older adult is in need of help include problems with: addictions (alcohol and drugs, e.g. over-the-counter and prescription medications); cognitive health (forgetting, personality changes, self-neglect); food (getting groceries, having adequate amounts of healthy fresh food, meal preparation, eating habits); hoarding; home care (house cleaning, garbage, laundry, home maintenance); personal care (bathing, medication management); personal mobility (falling); money management (paying bills on time, falling prey to scams, gambling); social isolation; and transportation (difficulty driving, problems using public transit).

The person you care for may resist using outside services. As discussed under Stress Management for Family Caregivers (item 11), our care recipients are living with a number of challenging stressors and are, understandably, concerned about maintaining their independence, dignity, privacy, and having control over their lives. If you are caring for a frail elder who hesitates to get or accept help, you can enlist others (e.g. health-care workers, faith group leader, friends) to encourage your care receiver to get the assistance they need. You can also offer gift certificates for services and, of course, services can be brought in on a trial basis. There is no shame in needing help; it has been likened to needing eyeglasses. Remember that you, the caregiver, also have needs and rights. While the person you are caring for may not think they need help, the day will likely come when you will. The needs of the care recipient AND the caregiver are important. Remember, as noted in the Welcome page of this handbook: you do not have to sacrifice your life for your care recipient.

The following types of services are available to family caregivers and the seniors they are caring for.

28. ADAPTIVE CLOTHING

Clothing is available that simplifies the dressing process for people with arthritis, dementia, MS, Parkinson’s and stroke, and for wheelchair users. Wide and extra-depth footwear is also available.

- Adaptive Comfort Clothing (formerly Comfort Classic): 604-984-8211; www.adaptivecomfortclothing.com.
- Debra Lynn Creations (604-596-5320) offers ready-made clothes and alters existing clothes to make them adaptive: www.debralynncreations.ca.
- Neway Adaptive Clothing: 604-940-9871; www.newayadaptiveclothing.com.
- Silvert’s Specialty Clothing (toll free: 1-800-387-7088) offers the largest selection in Canada. Call or email for a catalogue which is also on the website, www.silverts.com.

There may also be a seamstress/tailor in your community who can adapt existing clothing.

29. AIDS TO DAILY LIVING

Adaptive devices and equipment support the independence of older adults as they carry out their activities. Small items like button fasteners and large equipment such as hospital-style beds help compensate for some of the changes aging can bring and make life safer as well. Look in the Yellow Pages under medical equipment and supplies; some stores also rent equipment.

30. BC SENIORS' GUIDE (10th edition, 2012)

Toll free: 1-877-952-3181 www.gov.bc.ca/seniorsguide

This is a free comprehensive guide about provincial and federal programs and services for seniors, with sections on health benefits, lifestyle, housing, transportation, finances, safety and security, and other services. It is also available in Chinese, French, and Punjabi. Available at seniors centres, by phone, or from the website as a PDF document.

31. CANADIAN RED CROSS SOCIETY HEALTH EQUIPMENT LOAN PROGRAMS

604-709-6600

An accident or illness can lead to the need for health equipment such as a cane, walker, wheelchair or even bigger pieces of equipment. All equipment loans require a referral from a regulated health-care professional. The referral can be provided in writing or verbally. It should include the health-care professional's name, professional designation, and phone number, along with the specific equipment needed and any applicable measurements.

If you have used medical equipment that you no longer need, consider donating it to the Canadian Red Cross Society HELP program.

32. CATS FOR SENIORS PROGRAM

604-724-7652 www.actionforanimals.net

Having a pet can be tremendously therapeutic. If you are caring for a senior who might enjoy the company of a cat, Action for Animals in Distress Society is a Burnaby non-profit that places cats in foster homes. Its special Cats for Seniors Program can help match seniors with an older cat. All the foster senior needs to do is provide a nurturing and caring home for the pet. The program recognizes that seniors in the program may have to go to the hospital or a facility one day; in that case, Action for Animals takes the cat back.

33. CHRONIC DISEASE SELF-MANAGEMENT PROGRAMS

604-940-1273

Persons with chronic health conditions (e.g. arthritis, heart disease, hypertension, lung disease, stroke) and family members can participate in free self-management programs, led by a trained facilitator. These are evidence-based programs which provide information, teach practical skills and give people the confidence to manage their health condition(s). Note that medical professionals are not involved in any of these programs; rather, the expertise acquired by living with the various chronic health conditions provides the basis for sharing information and teaching practical skills among participants. Discuss the programs with your doctor. These programs are organized by the University of Victoria – Centre on Aging, and are offered across B.C.:

- Chronic Disease Self-Management Program

- Online Chronic Disease Self-Management Program accessible to those with all levels of computer experience
- Chronic Pain Self-Management Program
- Diabetes Self-Management Program
- Arthritis/Fibromyalgia Self-Management Program

Some programs are offered in [Chinese](#) and [Punjabi](#). For locations and dates of workshops visit www.selfmanagementbc.ca.

34. CNIB

604-431-2121 www.cnib.ca

Formerly known as the Canadian National Institute for the Blind, CNIB offers support, information and training to those with poor or deteriorating vision. Its library service has an extensive list of talking books and the CNIB store and catalogue offer products designed to help make life easier for people with visual impairments.

Make the most of the sight you have. As we age, the incidence of eye disease increases, hence the importance of regular eye exams. If you've experienced a partial loss of vision, learning to maximize your remaining sight can be life changing. Low-vision specialists at CNIB can help make the most of sight so one can live life to the fullest. Assessments with low-vision specialists are offered by appointment.

35. ELDERPOST.COM

www.elderpost.com

This is a B.C.-based website where you can find, give away or sell equipment for seniors, e.g. wheelchairs, ROHO mattresses, aids to daily living, lifts, walkers, etc.

Have equipment in good shape that others can use? Please consider donating it to the Canadian Red Cross Society Health Equipment Loan Programs described in this handbook (item 31).

36. FALLS PREVENTION

One in three seniors fall at least once a year, and these falls can be devastating. Falling can cause injury, loss of mobility and independence, and is the sixth leading cause of death in seniors. Seniors' falls and injuries cost Canadians over \$3 billion per year. All according to Statistics Canada.

The good news is that many falls can be prevented. There are programs dedicated to reducing the incidence of falls and fall-related injuries. These programs can be found in community and seniors centres, in AL facilities, in residential facilities, and in the hospital.

What You Can Do to Prevent Falls, a FH pamphlet, also available in [Chinese](#), lists four key things:

1. Have a regular exercise program to make you stronger and help you feel better. Exercises that improve balance and coordination (like tai chi and yoga) are the most helpful. Lack of exercise leads to weakness and increases your chances of falling. Ask your doctor or health-care provider about the best type of exercise for the person you are caring for.
2. Have a medication review. As you get older, the way medicines work in your body can change. Some medicines, or combinations of medicines, can make you sleepy or dizzy and can cause you to fall. See item 23a of this handbook for more about medication reviews.

3. Have your vision checked. Have your eyes checked by an eye doctor at least once a year. You may be wearing the wrong glasses or have a condition like glaucoma or cataracts that limits your vision. Poor vision can increase your chances of falling.
4. Make your home safer – about half of all falls happen at home. Remove things you can trip over (like papers, books, clothes, and shoes) from stairs and places where you walk. Remove small throw rugs or use double-sided tape to keep the rugs from slipping. Keep items you use often in cabinets that you can reach easily without using a step stool. The bathroom is the most dangerous room in the house for falls. Have grab bars put in next to your toilet and in the tub or shower and use non-slip mats in the bathtub and on shower floors. Improve the lighting in your home because, as you get older, you need brighter lights to see well. Hang lightweight curtains or shades to reduce glare. Have handrails and lights put in on all staircases. Wear well-fitting shoes both inside and outside the house; avoid going barefoot or wearing slippers.

Adapted from www.fraserhealth.ca/your_health/seniors/falls_and_injury_prevention

SteadyFeet®, a new VCH fall-prevention program, is a balance and mobility program recommended by doctors and physiotherapists for older adults to help increase their confidence, improve functional mobility, increase lower body strength, improve balance and reduce the risk of falling. Inquiries about SteadyFeet can be emailed to steadyfeet@vch.ca or a video on SteadyFeet can be found online at <http://steadyfeet.vch.ca/>.

Prevent Falls - Stay on Your Feet is an information booklet on falls prevention that can be downloaded in English, Chinese, Farsi or Punjabi at www.fallprevention.vch.ca/stay-on-your-feet-booklet/stay-on-your-feet-booklet.

The SeniorsBC website's Fall Prevention section, developed by the Ministry of Health in partnership with the B.C. Injury Research and Prevention Unit, lists more tips and resources at www.gov.bc.ca/fallprevention.

37. FAMILY MEMBERS, FRIENDS AND MEMBERS OF YOUR FAITH COMMUNITY

When others offer to help, it can be tempting to respond, "It's okay, I'm fine," either because we don't want to inconvenience anybody or we find it hard to admit that we need help. Sometimes spousal caregivers don't want to bother their adult children. Beware of perfectionism, too: we risk becoming convinced that we are the only person who can do anything right for the care recipient.

The refusal to accept help from family, friends and members of your faith community adds to the risk of the caregiver experiencing high levels of stress and developing issues, such as burnout, and they can even become more ill than the care recipient. Also, a stressed caregiver means that their care recipient is at greater risk of neglect and abuse. Accepting help is an affirmation of wisdom.

38. FOOD AND NUTRITION

38a) GROCERY SHOPPING

When it's difficult to get groceries, you should know that some seniors' programs either transport seniors as a group to grocery stores and back home to go shopping, or take orders over the phone and have volunteers do the grocery selection and delivery. Some stores provide their own delivery service; some offer discounts for delivery to seniors; some offer seniors' discount days; some have

even designed their stores to be age-friendly. If your local grocery store doesn't provide any special services or discounts for seniors yet, let them know you'd appreciate it.

Dairyland Home Service (604-421-4663; www.morethanmilk.ca) is a private service offering 700+ products. In addition to Dairyland dairy products, their home service delivers organic produce and groceries, Schneider's meats, baked goods, beverages, desserts, and household cleaning products. Weekly deliveries by refrigerated vehicles provide free delivery.

38b) MEAL DELIVERY PROGRAMS

Local Meals on Wheels (MOW) are non-profit agency-run programs delivering hot and sometimes frozen low-cost meals. Expect a starting cost of \$5.50 - \$6 per meal. In some communities, both MOW and similar style programs offer more than one style of food – e.g. Chinese, Japanese, Kosher, and Western.

- Burnaby – Burnaby MOW: 604-299-5754; Chinese and Western food.
- Burnaby – Tonari Gumi: 604-687-2172; Japanese food.
- Delta – Delta MOW: 604-946-9526.
- Delta (North) – Surrey-North Delta MOW: 778-590-1433.
- Langley – Langley MOW Services: 604-533-1679.
- Maple Ridge/Pitt Meadows – Maple Ridge Pitt Meadows Community Services MOW: 604-467-6911.
- North Shore – Kosher MOW: 604-257-5151; Glatt Kosher food.
- North Shore – North Shore MOW: 604-922-3414.
- Richmond – Health and Home Care Society of BC MOW
 - Western food: 604-732-7638.
 - Chinese food: 604-733-6615. Service in Cantonese and English. Food prepared by S.U.C.C.E.S.S.
- Richmond – Kosher MOW: 604-257-5151; Glatt Kosher food.
- Surrey (South) – White Rock MOW: 604-541-6325.
- Surrey/North Delta – Surrey-North Delta MOW: 604-588-6325.
- Tri-Cities (Coquitlam, Port Coquitlam, Port Moody) – PoCoMo MOW: 604-942-7506.
- Vancouver - Health and Home Care Society of B.C. MOW
 - Western food: 604-732-7638.
 - Chinese food: 604-733-6615. Service in Cantonese and English. Food prepared by S.U.C.C.E.S.S.
- Vancouver – Kosher MOW: 604-257-5151; Glatt Kosher food.
- Vancouver – Tonari Gumi: 604-687-2172; Japanese food.
- White Rock – White Rock MOW: 604-541-6325.

There are also private business meal delivery services such as Better Meals (604-299-1877). This company offers frozen meals from a menu that includes regular, diabetic, low-sodium, pureed and à la carte options (\$6.25/meal). Snacks, breakfast and lunch items are also available. A \$25 minimum order yields a free delivery. www.bettermeals.ca

Casalinga Food Services Inc. (604-435-1994) delivers frozen meals, prepared daily, to homes in the Greater Vancouver area. This business offers breakfast, lunch and dinner meals that are regular, vegan or gluten free and individual or family-sized. Deliveries are made once a week and are free with a minimum order of \$40. Visit the website at <http://casalingafoods.com/> or download the menu: www.casalingafoods.com/docs/files/menu/menu.pdf.

The North Shore Salvation Army (778-689-4673) offers low-cost frozen meals that can be picked up or delivered. These frozen meals include soups, casseroles, three-part meals, and world cuisine. See the menu and order online: www.northshoresalvationarmy.com/order-meals/.

38c) MEALS AT SENIORS CENTRES

Seniors centres sometimes offer meal programs which are not only nutritious but also provide important social contact. A few programs even provide a wheels-to-meals service which picks up frail seniors who can't get out on their own, and transports them to meals at a local centre.

38d) NUTRITION

Remember: if you have dietary concerns related to your health condition, you can speak with a registered dietitian (Monday to Thursday; 8 a.m. - 8 p.m.; Friday; 8 a.m. - 5 p.m.) by dialing 8-1-1, the free HealthLinkBC non-emergency health information line. 8-1-1 provides translation services on request in more than 130 languages. For deaf and hearing-impaired text telephone (TTY) assistance, call 7-1-1.

Healthy Eating for Seniors, a handbook published by SeniorsBC includes recipes and information on good nutrition. It is available in English, French and has been culturally adapted and translated into Chinese and Punjabi. www2.gov.bc.ca/gov/content/family-social-supports/seniors/health-safety/active-aging/healthy-eating/healthy-eating-for-seniors-handbook

39. FOOT CARE

Foot care is easily underestimated but it has implications to our health and well-being. For example, feet that are untended can develop sores and become painful, leading to a decrease in mobility, balance, and mechanical function. This can increase the risk for falls which are a serious cause of disability in older people. Foot care can also alert people of early symptoms for other more serious health issues such as diabetes or poor circulation.

Adapted from www.thefootnurse.com/id24.html

Some seniors centres and programs offer foot-care clinics at a moderate cost.

Podiatrists, medical doctors specializing in foot health, offer foot care at their offices. Expect a fee of approximately \$80 for your initial appointment; the fee is discounted through MSP for low-income seniors. A list of podiatrists, by community, is available from the B.C. Podiatric Medical Association (604-985-3338; www.foothealth.ca).

If your care recipient needs foot care at home, some private home support agencies offer this service by a certified foot nurse. See the item Home Support & Home Health-Care Services – Private Businesses, in this of the handbook (item 46). Some foot care nurses offer home services, but there is no association that lists them.

40. FORMS

Filling out government, medical and other forms can be a daunting task. Some seniors' programs offer assistance with this. Usually you have to go to the service agency or the seniors centre, but occasionally an outreach worker is available to visit the home of a senior who isn't mobile.

41. GERONTECHNOLOGY FOR CAREGIVERS

Gerontechnology is the combination of gerontology (the non-medical aspects of aging issues) and technology. Its goal is to match technology with a senior's needs including health, housing, mobility, communication, and leisure aspects, and create assistive technology to increase their independence and quality of life. Some technology seems scary, plus, the number of choices can seem overwhelming. Products are constantly upgrading, making it hard to keep up. However, a number of devices simplify caregiving so it is worthwhile investigating what's available. It is also a good idea to research different options with tech devices because different companies will offer similar products but they vary in terms of their aging-friendly design and features. It is important to note there are some ethical concerns with some technologies as they may be seen as an invasion of the care recipient's privacy. Below is a list of some well-known technologies and organizations offering technology solutions that can be beneficial to caregivers.

- Personal Emergency Response Systems (PERS). It is normal to be concerned about a frail care recipient who is home alone, at risk for falling or needing medical attention. A PERS can help alleviate some caregiver worry. These systems typically entail a medical alert pendant or wristband. When a senior falls or is having a medical emergency, so long as they remain conscious, the response system is there to be activated. A central call office is alerted, an operator communicates with the senior via a phone communicator, and a special call is then sent to a designated family member, friend, or neighbour in order to arrange help. Setting up one of these systems involves an installation fee, plus a monthly charge. Some companies require a long-term contract that locks you in for a fixed period of time. Lifeline is the best known supplier of PERS, but other companies are in the business too. Lifeline brochures are available in [multiple languages](#) and translators are available for the helpline. A new technology can now also detect some falls even when the senior is unconscious and unable to press their alert device. www.lifeline.ca
- GPS technology tracking is being used for seniors with dementia, and these devices are available in many different forms. For example, they can be found in shoe soles, bracelets, necklaces, and watches. This tracking helps caregivers keep track of their loved ones and makes sure they are not in harm's way, giving the caregiver peace of mind and reassurance. Senior Tech Daily lists and describes different GPS trackers: www.seniortechdaily.com/top-three-gps-tracking-devicesapps-for-caregivers/.
- Tablets for seniors. Tablets are computer pads that respond to touch; they are lightweight, mobile and completely wireless. Tablets that are specifically designed for seniors have large text and are easy to navigate, making them easier to use them regardless of the user's computer skills. Features that can be included on tablets include video calling, email and text messages that can be operated by voice recognition, medication reminders, calendar and appointment reminders, check-in notices so the care recipient can communicate with their caregiver and let them know they're okay, alerts that are sent to the caregiver if anything seems out of the ordinary such as missed check-ins or medications, photos and videos, and call requests. A great feature of some tablets is that caregivers can access and manage them, which is especially helpful for long-distance caregivers. Claris offers a tablet designed specifically for seniors called the Claris Companion: www.clariscpanion.com.
- Wireless home monitoring, also known as "granny cams," use cameras within the home of the care recipient so the caregivers can monitor them from a distance. As a caregiver, you can gain peace of mind being able to see your loved one and knowing they are eating well, taking

their medications and are not in any danger. Lorex is a company that offers such video monitoring products. Visit their caregiver solutions page online:

www.lorextechnology.com/solutions/Elderly-Monitor-solutions/2200031.s.

- The Alzheimer’s Store website (www.alzstore.com) sells devices such as memory phones, medication dispensers, alarm systems, visually relaxing DVDs, music boxes, etc. meant to assist caregivers and people with Alzheimer’s. While these products are created for people with dementia, many are helpful for a wide range of seniors.
- Online support communities for caregivers include discussion forums, chat rooms, lists of resources, etc. Visit Elder Care Online to see an example: www.ec-online.net/index.htm.
- Online support communities for care recipients. Online support communities provide care recipients with a place to share their stories and connect with people in similar situations. Daily Strength is a website with a variety of support groups for different issues seniors may be facing: www.dailystrength.org/support-groups/Seniors.
- CanAssist is a University of Victoria program that uses innovative technology solutions to improve independence of people with disabilities. Some of the devices it currently has to offer are a wandering redirect system, a phone-in monitoring system, and a manual wheelchair lift. These and others can be found on its website (www.canassist.ca). To request the use of a technology device from CanAssist, you must fill out a request form, click on the Access Our Services tab at the top of its web page and complete the “Individuals and families” request form. Your request acceptance is funding dependent. Also, if you are unable to find a technology device that fits your loved one’s needs, you can request that CanAssist develop one specifically for them. CanAssist is also able to modify and customize existing commercial technologies.
- Tetra Society is a non-profit with skilled volunteers who create and build customized devices to assist people with physical disabilities. See their website page that is dedicated to seniors: www.tetrasociety.org/about/seniors.php.

Contributed by Tasha Lorenzen-Ewing, M.A., Gerontology

42. HOME EQUITY MIGHT HELP FINANCE AGING IN PLACE

Some seniors own their own home but have very little money, i.e. they are house rich, but cash poor. Homeowners worried about the cost of paying for outside services to support their aging in place can look into a few options: selling their homes and downsizing to liberate some money; taking out a conventional mortgage or line of credit; using existing cash from investments; or getting a reverse mortgage.

Homeowners can learn about tapping into home equity with lines of credit and home equity loans by speaking with their bank or credit union, some of which have staff that will do home visits to meet with a senior wishing to learn more about these tools for converting home equity into cash.

Note that not all homeowners can qualify for these types of loans; a certain level of income and a good credit rating are required. If you are not eligible for a home equity loan, you might have to explore other more expensive options.

Reverse mortgages are a different type of loan, also secured by the equity in your home, but they are an expensive way to tap into home equity and other options should be explored first. In Canada, only CHIP (Canadian Home Income Plan) provides reverse mortgages. The CHIP website (www.chip.ca) contains a great deal of information about reverse mortgages including comparative information about the various ways of tapping into home equity.

The Frequently Asked Questions document offered by CHIP Home Equity Plan explains:

Q: What is the difference between a CHIP Home Income Plan and a conventional mortgage?

A: A conventional mortgage is a homeownership loan that is paid down on a monthly (or in some cases weekly or biweekly) basis. As the principal and interest on the loan are paid down, the equity in the home increases (or the percentage of the home's value that exceeds the balance of the mortgage). A CHIP Home Income Plan is a reverse mortgage. It is a life-term loan against the accumulated equity in a home that requires no repayment while the client(s) continues living in the home. The money plus interest is paid back when the homeowner dies, sells the home, or permanently moves out. Because there are no monthly payments, the amount owed grows larger over time. CHIP Home Income Plan clients, like conventional mortgage borrowers, continue to own their homes and are fully responsible for property taxes, insurance, and repairs.

If considering a reverse mortgage, be sure to read the free *Consultation Paper on Reverse Mortgages* by the Canadian Centre for Elder Law Studies, B.C. (2005) so that you understand the risks involved. It is at www.bcli.org/?s=Consultation+Paper+on+Reverse+Mortgages.

43. HOME IMPROVEMENT ASSISTANCE PROGRAMS

The following programs help seniors make their homes safer, more accessible, and more energy efficient. Much of this information was taken from www2.gov.bc.ca/gov/content/family-social-supports/seniors/housing/home-improvement-assistance-programs.

43a) HOME ADAPTATIONS FOR INDEPENDENCE (HAFI)

604-646-7055 www.bchousing.org/Options/Home_Renovations

This program, administered by B.C. Housing, provides financial assistance to help eligible low-income seniors and people with disabilities in B.C. continue to live in the comfort of their rented or owned primary residence by supporting certain home modifications. As your physical needs change, so too does the need to modify your home environment. Adapting a home improves accessibility and promotes safe and independent living. Even small home adaptations can make a big difference in the lives of people who wish to remain in their homes longer. If you or a member of your family are having difficulty performing day-to-day activities independently and safely, the HAFI program may be able to help. A HAFI brochure is also available in Chinese and Punjabi. Note: this program used to be called HASI and was formerly administered by CMHC.

43b) B.C. SENIORS' HOME RENOVATION TAX CREDIT

www2.gov.bc.ca/gov/content/taxes/income-taxes/personal/credits/seniors-renovation

This is a refundable personal income tax credit to assist individuals aged 65 and over with the cost of certain permanent home renovations to improve accessibility or help a senior be more functional or mobile at home. The renovation must be to your principal residence, which is the home you primarily live in (including a non-seasonal mobile home).

43c) RESIDENTIAL REHABILITATION ASSISTANCE PROGRAM ON-RESERVE

www.cmhc-schl.gc.ca/en/ab/hoprfras/hoprfras_007.cfm

This program offers financial assistance to First Nations' band councils and band members to repair substandard homes to a minimum level of health and safety and to improve the accessibility of housing for people with disabilities. Band councils or individual homeowners who require repairs to their homes may be eligible to apply.

43d) LIVESMART BC ENERGY-EFFICIENCY INCENTIVE PROGRAM

Toll free: 1-866-430-8765 E: EfficiencyIncentives@gov.bc.ca

This program gives B.C. homeowners cash back for making energy-efficient improvements to their homes. An energy-efficient home will save money, increase comfort, and reduce impact on the environment.

43e) RESIDENTIAL REHABILITATION ASSISTANCE PROGRAM (RRAP - SECONDARY/ GARDEN SUITE)

1-800-668-2642 www.cmhc-schl.gc.ca/en/co/acho/acho_013.cfm

Canada Mortgage and Housing Corporation offers financial assistance for the creation of a secondary or garden suite for a low-income senior or adult with a disability making it possible for them to live independently in their community, close to family and friends. A secondary suite, sometimes called an in-law suite, is a self-contained separate unit within an existing home or an addition to a home, and has full kitchen and bath facilities and a separate entrance. A garden suite is a separate living unit that is not attached to the principal residence, but built on the same property. Garden suites are sometimes referred to as granny flats because they were originally created to provide a home for the aging parent of a homeowner. Like a secondary suite, a garden suite is a self-contained unit. Regardless of which type of housing is chosen, secondary and garden suites must meet all applicable building code requirements as well as local municipal planning and zoning regulations.

44. HOME SUPPORT AND HOME HEALTH-CARE SERVICES – PUBLIC (GOVERNMENT-SUBSIDIZED)

See item 8 of this handbook to understand the HA-based home and community care services offered by FH and VCH.

45. HOME SUPPORT SERVICES – NON-PROFIT SOCIETIES

45a) BETTER AT HOME

604-268-1312 www.betterathome.ca

Better at Home is a United Way program that helps seniors continue living independently in their own homes by providing simple non-medical home support services. The provincial government has given United Way of the Lower Mainland funding to manage Better at Home across B.C. United Way designed the Better at Home program and supports local non-profit organizations in delivering services.

What services are provided?

The range of Better at Home services available varies from community to community, depending on the specific needs of local seniors. In each community, local non-profit organizations deliver Better at Home services. Services are provided by volunteers, contractors and paid staff. Examples of Better at Home services include: friendly visiting; transportation to appointments; light yard work; minor home repairs; snow shoveling; light housekeeping; and grocery shopping.

The services offered in each community were determined through a consultation process which involved seniors and service providers within the community. Better at Home services are designed to complement – not replace – existing health and community supports, such as the medical/personal-care home health services offered by the health authorities' Home and Community Care teams.

Service cost(s)

Seniors who receive Better at Home services pay a fee for some services, based on their income; some services may be free. Service fees are established on an income-based sliding scale, which ensures that services are free for low-income seniors and market rate for seniors with an income above the B.C. average. Service fees are fed back into the local program.

Site/community selection

Program sites were selected by engaging regional experts, e.g. people from seniors' organizations and the regional Health Authorities managing seniors' portfolios. A community development approach was used to identify communities with a high number of vulnerable seniors who would benefit from these services.

Better at Home programs

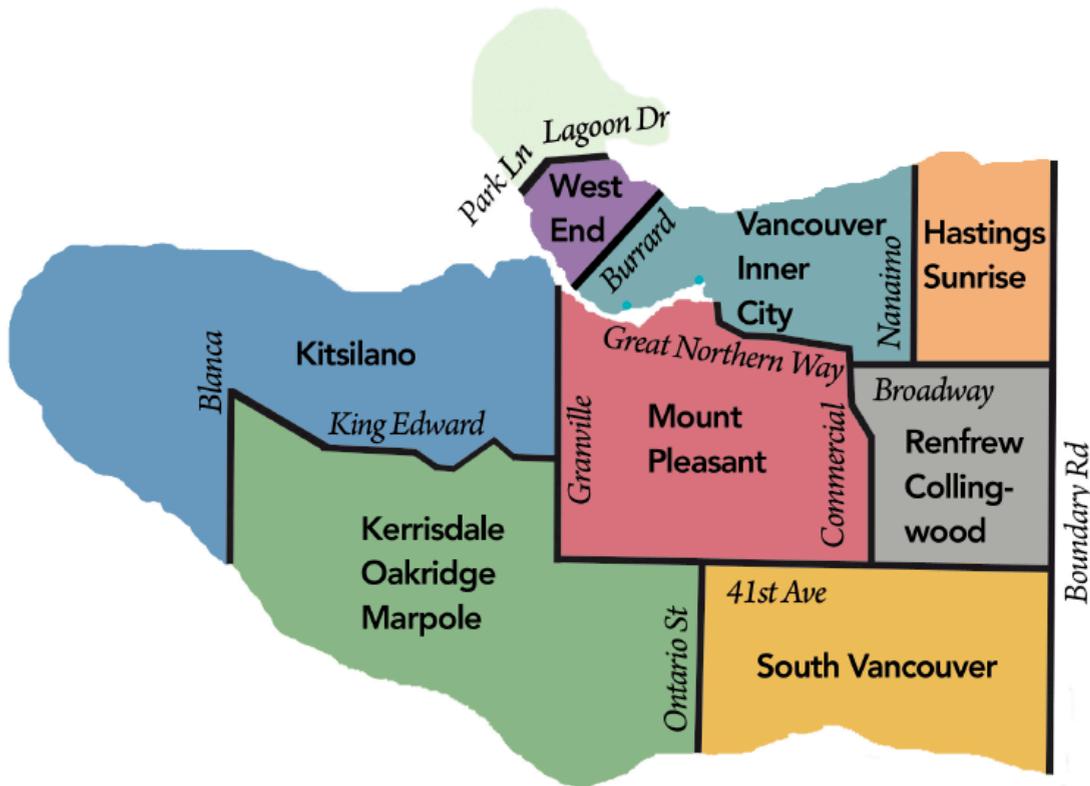
United Way manages 67 Better at Home programs across the province. You can find a list of current Better at Home communities and the most up-to-date list of services below or on the Better at Home website www.betterathome.ca.

If you are a senior living in a community that has a Better at Home program, you may be eligible to receive services. Apply by contacting your local Better at Home provider:

- Burnaby: Citizen Support Services, City of Burnaby (604-297-4877)
E: betterathome@burnaby.ca
Services: Transportation; light housekeeping.
- Delta: Deltassist Family & Community Services Society (604-946-9526)
E: lynw@deltaassist.com
Services: Transportation; light housekeeping; light yard work; minor home repairs.
- Langley: Langley Senior Resources Society (604-530-3020)
E: janicem@lsrs.ca
Services: Transportation; light housekeeping; friendly visiting; grocery shopping.
- Maple Ridge/Pitt Meadows: Maple Ridge/Pitt Meadows Community Services Society (604-467-6911)
E: jleginus@comservice.bc.ca
Services: Transportation; light housekeeping; friendly visiting; grocery shopping; light yard work; minor home repairs.
- New Westminster: Seniors Services Society of B.C. (604-520-6621)
E: support@seniorsservicessociety.ca
Services: Transportation; light housekeeping; friendly visiting; grocery shopping.

- North Shore: North Shore Community Resources Society (604-982-3313)
E: josh.cook@nscr.bc.ca
Services: Transportation; light housekeeping; grocery shopping; light yard work; minor home repairs.
- Richmond: Richmond Cares, Richmond Gives (604-279-7021)
E: ptang@volunteerrichmond.ca
Services: Transportation; light housekeeping; friendly visiting.
- Surrey: Central Intake (604-536-9348)
 - South Surrey/White Rock: Seniors Come Share Society
Services: Light housekeeping; grocery shopping; friendly visiting; light yard work; minor home repairs.
 - Surrey-Newton: DIVERSEcity Community Resources Society
Services: Transportation; light housekeeping; friendly visiting; light yard work; minor home repairs.
 - Surrey-Whalley: Progressive Intercultural Community Services Society
Services: Transportation; light housekeeping; grocery shopping; friendly visiting.
- Tri-Cities: SHARE Family and Community Resources Society (604-937-6991)
E: Paola.Wakeford-Mejia@sharesociety.ca
Services: Transportation; light housekeeping; grocery shopping.
- Vancouver
There are eight programs in Vancouver. See the map below for your local program office.
 - Hastings-Sunrise: S.U.C.C.E.S.S (604-408-7274)
E: daniela.rodriguez@success.bc.ca
Services: Transportation; light housekeeping; grocery shopping; friendly visiting.
 - Kerrisdale, Oakridge, Marpole: Jewish Family Services Agency (604-637-3310)
E: cmcmillan@jfsa.ca
Services: Transportation; light housekeeping; grocery shopping; friendly visiting; minor home repairs.
 - Kitsilano: Kitsilano Neighbourhood House (604-736-3588)
E: sylviek@kitshouse.org
Services: Transportation; light housekeeping; grocery shopping; friendly visiting.
 - Mount Pleasant: Mount Pleasant Neighbourhood House (604-879-8028)
E: cmatlo@mpnh.org
Services: Transportation; light housekeeping; grocery shopping; friendly visiting; minor home repairs.
 - Renfrew-Collingwood: Collingwood Neighbourhood House (604-435-0375)
E: sliddle@cnh.bc.ca
Services: Transportation; light housekeeping; friendly visiting; light yard work.
 - Vancouver Inner City: Network of Inner City Community Services Society (604-569-2787)
E: info@niccss.ca
Services: Light housekeeping; grocery shopping; friendly visiting.
 - Vancouver South: South Vancouver Neighbourhood House (604-324-6212)
E: jeannie@southvan.org
Services: Transportation; light housekeeping; grocery shopping; light yard work.

- West End: West End Seniors' Network (604-669-5051)
E: betterathome@wesn.ca
Services: Transportation; light housekeeping; grocery shopping.



The above information is subject to change. For more information, please contact the Better at Home Provincial Office via email: info@betterathome.ca or by phone: 604-268-1312.

45b) In addition to Better at Home, there are a small number of other non-profit programs that can help with tasks such as small home repairs, snow removal, and yard work.

46. HOME SUPPORT AND HOME HEALTH-CARE SERVICES – PRIVATE BUSINESSES

Private business agencies offer services on an hourly basis for companionship, home cleaning, meal preparation, accompaniment to places outside the home, personal care (bathing, dressing, grooming, toileting), assistance with medications, foot care, assistance with needs related to conditions such as dementia, MS, Parkinson’s, post-surgical help, nursing (wound dressings, IV therapy, ventilator care), palliative care and live-in companions. Hourly rates tend to begin at \$25 per hour plus tax and rise with the level of care needed. Each agency has its own requirement for minimum number of hours per visit. Some agencies provide all services, others only some. See home support services in the Yellow Pages for a list of agencies.

Note: There are no regulating bodies for home support agencies in B.C., so when hiring an agency, you might want to ask if the care staff are bonded, screened (criminal record check, past employment references checked), insured, trained, and supervised. If you or your care recipient will be transported by a staff person from a home support agency, ask if the agency runs staff through ICBC driver-record checks.

47. INCOME ASSISTANCE FOR SENIORS NOT RECEIVING OLD AGE SECURITY

If you are 65 or over and are not eligible for the Old Age Security Pension and the Guaranteed Income Supplement, you may still be eligible for B.C. Income Assistance (also known as welfare, and not the same as employment insurance) based on your income, assets and other factors. Call the B.C. Ministry of Social Development: 1-866-866-0800 (press 3 + 1).

48. INCOME TAX CLINICS FOR LOW-INCOME SENIORS

Held each March and April at seniors centres (toll free: 1-800-959-8281). Senior citizen volunteers trained by Canada Revenue Agency offer help with income tax forms for people 55 or older, or individuals who receive a disability pension. Other criteria: annual income must be less than \$25,000/individual or \$35,000/couple; must have a simple tax return, i.e. no returns involving rental income, self-employment income, complex stocks, bonds or dividends; and annual investment income must be under \$1,000. The clinics do not complete taxes for the deceased (final tax forms). Sometimes an outreach service is offered for seniors who are not able to get out of their homes.

It is very important that seniors file their forms on time each year. Some government home health service charges are based on after-tax income and, if forms have not been filed, higher rates may be charged and/or services might not be offered.

49. ISOLATED SENIORS

Many seniors have huge challenges getting out of their homes and become house bound. United Way of the Lower Mainland estimates that social isolation affects at least 10 per cent of seniors in the Lower Mainland. The following kinds of services offered by some non-profits can help:

- Friendly phone calls – Caring volunteers call isolated seniors for reassurance and to make sure they are okay; sometimes longer social conversations are possible.
- Friendly visits – Outreach programs for seniors offer friendly visits, home assistance with filling out forms, information and referral, and see if former links to the community can be restored.
- Outings – Some programs are able to transport seniors to meal programs or special event outings.

Caregivers: you are at risk for becoming isolated, too, if you do not take care of yourself. So please, remember: Don't try this alone! Tap into as many resources as you can to ensure the best possible quality of life for yourself and your care recipient.

50. LIBRARY HOME-DELIVERY SERVICE

Most libraries deliver library materials free of charge to members who have difficulty using the library because of ill health, disability, frailty or lack of access to transportation. Materials available typically include books in regular and large print, paperbacks, magazines, music, videos, DVDs, and audiobooks in four different formats: cassette; MP3; Spoken Word CD; and DaisyDisk.

51. LIVE-IN CAREGIVERS

If there is space in the home of a care recipient, and, if it is affordable, some elect to have a live-in caregiver. There are a number of ways to organize this.

51a) LIVE-IN CAREGIVER PROGRAM

1-888-242-2100

This federal Citizenship and Immigration Canada program makes it possible to hire a live-in caregiver from another country who is qualified to provide care for elderly persons or persons with disabilities in private homes without supervision. Under this program, live-in caregivers must live in the private home where they work in Canada. As an employer, you must meet certain requirements before you can take advantage of this program (see below). You will also bear certain responsibilities for the caregiver. You must consider if there is a Canadian or a permanent resident available to do this work. Since the process of applying to hire someone from a foreign country takes many months, you may want to look at another solution for your caregiving needs during that time.

Both the employer and the employee must follow several steps to meet the requirements of the Live-In Caregiver Program. To hire a live-in caregiver under this federal program, you must have made a sufficient effort first to fill your position with a Canadian, a permanent resident or a foreign worker already in Canada, have sufficient income to pay a live-in caregiver, provide acceptable accommodation in your home, make a job offer that has primary caregiving duties for an elderly or disabled person (a job offer with the primary duties of a housecleaner, for example, is not acceptable under the Live-in Caregiver Program, but could be appropriate under the Temporary Foreign Worker Program), and submit an application for a labour market opinion along with the employment contract to Human Resources and Skills Development Canada/Service Canada.

Caregivers will be carefully screened by a Citizenship and Immigration Canada visa officer before they enter Canada as they must meet the eligibility requirements of the Live-in Caregiver Program. A written employment contract will ensure there is a fair working arrangement between you and your employee. A contract template is provided by the program.

For more on hiring a live-in caregiver under the federal Citizenship and Immigration Canada program visit www.cic.gc.ca/english/work/hire/caregiver.asp.

51b) AGENCIES THAT WILL APPLY TO THE LIVE-IN CAREGIVER PROGRAM FOR YOU

There are also private business agencies that, for a fee, take care of all the paperwork and screening involved in this program, freeing family caregivers, or care recipients themselves, from that burden. Note: Payment for the caregiver and/or companion services themselves is separate and in addition to the finder's fee, which typically ranges between \$1,000 and \$5,000.

51c) PRIVATE HOME SUPPORT AGENCIES

These agencies also supply workers, for a fee, who live in the home on a short- or long-term basis. Look under home support services in the Yellow Pages for a list of agencies.

51d) RESPECTING THE RIGHTS OF LIVE-IN CAREGIVERS

Regardless of the method you use to obtain a live-in caregiver, you are always obligated to comply with the applicable laws. Note too that the non-profit West Coast Domestic Workers' Association (604-669-4482; www.wcdwa.ca) exists to protect the rights of live-in caregivers and families, and warn them about malpractice in this business. Both live-ins and their employers can contact the association to get the information and support they need. The Vancouver Committee for Domestic Workers' and Caregivers' Rights (604-874-0649; www.cdwcr.org/about.aspx) can also inform both parties.

51e) LIVE-OUT PAID CAREGIVERS

Don't forget the option of hiring someone who comes in to help care for your loved one a fixed number of hours a week. It could even be for the nighttime hours when many spousal family caregivers have trouble sleeping because their care recipient keeps waking them.

52. MUSIC THERAPY

Music therapy involves the skillful use of music by an accredited music therapist to promote, maintain, and restore mental, physical, emotional, and spiritual health. In the care of the elderly, this therapy can be an effective and enjoyable medium for the maintenance and improvement of cognitive, physical and socio-emotional functioning. Music therapy can stimulate cognitive functioning through providing opportunities to learn new skills as well as through utilizing previously acquired knowledge. Both long- and short-term recall can be stimulated through such experiences as musical associations, singing familiar songs, and sequenced activities utilizing rhythm instruments, songs and/or movement. It offers a positive approach for reinforcing quality of life for the elderly.

Therapy sessions are individually designed to meet the specific needs of the elderly client. Typical musical experiences can include singing, music listening, sharing and discussion of songs, learning to play instruments, song writing, moving to music, and participation in music activities designed to promote social interaction and self-esteem.

Music is one of life's earliest experiences and in late adulthood musical memories remain as some of the most deep-rooted. A person's musical history is an important component of the music therapy assessment and treatment plan. Providing music that is related to an individual's cultural and/or religious background, or providing opportunities to rediscover musical skills gives a personalized approach and is especially valuable when working with persons with dementia. For more information and to find an accredited music therapist in your area to hire for service (consider giving a gift certificate to a frail elder) contact the Music Therapy Association of B.C. (604-924-0046) or visit its website.

Adapted from www.mtabc.com

53. PAUL'S CLUB

778-558-1894 www.paulsclub.ca

This private-pay adult club is a social and recreational day program for those with early-onset dementia. It is the first program of its kind in Vancouver and was developed to cater to the specific needs of younger adults diagnosed or experiencing symptoms of early-onset dementia. This club is for men and women and it provides a safe environment, both physically and emotionally, with a welcoming atmosphere that is designed to be fun.

54. PROPERTY TAX DEFERMENT PROGRAM

604-660-2421 www.sbr.gov.bc.ca/individuals/property_taxes/property_tax_deferment/about.htm

This program helps older people who are struggling financially to stay in a home they own. This Ministry of Finance loan program allows you to defer your annual property taxes on your home (house or condo), providing it is your primary residence (i.e. where you live and conduct your daily activities) and you meet certain criteria. To qualify, you must be a Canadian citizen or permanent resident who has lived in B.C. for at least one year immediately prior to applying for tax deferral benefits and, in addition, be 55 years or older during that calendar year (only one spouse must be 55

or older), a surviving spouse, or a person with a disability. You can defer your taxes as long as you own and live in your home and continue to qualify for the program.

The deferred taxes must be fully repaid with interest before you can legally transfer your home to a new owner other than your surviving spouse, or upon the death of the agreement holders(s). Simple interest is charged on the deferment account at a rate not greater than two per cent below the bank prime rate.

55. SECOND-HAND THRIFT STORES

For those helping an older family member de-clutter their home or downsize after years of accumulating belongings, it is good to know that second-hand stores will take your donations. Note there are an increasing number of restrictions on the type of items these stores accept (many refuse electronics or upholstered furniture) and many no longer make pickups because of high gas prices.

56. SENIOR CITIZENS' REPAIR SERVICE

604-529-1100

This service provides minor house repairs, renovations, and maintenance for persons 55 years and over, and for people with disabilities. All services are guaranteed for 30 days and are offered by retired or semi-retired experienced tradespeople. There is a charge of \$35 for the service call, plus \$30/hour for labour, plus materials. This service is sponsored by the Plumbers and Pipefitters Union No. 170. Office hours are weekdays; 9 a.m. - noon.

57. SENIORS ABUSE AND INFORMATION LINE (SAIL)

604-437-1940; www.bcceas.ca

Daily, 8 a.m. - 8 p.m. (except holidays).

Formerly called the Seniors Advocacy and Information Line, this is a safe line for older adults and those who care about them to talk to someone when they feel they are being abused or mistreated, or to receive information about elder abuse prevention. See also Part IX for more information on seniors' abuse.

58. SENIORSBC

www.SeniorsBC.ca

This provincial resource provides information about government programs and services for older adults. The website offers information and resources for planning and living a healthy and active life. Information offered includes caring for seniors, finances, health care, housing, transportation and more.

You can also find PDF copies of the *SeniorsBC B.C. Seniors' Guide (10th ed., 2012)* at www.gov.bc.ca/seniorsguide or call toll free 1-877-952-3181. This is a free comprehensive guide about provincial and federal programs and services for seniors, with sections on health benefits, lifestyle, housing, transportation, finances, safety and security, and other services. It is also available in [Chinese](#), [French](#), and [Punjabi](#).

59. SENIORS EXERCISES ONLINE

Physical activity is good for everyone, including seniors. Exercise programs for older people are offered at community and seniors centres. Since some are not able to take advantage of those programs, Seniors Exercises Online provides a simple workout that can be done on the couch or in a chair. This is beneficial for seniors who have mobility issues or are homebound due to poor weather. The routine includes five exercises that only take about two minutes to complete – perfect to do while watching TV and the commercials come on. Even a few minutes of exercise is beneficial because it will get joints moving, muscles contracting, and blood pumping. To remind yourself to do these exercises, print them out or write them down on a piece of paper and put it by the chair you sit in when you watch TV or read the paper and try to complete them two to three times a day. Find the exercises at www.seniorexercisesonline.com/couch-exercises.html.

From www.fraserhealth.ca/your_health/seasonal-health/winter-safety/winter-exercise-for-seniors---couch-exercises

60. SERVICE BC

604-660-2421 www.servicebc.gov.bc.ca

Formerly known as Enquiry BC, this call centre provides information on provincial services and programs.

61. SERVICE CANADA

1-800-622-6232 (O-Canada) www.servicecanada.gc.ca

This toll-free call centre links you to federal programs, including Canadian pension programs for seniors (i.e. Old Age Security Pension, Canada Pension Plan), death benefit, disability benefits, Guaranteed Income Supplement, spouse's allowance, allowance for the survivor, old-age security identification card, and more.

62. SHELTER AID FOR ELDERLY RENTERS (SAFER)

604-433-2218 www.bchousing.org/programs/SAFER

If you are aged 60 or older with low to moderate income, the B.C. Ministry of Housing and Social Development subsidizes the SAFER program which helps make rents, including SH and AL rents, affordable for B.C. seniors (except for public (government-subsidized) AL units). To apply for the SAFER subsidy, contact B.C. Housing which manages the program.

63. SOCIAL RECREATIONAL PROGRAMS FOR SENIORS

Community centres and seniors centres throughout Metro Vancouver have a wide range of programs for seniors to break isolation and offer fitness, nutritional, social and recreational benefits. Some centres have seniors' wellness clinics that help monitor blood pressure, offer foot care, etc. These programs may be of interest to your care recipient if they are able to leave the home; they may also be of interest to you, the caregiver, for social, educational, and leisure activities.

64. SPCA PET SURVIVOR CARE PROGRAM

604-681-7271

This SPCA program addresses the concern of what will happen to your pet(s) when you die. Under this program, you give possession of your pet to the BC SPCA in your will. You can pay the program enrolment fee during your life, or through your estate. If you arrange for the program payment to come through your will, the BC SPCA will supply you with the correct legal language. There are several types of plans to choose from.

How does it work? After receiving a call from your executor, the B.C. SPCA will accept custody and assume ownership of your pet, provide it with care and attention in one of its facilities and arrange for a new adoptive home. It guarantees that your pet will not be euthanized, except in extreme circumstances (such as disease, sickness or severe temperament problems) and even then the approval of two veterinarians is required.

The program also addresses the question of what will happen to your pet(s) should you become ill or incapacitated. If you enroll a small animal at the silver or gold plan levels of the program, the BC SPCA will help you keep your pet in the event you become temporarily hospitalized or incapacitated. It will arrange for temporary foster care, with the understanding that you, your personal representative, or power of attorney will cover the costs of your pet care upfront.

Adapted from www.sPCA.bc.ca/support/legacy/pet-survivor-care-program/pscp-questions.html

65. S.U.C.C.E.S.S. CHINESE HELP LINES

Cantonese: 604-270-8233; Mandarin: 604-270-8222

These help lines offer information and referral as well as emotional phone support to the Chinese community from 10 a.m. - 10 p.m.

66. TRANSPORTATION

66a) DRIVING

Are you concerned about the driving ability of someone you are caring for? It is important that you discuss your concerns with the aging driver because they are part of the overall discussions you will want to have about their aging. Should the day come when their functional and cognitive abilities decline, their wishes and plans for the future must be heard and taken into consideration. In regards to driving, Senior Driving (www.seniordriving.aaa.com) says, “Seniors are outliving their ability to drive safely by an average of 7 to 10 years.” Therefore, it is vital to think about future transportation options.

One of the best ways to see if an older person is having problems driving is to be a passenger in their car. It may take several trips for you to gather the full scope of their abilities and what could happen. Note that their driving ability could vary by time of day, when they last took medication, or if night driving is involved. The Office of the Superintendent of Motor Vehicles provides a list of signs that an aging driver may be becoming a risk to themselves, their passengers and other road users:

- Changing lanes too quickly or without careful checking due to limited range of motion.
- Applying the brakes or the accelerator abruptly.
- Showing confusion when navigating and unable to read roadway signs.
- Exhibiting frustration or anxiousness when driving.
- Reacting too slowly to situations like light signal changes or cars stopped in front of them.

- Stopping well in advance of pedestrians crossing a roadway.
- Finding damage on the vehicle or to items along the driveway like scrapes on fences, knocked over planters or dents in the garage door.

It is possible that enrolment in a driving course could help eliminate some of these unsafe driving patterns. Restrictions may serve as solutions (for a while), like only driving in daylight hours and not driving during rush hour. Other suggestions include having a vision and/or hearing test, seeing the doctor about medications that can cause drowsiness, and suggesting alternative transportation.

Adapted from www.pssg.gov.bc.ca/osmv/seniors/index.htm

As the BCAA Road Safety Foundation correctly notes, age alone is not a good predictor of driving safety. But changes occur as we age, changes related to vision, strength, flexibility, coordination, reaction time and, very commonly, changes in medication use. For some, these changes can affect the ability to function safely as a driver, despite many years of driving experience.

We all hope our loved ones will be able to maintain their driver independence as long as possible and we also have to accept the reality that the day might come when that person can no longer drive safely. And we all know that the safety of others, as well as the safety of the driver we care for, has to override the desire to hold onto the independence that driving represents.

The following organizations provide helpful information on this matter:

- BCAA Road Safety Foundation (604-298-5107) offers information on age changes and driving behaviour including: the physical and sensory demands of driving; medications and driving; planning ahead to give up driving; and ways to communicate with frail drivers who, understandably, face feelings of sadness and anger when considering the possibility of not driving. The website has a written self-assessment test and links to AAA Roadwise Review (a computer-based self-assessment tool) as well as a link to the AAA Foundation for Traffic Safety's *The Older and Wiser Driver* in the form of a 12-page brochure or 22-minute video. Both versions include safety tips and information about what to expect with aging. The BCAA Road Safety Foundation also offers Living Well, Driving Well, a free workshop designed to increase awareness about the effects of aging on driving, with information and tools to assist older drivers to adapt to age-related changes, review their driving, and plan for mobile alternatives.
 - Adapted from www.bcaa.com/road-safety/older-drivers/overview
- The Canadian Association of Occupational Therapists (CAOT) created the national blueprint for older driver education when it published *Older Drivers in Canada and Their Families* and launched the Injury Prevention in Older Drivers program. In both resources, CAOT strives to enhance the capacity of older adults to maintain their fitness to drive and their ability to drive safely for as long as possible. In partnership with the Public Health Agency of Canada, CAOT offers an Older Drivers in Canada website (www.olderdriversafety.ca) that includes information on the impact of normal aging and common health conditions on safe driving, and tips based on scientific evidence of high-risk situations and risk-reducing strategies.
- The Driver Fitness Program of the Office of the Superintendent of Motor Vehicles (OSMV) allows for the testing of drivers of all ages to assess their continued fitness and ability to drive safely. The OSMV may decide to direct an individual to ICBC for testing based on a report from a medical professional. It may also choose to send an individual for a medical exam

based on the receipt of a reliable report from a police officer, concerned family member or other individual questioning the individual's driving fitness and ability (doctors, registered psychologists and optometrists have a reporting obligation under the *Motor Vehicle Act*).

- Note that, because of the challenges aging can bring, it is a requirement for all B.C. driver's licence holders over the age of 80 who hold a Class 5 driver's licence to have a Driver Medical Examination Report completed every two years, if they wish to renew their driver's licence. The form is sent to the driver's registered address in advance of their 80th birthday and every two years thereafter. If the doctor reports that the senior has a medical condition that may affect their ability to drive safely, the senior may be referred for a DriveABLE assessment (see below). This is used to evaluate cognitive skills such as memory, attention, reaction time and judgment that could affect driving ability.
 - Adapted from www.SeniorsBC.ca
- DriveABLE (toll free: 1-888-475-4666). Has the person you are caring for been referred for a DriveABLE assessment? A short video about B.C.'s DriveABLE program, including the medical assessment used to determine whether drivers have a cognitive issue that will impact their ability to drive safely, is available at the ICBC website. The video, *What is DriveABLE?*, explains what drivers can expect if they are asked to complete a DriveABLE in-office assessment. To learn more and see the YouTube videos, visit www.icbc.com/driver-licensing/re-exam/Pages/DriveABLE-assessment.aspx.

Meanwhile, DriveABLE provides an evidence-based means of identifying medically impaired drivers. Its services include:

- DriveABLE Cognitive Assessment Tool (DCAT), a touchscreen software that identifies drivers with impairments in cognitive abilities relevant to driving. DCAT quickly evaluates cognitive abilities required for fitness to drive and predicts on-road performance.
- DriveABLE On Road Evaluation (DORE) is a specialized on-road evaluation that offers the most accurate science-based determination of whether or not a medically at-risk driver's skills have been impaired to an unsafe degree.

As of March 2012, seniors no longer have a decision made about their ability to drive based solely on the DCAT on-screen assessment. People who do not pass the DCAT assessment have the opportunity to take an on-road DORE assessment. The provincial government pays for both assessments. Final decisions are based on a combination of the two, plus medical information provided by the doctor.

Adapted from www.driveable.com

- Unsolicited Driver Fitness Reports, Office of the Superintendent of Motor Vehicles (OSMV) (toll free: 1-855-387-7747). When the driving ability of someone concerns you, and that driver is not willing to address their driving challenges, you can notify the OSMV. The Unsolicited Driver Fitness Reports website fact sheet (revised July 2012) explains the reporting process. The full name of the person providing the written report, and a contact number or address must be supplied. Verbal reports are not accepted and OSMV will not consider anonymous reports. The driver will not know who contacted OSMV as confidentiality of the reporter is protected under the *Freedom of Information and Protection of Privacy Act*. Unsolicited reports are placed on the driver's file but OSMV will not release the report or information supplied by the writer to the driver. Due to client confidentiality, OSMV cannot disclose what action is taken, to anyone other than the driver, or a person

authorized by the driver, in writing, to have access to this information (for example, a driver may give this authority to their lawyer).

What happens after a report is received by OSMV? Unsolicited reports expressing concerns regarding a driver's safety on the road are given high priority by OSMV. The report will be reviewed and, if a decision is made that medical information or another exam is required, the driver will be contacted directly.

Taken from www.pssg.gov.bc.ca/osmv/shreddocs/factsheet-unsolicited-driver-reports.pdf

66b) TRANSPORTATION ALTERNATIVES TO DRIVING

- TransLink provides bus, SkyTrain, SeaBus and West Coast Express services in Metro Vancouver. A helpful trip-planner service is available at 604-953-3333 (press zero to speak with a trip-planning operator) to help with route and trip timing.

Riders over 65, with proof of age, are eligible for reduced concession price fares. Also, the B.C. Bus Pass Program offers an annual Compass Card pass at a reduced cost for low-income seniors and individuals receiving disability assistance from B.C. for travel on bus, SkyTrain and SeaBus. (HandyDart is not included in this program.): toll free 1-866-866-0800 (press extension 4, and then press extension 3), weekdays; 9 a.m. - 4 p.m. For more information: www.seniorsbc.ca/transportation.

- Family and friends can sometimes help drive someone. And, faith communities often connect driving members to those who have trouble travelling to their church, synagogue or temple services and events.
- TransLink's Access Transit program services include:
 - HandyDART – Call 604-953-3680 to register to become a HandyDART user. (DART stands for Dial A Ride Transportation.) This door-to-door, shared-ride service is a public transit service that uses specially equipped vehicles designed to carry passengers with physical or cognitive disabilities who need assistance. HandyDART picks you up at the accessible door of your starting point and drops you off at the outside door of your destination. If you have a physical or cognitive disability and are unable to use public transit without assistance, you are eligible to use HandyDART.

To apply to be a HandyDART user, complete a free application form which must be signed by a health-care professional (doctor, occupational therapist, physiotherapist, social worker) who knows your disability. TransLink will not reimburse customers for any fees incurred in completing the form. You can phone the office to request an application form or print one from www.translink.ca (search for HandyDART application). You will need to provide information on the confidential form about your date of birth, home address, doctor's name and phone number and any special medical facts affecting your use of HandyDART. The Access Transit office may contact your medical professional for further clarification as needed. You are not required to give a photo to be a HandyDART user. Within 10 days of submitting your application, you will receive your HandyDART identification number.

Once you are registered with HandyDART, call 604-575-6600 to book trips. Have your HandyDART identification number ready as well as the address and telephone

number of your destination.

Rides can be booked one to seven days in advance. Reservations are on a first-come, first-served basis, so book as far in advance as possible. If you are unable to book a ride on your first call, call again. Space may become available as other customers may cancel their rides.

Note that “subscription trips” (regular same day/same time trips for travel to destinations such as adult day programs or dialysis) do not have to be repeatedly booked. Subscription trips are automatically booked for you after being set up. If your trip qualifies for subscription service it may take up to two weeks for the subscription to take effect. Until that time, each ride must be reserved and scheduled separately. Like all rides, subscription availability depends on the availability of service at that time.

The B.C. Ministry of Housing and Social Development discounted yearly bus pass, the provincial B.C. Bus Pass, and the CNIB pass are NOT accepted on HandyDART.

- HandyCard (778-452-2860) is a form of TransLink identification for those with a permanent physical or cognitive disability that makes it difficult to use the public transit system without assistance. The HandyCard discount allows someone with a permanent physical or cognitive disability travel for concession (reduced) fares on the bus, SkyTrain, SeaBus and West Coast Express. If the HandyCard user is accompanied by someone who assists them, that person can ride for free. Note that HandyCard cannot be used on HandyDART. When you begin your transit trip on HandyDART, you pay the regular HandyDART fare, not a concession fare.

The application process for a HandyCard is the same as the application process for HandyDART, except you must also submit two hardcopy or one digital picture with your application. It takes four to six weeks to receive your non-transferable photo ID HandyCard.

- TaxiSaver (778-452-2860) is a program available for people with permanent disabilities. It provides the opportunity for spontaneous travel when HandyDART cannot accommodate travel schedule needs. Passengers use taxi travel by booking directly with a participating taxi company without having to pre-plan the trip. The program provides a 50 per cent subsidy toward the cost of taxi rides. Passengers use coupons that are pre-purchased through the TaxiSaver program. An eligible customer may purchase a maximum of two booklets each month. Each booklet costs the customer \$25 and is worth \$50 of taxi vouchers. To purchase TaxiSaver coupons you must have a HandyCard (see the item above for how to apply for a HandyCard). These vouchers are not transferrable to other passengers, family or friends. Please be prepared to display your HandyCard at the request of the taxi driver.
- Community seniors’ transportation programs. In some communities there are small programs to assist seniors with transportation. E.g. in North Vancouver, the North Shore Seniors Go Bus program transports seniors to malls, medical buildings, and recreation centres.
- Better at Home (BH) is a low-cost non-profit seniors’ services program that is available in many communities across B.C. Some BH communities offer some transportation services,

usually to medical appointments. For much more on the BH program, see item 45a.

- Store delivery service by grocers, pharmacists, and others is sometimes available. Let your local businesses know if this is important to you.
- Private driving businesses are an option. People who have driven for many years may hesitate to use a private driving service because of the cost but it could be helpful to recall the full cost of car ownership (car payments, insurance, maintenance, gas, parking, repairs) when comparing costs of transportation alternatives. Driving services can also help reduce caregiver responsibilities.
 - Driving Miss Daisy (toll free: 1-877-613-2479; www.drivingmissdaisy.net) provides through-the-door (not just door-to-door) transportation assistance and accompaniment services including shopping, social engagements, medical appointments, airport service (assistance through to departure gate), etc. Depending on the city and a client's needs, expect charges in the range of \$50-\$60/hour for an all-inclusive service. Charges are pro-rated so clients don't pay for a full hour if they don't use that much time. Services are pro-rated to the quarter hour with a minimum charge of typically half an hour. Driving Miss Daisy is an accepted service provider for Veteran's Affairs Canada. To see if this Canadian franchise company has an owner/operator in your care recipient's community visit its website.
 - Home James - Opening Doors for Seniors (604-928-7789; www.homejamesforseniors.ca) is a private through-the-door (not just to the curb) driving and accompaniment service. Trips can include attending a theatre or sporting event, medical appointments, haircuts, library, grocery shopping (and assistance with putting groceries away), airport accompaniment to the departure gate or pick up at the arrivals area, etc. Veteran's Affairs Canada's Health Identification cards are accepted for veterans. Gift cards are available. Cost is \$60/hour; services are pro-rated to the quarter hour (\$15), minimum charge of half an hour (\$30). To see if this Metro Vancouver-based company operates in your area visit its website.
 - Private home support and home health-care services sometimes offer transportation as one of their services. Expect a rate of between \$25 and \$32/hour plus a per-kilometre charge. Expect a minimum charge of between two to three hours of service; some offer a one-hour minimum at a premium rate. See also the full Home Support and Home Health-Care Services – Private Businesses listing in item 46 of the handbook for a description of the variety of services these businesses offer.
 - SNTransport (toll free: 1-800-768-0044; www.sntransport.ca) is a private-pay, pre-booked, assisted transportation service operating throughout the Lower Mainland for those unable to use conventional transit. Wheelchair-friendly accessible vehicles offer door-to-door (not curb-to-curb) service. Collapsible wheelchairs are also available to assist those who need one. Staff have received extensive training in transporting those with mobility impairments. The hospital transfers service also offers non-emergency bed-to-bed transportation by wheelchair or stretcher.
 - Taxis can provide you with an estimated trip cost. Also, TaxiMe is a website that estimates how much your cab fare will cost using Google Maps. Enter your start and finish address at www.taxime.com.

Those with physical or cognitive disabilities, who have a HandyCard, are eligible for the TaxiSaver program (see earlier description) which provides some subsidized taxi coupons.

66c) TRANSPORTATION ADVOCACY

www.coscobc.org

COSCO (Council of Senior Citizens Organizations of British Columbia), a large federation of B.C. seniors' organizations, is actively working to ensure driver testing procedures are fair for older people. They also remind us that driving is a privilege we might not always be eligible for and encourage older drivers to think ahead and plan for the day they won't be able to drive.

Note: In spring 2012 TransLink announced plans to cancel the TaxiSaver program in 2013. However, as the result of community consultations and strong community advocacy by many seniors and disability groups, TransLink's board of directors reversed its decision in July 2012 and the TaxiSaver program continues. This is a good example of the power and influence seniors have when they work together and advocate for a cause.

67. TYZE ONLINE PERSONAL NETWORK

www.tyze.com

Tyze (pronounced 'ties') is a set of online tools to make it easy for people to form personal networks of support. Tools include: a private and secure way to communicate; a message and shared calendar system; ability to assign and accept tasks for family members and friends wanting to help; a way to share pictures and stories; and a way to securely store and access files related to the care recipient who is at the centre of the network. It removes the hassle and time of emailing and calling everyone, one at a time, in the event of a doctor's appointment, for example. Busy people on the go can manage Tyze from their smart phone or tablet and connect with their caregiver circle network from anywhere. You can request a free demo.

68. VETERANS AFFAIRS CANADA (VAC)

Toll free: 1-866-522-2122 www.veterans.gc.ca

Call for information on pension benefits plus VAC case-management services that can help seniors aging in place. You must have the veteran's service number available in order to talk with an agent.

69. WHEN I'M 64

604-331-5400

This classic made-in-B.C. handbook for seniors was revised in 2012 and is now published as three separate booklets by People's Law School and B.C. Centre for Elder Advocacy and Support (BCCEAS). Find the booklets at seniors centres or at the indicated websites.

- *When I'm 64: Benefits* describes the federal and provincial government benefits available to seniors, including Old Age Security program, Canada Pension Plan, and employment insurance benefits: www.publiclegaled.bc.ca/product/when-im-64-benefits.
- *When I'm 64: Controlling Your Affairs* contains information about planning for the future. It covers power of attorney, representation agreements, wills, staying safe and secure, and protection from frauds and scams:

www.publiclegaled.bc.ca/product/when-im-64-controlling-your-affairs.

- *When I'm 64: Services* lists services available to seniors in health care, housing, transportation, and recreation: www.publiclegaled.bc.ca/product/when-im-64-services.

Want to know if services, like ones in this handbook, are available in your community?

Just dial **2-1-1**

bc211 is a free information service funded by the United Way Of The Lower Mainland

bc211 can help you find social and government services.

Or visit www.bc211.ca to check its database of resources.

You can also email your question to help@bc211.ca

For deaf and hearing-impaired text telephone (TTY) assistance call 604-875-0885

PART V. HOUSING – WHEN A LOVED ONE HAS TO MOVE

No matter how many community supports are in place, the day may come when your care recipient is simply no longer able to remain living in their current home. It may be they need increased care, it may be caregiver exhaustion or, as is commonly the case, a combination of the two that forces the decision. The prospect of leaving home and moving to a new place looms large, and is upsetting. “Home” is filled with so many meanings and memories.

Relocation stress syndrome defines the common changes in behaviour, mood, and health that can accompany the moving process for an older person. Expect also to find yourself tired and confused and sorting through many feelings, including anger, guilt, helplessness, a lot of sadness, and relief too since your loved one will have others to help them, relieving you of some caregiving tasks. Brace yourself as you all prepare to manage the plethora of practical issues related to a senior moving.

70. PREPARING TO MOVE

Start early. Don’t wait until a crisis hits to talk with a loved one about what future housing options they would like to consider. Being prepared, well in advance of the need to move, is a sure way to reduce the stress of relocation. Inform yourself about the professional organizing and relocating services that exist to help with downsizing, i.e. businesses that streamline the culling of a lifetime’s worth of possessions, and the packing, transporting, and arranging of possessions in the new location. Get help wherever possible as the transition can be physically and emotionally exhausting.

Some families consider the possibility of an older family member moving into the home of an adult child. The book *When Your Parent Moves In: Every Adult Child’s Guide to Living with an Aging Parent* (2009) addresses this housing option in a comprehensive manner.

Sometimes there is very little time to prepare. A sudden health change (e.g. a bad stroke) or a fall that results in a broken hip – and home is a place with many stairs – can necessitate a change in housing with almost no notice at all. The time between receiving notice of a vacancy for a place where a senior is on a wait list and the move itself can be extremely short (as little as 24 hours) so, again, it is best to organize for a move in advance. These are the most important steps that you and your family should take in preparation for the move: review eligibility for available financial benefits such as Guaranteed Income Supplement or Veterans Affairs’ benefits; talk about future wishes for medical treatment with your family and doctor; ensure you have the up-to-date legal documents needed to ensure the wishes of the senior are respected and protected; confirm whether your family doctor will continue to provide medical care after the move; know what you will need to do about your current housing arrangement (if rented, know your obligations to your landlord about proper vacancy notice procedures; if owned, will the place be sold or rented out); put plans in place for all the household goods and furniture that will not move with the senior; have a list of places that will need a change of address notification; and do budget planning to include the costs of the new accommodation that will be payable on admission and monthly after that.

Above paragraph adapted from FH’s booklet *Residential Care in Fraser Health*

Remember there are services to support you and your care receiver with the turmoil of moving house late in life. See Part II. Education and Support for Family Caregivers, about support lines, support groups, counselling services and crisis lines.

COMING UP IN THE NEXT THREE PARTS OF THIS HANDBOOK: SENIORS HOUSING

The next three parts of this handbook explains the three types of seniors housing that an older person who can no longer live independently at home might need:

1. Supportive Housing – SH (Part VI)

(Also called congregate housing, independent housing, and retirement community living)

2. Assisted Living – AL (Part VII)

3. Residential Care – RC (Part VIII)

(Also called long-term care, complex care, continuing care, facility care, and nursing homes)

These are parts of what is known as “the continuum of care,” which ranges from low to high levels of care. In some places, more than one type of care is available in a given housing development, e.g. in different buildings on a site or on different floors of a building. When there are different levels of care provided in the same space, it is referred to as “a campus of care.” It makes future moves from one level of care to another, should that be needed, much simpler than moving to a different place.

Also explained are the three kinds of housing providers:

1. Public (also known as Government-Subsidized)

2. Non-Profit (also known as non-profit societies, and non-profit organizations or NPOs)

3. Private (also known as for-profit, and business)

WAIT LISTS

Regardless of the type of housing or kind of service provider, wait lists are common. Public housing (the least expensive) has the longest wait lists; non-profit housing has long wait lists too; and the private providers often have wait lists too. Never assume that a space will be available on demand. This is one of many reasons this handbook stresses the point **TALK WITH THE PEOPLE YOU CARE FOR ABOUT PLANNING AHEAD AND THEIR WISHES FOR THEIR “OLD AGE” – PLEASE DON’T WAIT UNTIL A CRISIS OCCURS.**

Where are the different types of seniors’ housing complexes in B.C.?

The following keep lists of housing providers across the continuum of care. N.B. It is expensive to keep housing lists current; never rely on just one database and always check the “last updated” note.

- The Ministry of Health lists all registered AL complexes in B.C. at www.health.gov.bc.ca/assisted/locator/index.php/displayhealthauthority/index. The list is first broken down by HA area (e.g. FH covers Burnaby), and second by city (e.g. Burnaby).
- FH (www.fraserhealth.ca) and VCH (www.vch.ca) websites list the public (government-subsidized AL and RC buildings in their areas.
- Seniors Services Society (604-520-6621), formerly named Seniors Housing Information Program – aka SHIP, has the *Seniors Housing Directory of B.C.* which lists all seniors housing: www.seniorsservicessociety.ca/hhousingdirectory.htm. (The URL has 2 h’s in it.)
- Senior Living Magazine, a free business publication, offers a web-based housing directory of SH, AL and RC housing in B.C. at www.seniorlivingmag.com/housingdirectory.
- *The Care Guide – B.C. Edition* is a free business booklet about some seniors housing and providers. Visit www.thecareguide.com. You can request a print copy.
- The names of buildings and housing providers can also be individually searched online.
- Your public library can also help you find seniors’ housing information.

PART VI. HOUSING OPTIONS – SUPPORTIVE HOUSING (SH) (also called CONGREGATE HOUSING, INDEPENDENT HOUSING, RETIREMENT COMMUNITY, and RETIREMENT LIVING)

71. WHAT IS SH AND WHO IS IT FOR?

If needs are relatively simple, SH might be sufficient. It includes a number of basic supports in the fee. SH provides a private suite with locked door, at least one meal daily (often two or three), an emergency response system, some social/recreational activities, and housekeeping services (weekly vacuuming and dusting, plus bed linens and towels). Personal laundry can be done in a communal laundry room or laundry service is often available for an additional fee.

The SH monthly rent fee does not include personal health-care services, e.g. bathing, help with getting dressed, and taking medications. But, just as if you were living in your own home, you have the option of bringing in your own personal-care service which may be prescribed by your case manager from your local HA Home and Community Care office or, alternatively, a home support service that you hire privately. Sometimes a SH provider offers its own support services for extra.

72. WHO REGULATES SH?

SH is not regulated at this time.

73. WHO OFFERS SH?

73a) PUBLIC (GOVERNMENT-SUBSIDIZED) SH

Because SH does not offer personal health care, it is not subsidized by the B.C. Ministry of Health.

73b) NON-PROFIT SOCIETY SH

To apply to SH units offered by non-profits, contact the building providers directly.

Costs vary and are set by each non-profit. Remember: for those aged 60 or older with low to moderate income, B.C. Housing 604-433-2218 subsidizes the Shelter Aid for Elderly Renters (SAFER) program which helps make rents, including the rent portion of SH costs, affordable for B.C. seniors: www.bchousing.org/Initiatives/Providing/SAFER.

List of buildings: see box on page 82 for how you can find a list of non-profit SH buildings.

73c) PRIVATE (FOR-PROFIT/BUSINESS) SH

To apply to private SH units, contact the businesses directly.

Costs vary and are set by each provider. For those aged 60 or older with low to moderate income, B.C. Housing 604-433-2218 subsidizes the Shelter Aid for Elderly Renters (SAFER) program which helps make rents, including the rent portion of SH costs, affordable for B.C. seniors: www.bchousing.org/Initiatives/Providing/SAFER.

List of Buildings: see box on page 82 for how you can find a list of private SH buildings.

PART VII. HOUSING OPTIONS – ASSISTED LIVING (AL)

Some of the information in this part of the handbook has been copied or adapted from the Office of the Assisted Living Registrar’s brochure: *Information About AL for Seniors*.

74. WHAT IS AL AND WHO IS IT FOR?

The next service level on the care continuum of seniors’ housing is called AL. AL is an option if a little more assistance is required than SH provides. AL is semi-independent housing for those cognitively able to make their own decisions about day-to-day activities, or are living with a spouse who qualifies for AL and who can make decisions on behalf of their spouse. Some people in AL may have mild dementia, e.g. they might need cues to help them find their suite consistently. Note: When residents are no longer able to make decisions that allow them to function safely in AL, they must move to a setting that offers more oversight, care and protection, such as RC.

AL residences offer three key components: housing, hospitality services, and personal assistance.

74a) HOUSING

AL typically takes the form of apartment-style buildings that include private self-contained bachelor, one-bedroom or two-bedroom suites with modified or full kitchens. Buildings include common dining and recreational space where people can eat together and socialize.

74b) HOSPITALITY SERVICES

By law, AL operators must offer five hospitality services:

1. Meals: one to three a day plus snacks. Meal services provide balanced and adequate nutrition for residents; safe practices are followed in meal preparation and delivery. A dietary plan is established for each resident who has food allergies, intolerances, and special or therapeutic dietary needs. Appropriate professional advice (e.g. from a registered dietitian) is obtained for the menu plan and when preparing meals for special and/or therapeutic diets.
2. Housekeeping: light housekeeping is provided at a frequency to meet residents’ health and safety needs.
3. Laundry: laundering of flat linens (sheets and towels, whether supplied by the resident or the operator) once a week.
4. Social and recreational opportunities.
5. A 24-hour emergency response system to provide residents with the ability to summon emergency assistance 24 hours a day.

Some operators may provide additional hospitality services, such as escorts to doctor’s appointments, washing of personal laundry, and hairdressers for an additional fee. For more information about the services offered in public (government-subsidized) AL, ask your HA case manager; for services offered in non-profit or private-pay AL, ask the operator directly. Note also that operators provide hospitality services either through their own staff, or through a contract with third parties.

Note also the United Way of the Lower Mainland-managed Better at Home (BH) non-medical home support program is available in some B.C. communities. BH offers extra services that can help residents living in AL. Read more about BH in item 45a.

74c) PERSONAL ASSISTANCE SERVICES

AL is modelled on home support, which means that operators provide the same types of personal-care services people would expect to receive from unregulated care providers in their own home in the community. Some residences provide only scheduled personal assistance that can be delivered at a set time of day, e.g. help with bathing or medications. Others also accommodate residents' unscheduled personal assistance needs, e.g. toileting at night.

Seniors in AL, by law, must be offered help with at least one, but not more than both of the personal assistance areas below. To provide personal assistance to seniors beyond two areas would contravene the AL regulations.

1. Regular assistance with activities of daily living, including eating, mobility, dressing, grooming, bathing and personal hygiene.
2. Central storage of medication, distribution of medication, administering or monitoring the taking of medication.

AL services do not include skilled 24/7 professional nursing care, although most providers have licensed practical nurses on staff for some duties. Ask about the services available and the charges that apply. Some nursing care can be paid for separately, either from the housing supplier or a home support services agency, but only on a short-term basis, e.g. for residents who are recovering from an illness, waiting to transfer to long-term care, or requiring palliative care. If you require the services of a registered nurse, speak with your case manager if you have one, otherwise the building manager.

AL operators must not house people who cannot make decisions on their own behalf as per the *Community Care and Assisted Living Act*, section 26 (3). For those who are in AL but are losing this cognitive ability, operators must develop an "exit plan" with the resident, their family, physician, support network and, in the case of publicly subsidized AL, the HA case manager, to transfer the resident to another place. The exit plan indicates the resident's relocation plan, the person responsible for the arrangements, and the additional services required to ensure the resident's health and safety are not in jeopardy while awaiting the transfer.

When considering a move to AL, ask the following sorts of questions about the services offered, their frequency and the charges involved.

- Will you get one, two or three meals a day?
- What type of food is served?
- Who will provide the services?
- What languages are spoken?
- What are the extra charges for additional services, such as personal laundry service?
- What are the various costs, the monthly charges and the security deposit?
- Will your equipment (e.g. walker) fit in the suite?
- Is it a non-smoking building?
- Is it possible to keep a pet? Can pets visit?
- Is it possible to have overnight guests?
- What kind of storage is available?
- Will you get your own parking spot?
- And so on.

75. WHO REGULATES AL?

In B.C., AL services are regulated under Bill 73 (2002), the *Community Care and Assisted Living Act*, (www.bclaws.ca/EPLibraries/bclaws_new/document/ID/freeside/00_02075_0) through the Assisted Living Registrar (toll free: 1-866-714-3378). The registrars' role is to protect the health and safety of AL residents in public, non-profit, and private AL residences. The registrar administers the AL provisions of the *Act*, which require all AL operators that meet the definition of an AL residence under the *Act* to register their residences with the provincial AL registrar and meet provincial health and safety standards.

The office must also ensure timely and effective investigation of complaints about the health and safety of AL residents.

76. WHO OFFERS AL?

76a) PUBLIC (GOVERNMENT-SUBSIDIZED) AL

How to apply

The person needing assistance must go through an assessment by a local HA office case manager, and be assessed as requiring AL, before being placed on a wait list. Do not contact subsidized AL providers directly regarding units; they can only refer you back to your local HA office.

If you are a current client of your local HA's Home Health services and believe you need AL, discuss your care needs with your case manager. If you are not a current client, call your local Home and Community Care office. See item 8a for contact information.

N.B. If couples wish to move into an AL residence, only one member needs to meet the eligibility requirements for both to move in together.

Cost

If you receive public AL services, you will pay a monthly rate based on your after-tax (net) income (and the income of your spouse, if applicable) for rent, hospitality services and personal assistance services, subject to a minimum and maximum monthly rate which is set annually by the B.C. Ministry of Health. Your monthly rate is calculated by multiplying your after-tax income (as defined in the Continuing Care Fees Regulation) by 70 per cent. There is a minimum monthly rate for clients receiving AL services; there is also a maximum cap.

If you and your spouse are living together in AL, your monthly client rate is calculated based on both of your incomes, subject to a minimum and maximum monthly rate. Your rate will be recalculated if your living situation changes for any reason and you are no longer living with your spouse.

The maximum monthly rate for public AL, for individuals or couples, is based on the market rent for housing and hospitality services for the geographic area where you live, as well as the actual cost of personal-care services you receive. For more information, ask your case manager or contact your Home and Community Care office.

If payment of your assessed monthly rate would cause you or your family serious financial hardship, you may apply for a temporary reduction of your monthly rate. See [What if I cannot afford my assessed monthly rate?](http://www2.gov.bc.ca/gov/content/health/accessing-health-care/home-community-care/who-pays-for-care/temporary-reduction-of-your-client-rate) at www2.gov.bc.ca/gov/content/health/accessing-health-care/home-community-care/who-pays-for-care/temporary-reduction-of-your-client-rate.

N.B. SAFER does not apply to AL units which are public, because rent cannot be subsidized by two different government programs.

Also, funding from a public AL program is not transferable to private-pay AL.

List of buildings

A list of public AL buildings can be found at www.health.gov.bc.ca/assisted/locator/index.php/displayhealthauthority/index. The list is broken down first by HA and then by city. At the bottom of each building listing, both the number of public units and the number of private-pay, i.e. non-profit society and business, units in the building are noted. The local case manager will also provide you with a list of public buildings in your area.

76b) NON-PROFIT SOCIETY AL

How to apply

For AL units offered by non-profits, contact the buildings directly. An assessment by your local HA Home Health staff is not needed for admission to a non-profit residential facility but there will be an assessment that will be somewhat different from the Ministry of Health form used by all the HAs.

Cost

Rates begin at approximately \$2,000/month but can be much higher and differ widely.

Operators may charge a fixed rate for a package of services, charge on a fee-for-service basis, or a combination of the two. Remember: for people aged 60 or older with low to moderate income, B.C. Housing (604-433-2218; www.bchousing.org/Initiatives/Providing/SAFER) subsidizes the Shelter Aid for Elderly Renters (SAFER) program which sometimes helps make rents, including the rent portion of AL costs, affordable for B.C. seniors.

List of buildings

A list of non-profit societies offering AL can be found at www2.gov.bc.ca/gov/content/health/accessing-health-care/assisted-living-registrar. The list is broken down first by HA and then by city. At the bottom of each building listing, both the number of government-subsidized units and the number of private-pay (i.e. non-profit society and business) units in the building are noted.

76c) PRIVATE (FOR-PROFIT/BUSINESS) AL

How to apply

For AL units offered privately, contact the businesses directly. An assessment by your local HA Home Health staff is not needed for admission to non-profit residential facilities but there will be an assessment that will be different from the Ministry of Health form used by all the HAs.

Cost

Each private provider sets its own price and residents must pay all costs. Private residences may charge a fixed rate for a package of services, charge on a fee-for-service basis, or a combination of the two. Expect a range of approximately \$1,900 - \$6,000/month. Remember: for people aged 60 or older with low to moderate income, B.C. Housing (604-433-2218) subsidizes the Shelter Aid for Elderly Renters (SAFER) program (www.bchousing.org/Initiatives/Providing/SAFER) which sometimes helps make the rent portion of AL costs affordable.

List of buildings

A list of operators offering private AL can be found at

www.health.gov.bc.ca/assisted/locator/index.php/displayhealthauthority/index. The list is broken down first by HA, and then by city. At the bottom of each building listing, both the number of government-subsidized units and the number of private-pay (i.e. non-profit society and business) units in the building are noted.

76d) AL ADVOCACY.

The Office of the Seniors Advocate May 2015 report *Seniors' Housing in B.C.: Affordable, Appropriate, Available* found that "...as a result of outdated regulations, many seniors were being denied the ability to stay in assisted living and were being pushed into residential care before it was clinically necessary."

A number of recommendations regarding AL were made in the report; see item 102 for more.

PART VIII. HOUSING OPTIONS – RESIDENTIAL CARE (RC) (also called COMPLEX CARE, CONTINUING CARE , FACILITY CARE, LONG-TERM CARE and NURSING HOMES)

77. WHAT IS RC AND WHO IS IT FOR?

RC is known by many names (see the title bar above). It offers 24/7 personal-care assistance and support, skilled nursing care, a safe and secure living environment, nutritious meals, basic linen and personal laundry services, and recreational and activity programs. It is for those with complex health-care needs.

Note that RC includes dementia care; this is because about 60 per cent of RC residents have dementia. A few facilities also have a “special care unit” (SCU) to care for people with dementia, but a facility does not need to have an SCU to serve this population.

Residential placement can be a gut-wrenching process for family caregivers and care receivers. But the health condition of your care recipient can get to the point where, no matter how much you love a person and how hard you try to care for them, they need professional 24/7 assistance. As a family caregiver, you just cannot continue to be the primary care provider. This is not an unusual state of affairs. In fact, to have a caregiver living with unacceptable risk to their well-being, no longer able to provide care and support, is one of the eligibility criteria for public RC services.

Be prepared for the prospective resident, yourself as caregiver, and other family members to go through an adjustment phase when this move is being made. Do not be surprised if your first impression of a care facility is negative. It takes time to get to know the staff, other residents and family members, and to begin to adjust to the routines. You still have the role of a family caregiver, but the things you do will change.

Supplementing what RC offers

Sometimes family members wish they could do more for a loved one living in long-term care. Whether your loved one is in a public or a private-pay (i.e. either a non-profit or private/business) facility, you can supplement or enrich the services included in the monthly fee if the financial resources are available. Speak to the facility and discuss what additional services you can purchase. E.g. it might be a private companion/care aide that you can hire to give more one-on-one attention to a resident. This might be a short-term service for when you are away on holiday and not able to visit your loved one, or it may be an ongoing service you wish to have for your care recipient.

78. WHO REGULATES RC?

RC facilities are licensed under the B.C. *Community Care and Assisted Living Act* or the *Hospital Act*. In either case, community care licensing programs are mandated to protect vulnerable individuals in all licensed care facilities in B.C. The *Acts* provide public assurance that the established minimum standards for health, safety and well-being are maintained. Facilities are supposed to be inspected regularly to ensure compliance with the *Community Care and Assisted Living Act* and regulations, and to determine if minimum health and safety standards are being followed. In addition, follow up is done in response to complaints, allegations of abuse, and reportable incidents.

Facility inspection reports

Licensing officers carry out inspections to assess whether facilities are meeting the requirements of the *Community Care and Assisted Living Act* and its regulations (RC Regulation). During inspections, licensing staff look for items typically divided into these 10 broad categories to determine if they meet the minimum requirements to ensure the health, safety and well-being of persons in care: care and/or supervision; hygiene and communicable disease control; licensing; medication; nutrition and food services; physical facility, equipment and furnishings; policies and procedures; programming; records and reporting; and staffing.

HA inspection websites provide the results of routine inspections. Inspection reports for RC facilities in FH areas can be found at www.healthspace.ca/fha/rescare. VCH areas can be found at www.inspections.vcha.ca. If you cannot find a facility you are looking for on either of these websites, it may be governed by a different act, the *Hospital Act*. You can ask any facility you are considering for a copy of its latest licensed RC facility inspection report. Note that after every inspection, the facility will have a report that identifies regulatory requirements that were not met, and states the corrective actions to be taken, as well as the dates these actions are to be completed.

What will the inspection reports tell you?

You can find information on capacity, contact information, routine inspection findings, and follow up to routine inspection conclusions. However, the information provided on the website is not enough to determine if a facility is the best one for your loved one or you, the caregiver, who will want it to be easy to visit your care recipient.

What will the HA inspection website NOT tell you?

Posted inspection reports will not recommend a facility to you, rank or rate facilities against one another, issue a report card that grades facilities on their current status in meeting the current regulations, provide information on complaints, or provide information on inspections that are not routine ones. You are encouraged to visit each facility that is being considered before making a choice. Call ahead to make an appointment; you cannot just drop in – these are the homes of seniors with complex care needs that you will be visiting.

How to make a complaint about a licensed long-term care facility

If your concern is about a serious issue regarding the health, safety or well-being of a person in care, you should immediately contact your local HA and ask to speak to a community care facilities licensing officer.

However, if your concern is about the quality of care that you or a loved one is receiving, it is best to share your concerns first with the facility in question. If your concern is not addressed to your satisfaction, you can take your complaint to the Patient Care Quality Office (FH: 1-877-880-8823) or (VCH: 1-877-993-9199). The Ministry of Health states that once a complaint has been investigated and is substantiated, a summary of the complaint is posted on the HA website. Personal identifying information regarding the residents, staff or complainants will not be posted on the website. The facility operator name and business contact information will be posted to allow people to contact the facility if they have any additional questions or concerns.

If your concern is still unresolved after that step, you can contact the independent Patient Care Quality Review Boards. If that doesn't work you can call the Office of the Seniors Advocate (toll free: 1-877-952-3181) for suggestions. E: info@seniorsadvocatebc.ca

If the above processes do not resolve your concern, contact the Office of the Ombudsperson

(toll free: 1-800-567-3247) to see if that office can help. See also Part XII for more on advocacy.

79. WHO OFFERS RC?

79a) PUBLIC (GOVERNMENT-SUBSIDIZED) RC

How to apply

For placement in a public RC bed, never contact the facility (or the housing provider) directly, because they can only refer you back to your local HA office. For a public long-term care bed, the first step is to see that your care recipient is assessed by the local HA office case manager (or by the hospital case manager liaison in the case of seniors who are in the hospital and being assessed there). The assessment will determine if your loved one has:

- Complex care needs that require continuous care.
- Care needs that cannot be met safely by community-based resources.
- An immediate need for RC (note it could take some weeks to get a bed).

Under the Ministry of Health's priority access program, (implemented May 2002), once a person has been assessed as eligible for and in need of subsidized RC, that person will be asked about their preferred geographic area for residential placement.

Your case manager or hospital social worker or home health liaison will give you a list of facilities to choose from. Then your name will be forwarded for the first available and appropriate bed vacancy. Priority will be given to clients with the highest need and who are at greatest risk. Wherever possible, the HA will do its best to offer you a bed in your requested geographic area; however, it cannot guarantee that you will be placed in any particular facility.

At times, the HAs experience shortages in RC beds in a particular geographic area, which can in turn cause extreme congestion in the local acute-care hospital. (The media sometimes refers to people waiting in acute-care beds for a long-term care bed as "bed blockers.") Occasionally when this happens, a senior will be asked to accept a RC bed in an adjacent area, because the hospital bed is required for an acute-care patient. If this occurs, the senior will be given high priority for a transfer to a facility of their choice.

N.B. Policy states that your loved one will move into the residential facility between 24 and 48 hours after the offer of a bed has been made. Therefore, the time to start planning the termination of existing housing arrangements and the disposition of household possessions is when your care recipient's name goes on the government-subsidized wait list. That way, things will be ready for the short-notice move.

When moving in, an orientation to the facility will be provided by staff. This offers an opportunity to answer specific questions related to daily routines and care personnel. Get a facility booklet.

Once moved into the assigned bed, it is possible to ask to go on a transfer list for your preferred RC facility if you did not get your desired choice and still want it. When a vacancy arises at the desired place of transfer, there will be the choice of accepting that new bed or declining to move again.

Adapted from FH, November 2011

First Appropriate Bed...Patients/Clients Being Cared for in their Most Appropriate Setting

Cost

In public RC, the HAs pay for the health-care portion of services; residents contribute towards the accommodation and the daily costs of food. This room-and-board charge depends on the annual income of the resident. The rate is calculated and determined according to a rate schedule and is payable on admission and at the beginning of each month.

As explained at www2.gov.bc.ca/gov/content/health/accessing-health-care/home-community-care/care-options-and-cost/long-term-residential-care:

You will pay up to 80 per cent of your after-tax income on a monthly basis, subject to a minimum and maximum monthly rate. Your monthly rate is calculated based on your after-tax income in one of two ways:

1. If your after-tax income is less than \$19,500 per year, your monthly rate is calculated as your after-tax income less \$3,900 and divided by 12 (Formula A). Note: The \$3,900 deduction (\$325 per month x 12 months) is set to ensure that most clients have at least \$325 of income remaining per month after paying their monthly rate.
2. If your after-tax income is equal to or greater than \$19,500 per year, your monthly rate is calculated as your after-tax income multiplied by 80 per cent and divided by 12 (Formula B).

The minimum monthly rate is adjusted each year based on changes to the Old Age Security/ Guaranteed Income Supplement (OAS/GIS) rate as of July 1 of the previous year. For 2015, the minimum monthly rate for a client receiving long-term RC services is \$991.20 per month. The maximum client rate is adjusted each year based on changes to the consumer price index over the previous year. For 2015, the maximum monthly rate for a client receiving long-term RC services is \$3,157.50 per month.

If payment of your assessed monthly rate would cause you or your family serious financial hardship, you may apply to your HA for a temporary reduction of your monthly rate. Serious financial hardship means that payment of the assessed monthly rate would result in you or your spouse (if applicable) being unable to pay for: adequate food; monthly mortgage/rent; sufficient home heat; prescribed medication; or other required prescribed health-care services.

What optional services can I choose to pay for in addition to my monthly rate?

RC service providers may also offer you optional equipment, products, and services in addition to those that are included as part of your RC services. If you choose to receive any of these optional services, you may be required to pay an additional fee over and above your monthly rate. These optional services may include: personal cable connection and monthly fee; personal telephone connection and basic services; nutrition supplements, where the client requests a specific commercial brand rather than the brand provided by the service provider; personal newspaper, magazines and periodicals; hearing aids and batteries, including replacement batteries; personal transportation; extra or optional craft supplies, entertainment and recreational activities that are additional to activities and supplies provided as benefits above, and are chosen by the client; an administration or handling fee associated with the service, where reasonable, to perform a task or service that would normally be the client's responsibility; purchase or rental of equipment that is for the exclusive use of the client (e.g., walker, wheelchair, crutches, canes or other devices, and maintenance as required); companion services; personal dry cleaning or laundry services for items requiring special attention; and personal hygiene and grooming supplies that the client chooses in preference to general supplies provided by the service provider including facial tissue, hand lotion, denture cleaner, brush and comb, toothpaste,

hair shampoo and conditioner, talcum powder, shaving cream, special soap, preferred incontinence supplies.

Note: Some facilities may have a single or larger room available for an additional daily charge called a room differential. Should you want a single or larger room, advise the facility.

List of buildings

For a list of public RC facilities in FH go to www.fraserhealth.ca/your_care/residential_care/residences/residential_care_facilities; in VCH go to www.vch.ca/your_health/seniors/residential_care.

79b) NON-PROFIT RC

How to apply

Since your loved one would not be in a public bed, and you will be paying 100 per cent of the cost of housing and care, you can apply to any non-profit RC facility. You can contact non-profit facilities directly for detailed information about availability, costs and services. Remember that non-profit facilities have waiting lists too. An assessment by your local HA Home Health staff is not needed for admission to a non-profit residential facility but the facility will conduct its own assessment.

Cost

Rates begin at over \$3,500/month but can be much higher and differ among buildings.

List of buildings

The following websites contain listings of all RC facilities in B.C. – public, non-profit and private – licensed under the *Community Care and Assisted Living Act* or the *Hospital Act*. Remember to call ahead and visit the facility you are interested in to ensure it meets your needs:

www.health.gov.bc.ca/ccf/survey/index.php/displaycommunity/index and www.seniorsservicessociety.ca/find_housing.html.

79c) PRIVATE (FOR-PROFIT/BUSINESS) RC

How to apply

Private businesses also offer RC where rooms and services are paid for by the resident and are not subsidized by the HAs. Depending on individual financial circumstances, a private RC may be the right option for either temporary or permanent care. Approximate total care costs and the type of care required should be carefully considered when choosing a private facility. An assessment by HA case management staff is not needed for admission to a private-pay residential facility but the facility will conduct its own assessment. Contact these facilities directly for detailed information about availability, costs and services. Be mindful of the fact that private facilities often have wait lists too.

Note: Some long-term care facilities provide both HA government-subsidized and private-pay beds. That is to say, they have a blend of beds. Choosing to pay privately (on a temporary basis) while you wait for a public bed to become available does not ensure that a resident will be transferred to a subsidized bed in the same facility.

Cost

Costs vary amongst housing providers, ranging from approximately \$4,000 to \$8,500/month depending on the building and level of care available. Residents are responsible for 100 per cent of all costs.

List of buildings

The following websites contain listings of all RC facilities in B.C., regardless of the kind of housing provider, licensed under the *Community Care and Assisted Living Act* or the *Hospital Act*.

Remember to visit the facility you are interested in to ensure it meets your needs:

www.health.gov.bc.ca/ccf/survey/index.php/displaycommunity/index and

www.seniorsservicessociety.ca/find_housing.html.

80. OTHER IMPORTANT ISSUES IN RC

80a) RESIDENTS' BILL OF RIGHTS

The B.C. Ministry of Health passed this bill of rights for residents in 2009, pursuant to section 7 (1)(c.1)(ii) of the *Community Care and Assisted Living Act*, and to section 4(4)(a) of the *Hospital Act*:

Commitment to care

1. An adult person in care has the right to a care plan developed:
 - a) specifically for him or her, and
 - b) on the basis of his or her unique abilities, physical, social and emotional needs, and cultural and spiritual preferences.

Rights to health, safety and dignity

2. An adult person in care has the right to the protection and promotion of his or her health, safety and dignity, including a right to all of the following:
 - a) to be treated in a manner, and to live in an environment, that promotes his or her health, safety and dignity;
 - b) to be protected from abuse and neglect;
 - c) to have his or her lifestyle and choices respected and supported, and to pursue social, cultural, religious, spiritual and other interests;
 - d) to have his or her personal privacy respected, including in relation to his or her records, bedroom, belongings and storage spaces;
 - e) to receive visitors and to communicate with visitors in private;
 - f) to keep and display personal possessions, pictures and furnishings in his or her bedroom.

Rights to participation and freedom of expression

3. An adult person in care has the right to participate in his or her own care and to freely express his or her views, including a right to all of the following:
 - a) to participate in the development and implementation of his or her care plan;
 - b) to establish and participate in a resident or family council to represent the interests of persons in care;
 - c) to have his or her family or representative participate on a resident or family council on their own behalf;
 - d) to have access to a fair and effective process to express concerns, make complaints or resolve disputes within the facility;
 - e) to be informed as to how to make a complaint to an authority outside the facility;
 - f) to have his or her family or representative exercise the rights under this clause on his or her behalf.

Rights to transparency and accountability

4. An adult person in care has the right to transparency and accountability, including a right to all of the following:

- a) to have ready access to copies of all laws, rules and policies affecting a service provided to him or her;
- b) to have ready access to a copy of the most recent routine inspection record made under the Act;
- c) to be informed in advance of all charges, fees and other amounts that he or she must pay for accommodation and services received through the facility;
- d) if any part of the cost of accommodation or services is prepaid, to receive at the time of prepayment a written statement setting out the terms and conditions under which a refund may be made;
- e) to have his or her family or representative informed of the matters described in this clause.

Scope of rights

5. The rights set out in clauses 2, 3 and 4 are subject to:

- a) what is reasonably practical given the physical, mental and emotional circumstances of the person in care;
- b) the need to protect and promote the health or safety of the person in care or another person in care, and
- c) the rights of other persons in care.

80b) ANTIPSYCHOTIC DRUG USE IN RC

The B.C. Ministry of Health report, *A Review of the Use of Antipsychotic Drugs in British Columbia Residential Care Facilities (2011)*, explains antipsychotic drugs were originally developed to treat schizophrenia and other psychoses, but have increasingly been used to treat behavioural and psychological symptoms (e.g., delusion, aggression and agitation) of people with dementia. The appropriate use of antipsychotic prescription medications for residents with dementia is a complex concern, as persons with advanced dementia might experience symptoms including delusions, hallucinations, verbal outbursts, agitation and physical aggression, creating challenges related to the safety of staff and other residents. At the same time, inappropriate medication or medication errors can have serious adverse effects. There are many calls to better manage the aggressive behavioural and psychological symptoms of dementia to reduce antipsychotic use using new B.C. guidelines.

Research conducted in 2014 by the Canadian Institute for Health Information shows that 33 per cent of residents in B.C. RC may have their quality of life affected because they are taking potentially inappropriate antipsychotic medications. The BC Patient Safety and Quality Council has launched a “Call for Less Antipsychotics in RC” (CLeAR; www.bcpsqc.ca/clinical-improvement/clear) and is working towards reducing the number of residents on antipsychotic medications by 50 per cent across B.C. Advocates for Care Reform (www.acrbc.ca) has a fact sheet, *Antipsychotic Medications In Long Term Care (2012)*, with guidelines on what you can do as an involved family member. In April 2015 the Office of the Seniors Advocate (see item 102) released its [Placement, Drugs, Therapy Report](#); it too expresses concern about the overuse of antipsychotics in RC.

80c) QMUNITY GENERATIONS – AGING OUT PROJECT POLICY DIALOGUE 604-684-8449

B.C.’s Queer Resource Centre has a two-year public education and policy development project, *Aging Out Policy Dialogues*, through its Generations program. The purpose of the dialogues is to create policy recommendations and competency training that affect positive change regarding the understanding of the needs and issues of LGTBQ2SQ seniors, including those in seniors housing.

The competency training is meant to ensure that proficient care is provided by all staff, in a way that creates an inclusive environment. Organizations that have undergone competency care training display the rainbow sticker on their property and in their materials. You can also ask what queer competency training staff has received and if there are queer staff, or queer clients. The Qmunity Generations staff can assist: www.qmunity.ca/get-support/olderadults.

80d) FAMILY AND RESIDENT COUNCILS

In addition to the regulations and rights in long-term care, some facilities have resident councils and family councils so that residents, family members, and staff can connect and work together to promote quality of life in a facility. If the facility of your care recipient does not have a family council and you would like to help establish one, or if you are looking for ways to help strengthen an existing family council, the Ministry of Health provides a short guide book, *Guidelines for the Development of Resident or Family Councils*. Google the title for the PDF. More information on the topic can also be found at www2.gov.bc.ca/gov/content/health/accessing-health-care/home-community-care/accountability/family-and-resident-councils.

Advocates for Care Reform (ACR; www.acrbc.ca), a non-profit society dedicated to improving the quality of care and quality of life for people living in RC in B.C., offers family council guidelines and has a *Family Council Handbook*. ACR worked many years to create awareness and facilitate dialogue and consultation around the issues of care and quality of life for those living in RC through advocacy and education. In October 2012, the non-profit was dissolved but members have kept information and materials on the website.

Find out more about RC through these Ministry of Health resources:

- *Planning for Your Care Needs: Help in Selecting a Residential Care Facility (February 2013)* is an 18-page PDF handbook. Search online by the handbook title.
- Visit www2.gov.bc.ca/gov/content/health/accessing-health-care/home-community-care/care-options-and-cost/long-term-residential-care.

PART IX. LEGAL ISSUES IN FAMILY CAREGIVING – ABUSE

The information below is available in [Chinese](#) (Traditional), [English](#), [French](#), [Punjabi](#), [Spanish](#), and [Vietnamese](#) and can be downloaded at www.healthlinkbc.ca/healthfiles/hfile93a.stm.

81. MOST FAMILIES ARE SUPPORTIVE

Most caregiving to older adults is done by family members who may take on care responsibilities out of love, a sense of personal or family duty, feelings of guilt, or because there is no one else available. Every family is different. Some family relationships are very positive and mutually supportive. Others are filled with mixed feelings, conflict and tension. Sometimes abuse and neglect occur, even when a family member means well but becomes overstressed. In many cases, the abusive person is a spouse or partner, another family member or someone else a care recipient relies upon and trusts. Abuse and neglect in later life can affect an older adult's health, happiness and safety. It can take many forms, including physical, emotional, financial, sexual, medical, spiritual or social isolation.

Most people do not intend to become abusive or neglectful but may not feel comfortable with the changing roles in their family, especially if the older adult now needs to rely on them. Some family members may not know how to provide the care or assistance needed. They may not understand the nature of the disease or condition and how it affects the older adult's abilities or behaviour. In later life, it is not uncommon for both the person providing care and the person receiving care to have difficulties with their health, memory or ability to make decisions. This can affect how people relate and react to each other. In some situations of abuse, people have used physical force or emotional control over the other person throughout the relationship. Some people receiving care may have been abusive or controlling earlier in life. Now that the older person depends on others, the caregiver may feel it is their turn to treat the parent or spouse in a damaging way.

Carers often have many competing responsibilities, with their children, their spouse or partner, and their job. Trying to juggle these can lead to tensions and conflicts within the family. Sometimes family caregivers may have significant personal problems, including financial, mental health, substance abuse, or gambling. This may mean that it is more difficult for them to safely offer hands-on caregiving.

Helping with finances creates special risks. A caregiver may not realize what their legal responsibilities and obligations are when assisting an older adult with finances, especially when exercising a power of attorney. They may take over the finances as it seems easier. Some incorrectly think they are entitled to the money or property, or assume they will get it anyway when the person dies, so they might as well take control or and use it now. This may lead to financial abuse.

Adapted from www.healthlinkbc.ca

HELP IS AVAILABLE

- If you discover a crime or dangerous situation is occurring to an older adult, call 9-1-1 NOW.
- If you are not sure if an older person is being abused or neglected, call HealthLinkBC at 8-1-1 to speak with a health professional for information, 24/7. [Translation](#) service is available on request.
- The Seniors Abuse and Information Line (SAIL) 604-437-1940 or toll free 1-866-437-1940 is a safe place for older adults and those who care about them to talk to someone if they feel they are being abused or mistreated. Daily, 8 a.m. – 8 p.m. (except holidays). www.bcceas.ca/

PART X. LEGAL ISSUES IN FAMILY CAREGIVING – PERSONAL PLANNING

This part of the handbook introduces you to the idea of personal planning and the legal documents available to you. You may be reading this as a caregiver; the information not only applies to the person you are supporting but also to you. Personal planning can help make the caregiving experience more manageable. It ensures someone has authority, for example, to pay bills and access health and personal-care services and supports. This part was written by the Nidus Personal Planning Resource Centre and Registry. (The handbook's presentation of legal information departs from the usual style. We hope it makes the key information accessible and simplifies your preparation of the recommended legal documents.)

82. PERSONAL PLANNING – MAKING ARRANGEMENTS IN CASE OF INCAPABILITY

What is personal planning?

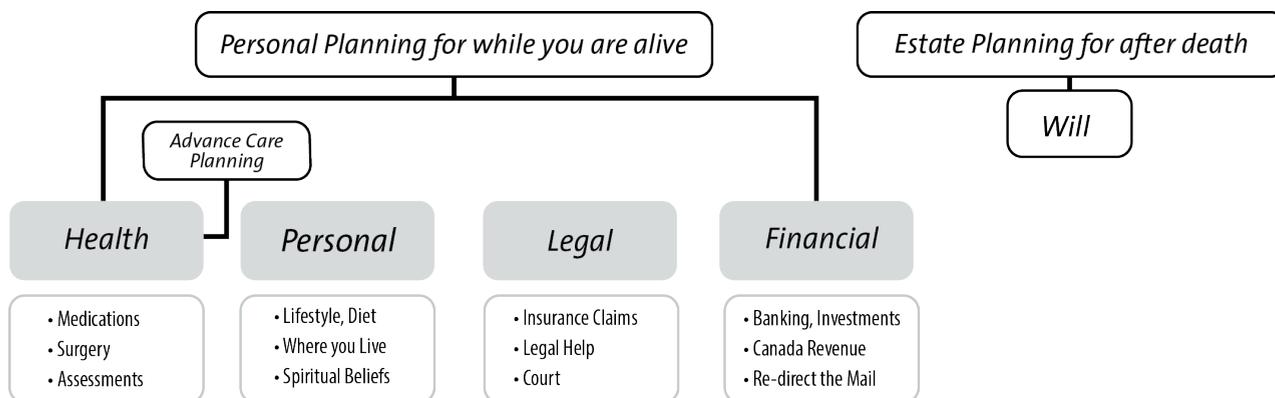
We are all familiar with estate planning, which is about making arrangements for after we die. A will is the legal document people use to give legal authority to someone (an executor) to settle their estate. The term “personal planning” is about making arrangements in case you need help managing your affairs during your lifetime due to illness, injury, or disability. The key legal document for personal planning is a Representation Agreement and, for some, also an Enduring Power of Attorney.

Who should plan ahead?

Personal planning is for everyone 19 years or older (adults). An unexpected health crisis like a bad fall or a stroke can happen to anyone. The older we become, the greater the likelihood of a diagnosis of a long-term degenerative illness, such as dementia. While we dislike thinking about losing the ability to make decisions and express ourselves, personal planning lets us be pro-active.

What does personal planning cover?

Personal planning covers all areas of life: our health; personal matters; legal affairs; and finances. You may encounter the term “advance care planning” – it is used by the Ministry of Health and the health authorities. It focuses on discussions about health care, which is just one area of personal planning.



Why plan?

Making your own arrangements has many benefits:

- It makes things easier on your family and friends.
- It avoids the need for the government to be involved in your personal and private affairs.
- It lets you stay in control of your life by ensuring that those you trust can advocate for you and carry out your wishes, if you need help speaking up for yourself.

What if I do not plan?

Planning is voluntary, but if you cannot manage your own affairs and do not make arrangements, other laws or the court will determine who can make decisions for you. This is referred to as the “default scheme” and is discussed later in this section.

83. TWO PATHS FOR PERSONAL PLANNING IN B.C.

There are two paths for personal planning: 1) planning for the future; or 2) needing help today. The differences between these two paths have to do with different definitions of capability.

The FUTURE PATH is for adults who are capable and able to make decisions independently and manage their own affairs. These adults want to plan in case they need assistance in the future. It is important to make the legal documents now so they are “ready to go” in the future if a health crisis or other situation arises.

The HELP FOR TODAY PATH is for adults whose mental capability is in question. These adults need assistance now with decision-making and/or managing their affairs. They might need help for a temporary period, a chronic or episodic illness, or a longer term or ongoing condition.

EXAMPLE: John and Mary are spouses in their 70s and live together in their own home. Mary has dementia and requires considerable help from John with daily living activities, including dealing with financial affairs and making health-care decisions. John worries about Mary’s well-being if something happens to him. He also wants to be sure his wishes are carried out if he becomes incapable. It is important that John get his own affairs in order as this will also make things easier for Mary’s situation and her plan.

John is on the FUTURE PATH. Mary is on the HELP FOR TODAY PATH.

84. LEGAL DOCUMENTS FOR PERSONAL PLANNING IN B.C.

Which legal document(s) do I make?

The legal document(s) you make depends on the planning path.

Remember the motto of the U.S. Family Caregivers Alliance:

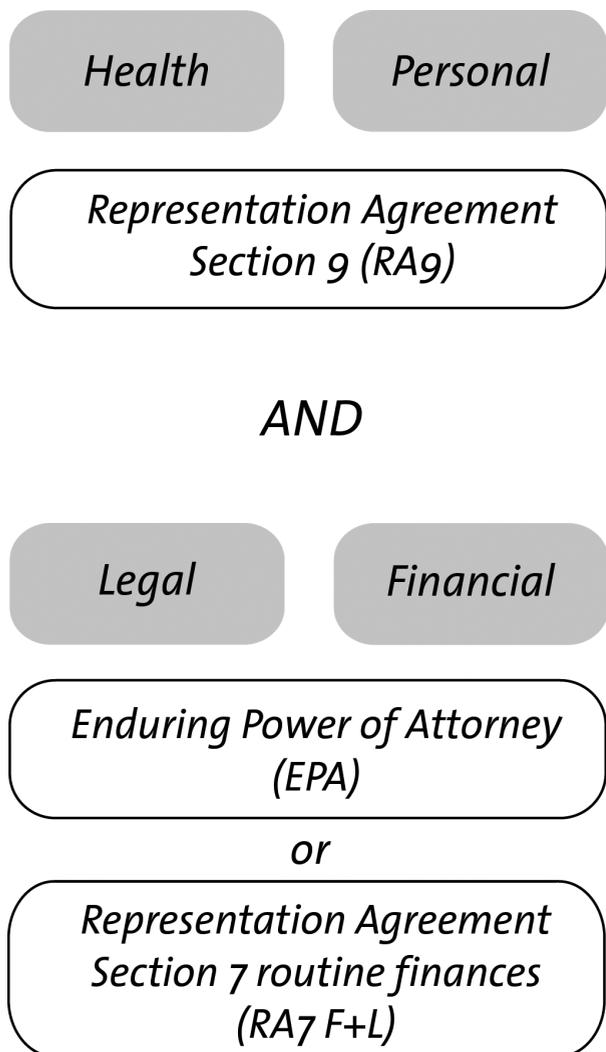
CAREGIVING – DON’T TRY THIS ALONE!

Are you on the FUTURE PATH?

People like John, who are on the future path, will make two separate legal documents to cover all life areas.

1. The Representation Agreement Section 9 (RA9) for health and personal care matters.
2. An Enduring Power of Attorney (EPA) for financial and legal affairs. (Some people can use the Representation Agreement Section 7 (RA7 F+L) instead of the EPA depending on their circumstances. An EPA covers more than the RA7 F+L.)

PLANNING FOR THE FUTURE PATH



The Representation Agreement Section 9 (RA9) requires that you are mentally capable of understanding its purpose at the time of making it. The RA9 authorizes someone – your representative – to do whatever is necessary for health and personal-care matters if you need assistance to make an informed decision or manage related tasks. It covers major and minor health-care matters and includes refusing health care necessary to preserve life (life support). The RA9 also covers personal-care matters such as living arrangements, including facility placement.

An Enduring Power of Attorney (EPA) is the most comprehensive legal document for financial and legal affairs. Some people might be able to use the Representation Agreement Section 7 for routine finances (RA7 F+L) instead of an EPA. You would make one of these documents, not both.

The RA7 F+L does not cover as much as the EPA, e.g. it does not cover dealing with real estate. There are six items you must understand to be considered capable of making an EPA. E.g., you must know what you own and the approximate value and that the people you appoint will be able to do anything you can with respect to your finances.

John is going to name his daughter and son in his RA9 and EPA.

NOTE: The term “Section 9” or “Section 7” in relation to a Representation Agreement refers to a part of the *Representation Agreement Act* that lists the powers or authorities a representative may have. Other parts or sections of the *RA Act* deal with other legal requirements or definitions. For example, Section 10 spells out the capability requirements for making an RA9.

Nidus has detailed information about what an EPA covers versus an RA7 F+L. Read further in this part.

Are you helping someone who is on the HELP FOR TODAY PATH?

If you are helping someone like Mary, whose mental capability is in question, they may make a Representation Agreement Section 7 to cover one or more life areas.

NEED HELP TODAY PATH

For example, Mary's dementia is advanced and she cannot meet the capability requirements to make an RA9 or an EPA. Mary cannot demonstrate that she understands the meaning of these documents.

Health

Personal

Legal

Financial

Representation Agreement Section 7 (RA7 All)

However, Mary may make a Representation Agreement Section 7 (RA7).

The RA7 looks at capability differently.

The *Representation Agreement Act (RA Act)* says Mary is presumed capable and it says that she may make an agreement under Section 7 even if she cannot make decisions independently or manage

her own affairs. The *RA Act* also recognizes all forms of communication.

We may not know all that Mary understands because she cannot demonstrate it in the same way as before. What is important is that the people she trusts and who know her are listening to her communication, which may now be expressed through her behaviour. Mary is always at the centre of decisions as the representative helps others know her wishes, values and beliefs. With an RA7 Mary will be treated with respect and dignity. This is referred to as supported decision-making.

Mary will make an RA7 All to cover all four life areas as she did not make an EPA or an RA9 when she was considered capable to do so.

John will be her representative, their daughter is the alternative, and their son is the monitor. With the RA7, John has authority to help Mary with major and minor health-care decisions, personal-care matters including facility placement and legal affairs. There are also a number of practical things he can do under routine finances including selling their jointly owned motorhome.

Nidus has detailed information about RA7 authorities and also the RA7 legal forms. Read further in this part.

Who can I name in my documents?

Most people appoint their spouse, a family member or a friend in their legal documents. Those appointed must be 19 years or older; they do not have to live in B.C. Some people may appoint a trust company or a credit union, but this can only be for financial and legal affairs (e.g. for the EPA). These companies will charge a fee.

There are some restrictions on who you can appoint. You cannot appoint:

- Someone who is paid or receives other compensation for providing health-care or personal-care services to you, such as your doctor or a paid caregiver, unless they are your spouse, parent or adult child.
- An employee of a facility where you live and who provides health-care or personal-care services to you such as an employee of an assisted living residence or care facility where you live unless they are your spouse, parent or adult child.

What are the roles available in a Representation Agreement?

A Representation Agreement has three roles that you can assign to the people you want to name. Each person must be 19 years or older.

1. Representative: a person who has authority to assist you or, if necessary, to act on your behalf. A representative also has authority to access information that you are entitled to.
2. Alternative: a person who is a backup in case the representative is not available.
3. Monitor: a person who acts as a support and safeguard to ensure the agreement is working for you.

NOTE: If you make an RA7 that includes routine management of financial affairs, an extra safeguard is required. You must: 1) appoint someone in the role of monitor; or 2) appoint at least two representatives to act jointly for finances. The only exception to this requirement is if the representative is your spouse.

What are the roles available in an Enduring Power of Attorney?

An Enduring Power of Attorney has two roles:

1. Attorney: a person (or institution such as a credit union or trust company) who has authority to do anything you can for legal and financial matters except make or alter your will. The term attorney does not refer to lawyer; it is the term for the person you appoint in your EPA.
2. Alternative attorney: a person (or institution) who is a backup in case the attorney is not available.

Where do I obtain the legal forms?

There is no required form that you must use for any of the legal documents. However, it would be difficult to draft a document on your own that meets the legal requirements.

REPRESENTATION AGREEMENT FORMS

Nidus provides RA9 and RA7 forms through its website (www.nidus.ca). Nidus forms are based on the requirements of the legislation as well as practical needs. Nidus collaborates with legal experts on its forms and has been helping people make and use Representation Agreements since 2000, when the law first came into effect.

You can also find Representation Agreement forms on the government website and in the Ministry of Health publication called *My Voice: Advance Care Planning Guide* (see Resources – item 90 – in this section). The government forms were produced by staff of the Ministry of Attorney General in September 2011. The government forms meet the legal requirements but do not take into account some important practical issues. Government staff did not consult with Nidus or the legal experts when they made up the forms.

A key difference between the Nidus and the government forms is that the Nidus RA forms include wording to allow the alternative to act on a temporary basis if the representative is not available. This reflects real-life situations (especially caregiver situations). A representative may be taking a break or on vacation, they may be ill, or out of cell phone range. The government forms only allow the alternative to step up if the representative is permanently unavailable. There are some other drawbacks that may affect the practical use of the government forms. Nidus prepared a chart to show the differences. See the heading on Resources (item 90) for information on using the Nidus website.

NOTE: Both the Nidus and government forms are simple and short. Unfortunately, some of the forms produced by legal professionals may be long and complicated. It is important that you and your representative can understand the form as well as any health-care provider who has to follow it.

The government also produced an Enduring Power of Attorney form. It is available at www.ag.gov.bc.ca/incapacity-planning/. Some financial institutions may expect your EPA to be signed by a lawyer or notary public, but they generally will not sign a form they did not draft.

Nidus recommends going to a legal professional to make your EPA. You have options that may not be addressed by the government EPA form.

Your EPA must be signed by a lawyer or notary public if the person you appoint might need to use it to deal with real estate on your behalf. If you fail to do this, someone may have to apply to court to get this authority which takes time and is costly.

See the heading on Resources (item 90) for information on locating a legal professional. Nidus has fact sheets and other information about the EPA that you can use to prepare for your meeting with a legal professional.

Frequently Asked Questions

1. If I am incapable, doesn't the doctor make health-care decisions for me?

No. In B.C. the law requires the doctor or other health-care providers to get consent. If you are incapable, the doctor will ask if you have a representative, appointed in a Representation Agreement. A doctor can only make the decision if you are incapable, facing a life-and-death situation and your representative or someone appointed by the court as committee (pronounced *kaw-mi-tay*) of person is not available. See the heading and chart further down (item 86) about Legal Requirements for Health-Care Consent.

2. If I have a living will, do I need a Representation Agreement?

Yes. A living will is not a legal document under B.C. legislation or any legislation in Canada. It is a term that describes a written document for expressing wishes, values, and beliefs about health care – usually for refusing care at end-of-life. A living will does not give anyone legal authority to carry out your wishes. This is the purpose of making a Representation Agreement, which is a legally enforceable document. A representative must follow your wishes when making decisions, whether you expressed them in a living will or verbally.

3. What about other forms such as a No-CPR/DNR Order or the MOST form?

The health system uses many forms to record information. The No-CPR/DNR Order and Medical Order of Scope for Treatment (MOST) form are not a consent. These forms record a discussion with a physician. If the physician's discussion was with a capable patient and the patient signed the form, it can be treated like a living will for a representative or a temporary substitute decision maker (TSDM) to follow. See the heading on Legal Requirements for Health-Care Consent (item 86).

Levels of Care is a form commonly used in residential care. It is not a consent. If it is signed by a resident who is capable, it can be used like a living will for a representative or TSDM to follow.

4. *What is advance care planning?*

Advance care planning is a term used by the health-care system. It encourages people to plan for health care, in case you become incapable. A Representation Agreement is the key document for health-care planning and it also covers personal-care matters.

The Ministry of Health produced a publication called *My Voice: Advance Care Planning Guide*. *My Voice* also includes the government forms for Representation Agreements. See the previous section and the question “Where do I obtain the legal forms?” (item 84).

5. *What is an Advance Directive?*

An Advance Directive (AD) is a legal document under B.C. legislation as of September 1, 2011. It is for writing an instruction about health care you do or do not want if you become incapable. An AD cannot appoint a person; it is only for writing an instruction and only about health care. You must be capable of understanding the health-care matters covered in order to make an AD.

The *Health Care Consent and Care Facility Admission Act* sets out the requirements for making an AD, but it does not provide any wording for instructions that can be relied on. You might talk with your family doctor about your AD and they may agree to follow the wording you have come up with for your instruction(s) – because you discussed it. However, you cannot be sure a hospital doctor, who does not know you, will follow it. They may interpret it differently.

An AD is not equivalent to making an RA9 or having a representative. An AD can only address specific health-care issues and if you become incapable, a health-care provider has to take it “as is.” If your instruction seems unclear, the health-care provider does not have to follow it.

You can make an AD as well as an RA9. Give your representative a copy of your AD and discuss it with them. If you are incapable, your representative will be able to have a discussion with the health-care provider to clarify the meaning of your instruction and say when it must be applied.

An Advance Directive form is provided by the Ministry of Health on page 50 of their *My Voice* guide. See Resources on Personal Planning (item 90) to locate the guide.

6. *Is my bank power of attorney enough?*

No. A bank EPA is not enough. You still need a general EPA or an RA7 with routine finances. A bank EPA only covers dealing with accounts at that institution. It is not useful for planning and does not help with other financial affairs such as dealing with Canada Revenue Agency, renewing car insurance, re-directing the mail and much more.

7. *If we have everything in joint names, do we still need an EPA or RA7 for financial/legal?*

Yes. Joint ownership is not enough; you still need an EPA or RA7 with routine finances. Joint ownership with right of survivorship applies when an owner dies, but it is a different story if one of the owners becomes incapable. If you and your spouse own a house jointly, and your spouse becomes incapable, you cannot sell the house unless your spouse made an EPA ahead of time. If there is no real estate but you have a jointly owned vehicle, you will need an EPA or RA7 with routine finances in order to sell it if your spouse is incapable.

Hope for the best, but plan for the worst.

85. THE DEFAULT SCHEME – WHAT HAPPENS IF YOU DO NOT PLAN?

If you do not make your own legal arrangements or you have gaps in your plan, and you become incapable, other laws or the court will determine who can act on your behalf. This is referred to as the “default scheme.” There are different approaches, depending on the life area involved.

Default for health care – Temporary substitute decision maker

If you do not have a Representation Agreement (RA9 or RA7) that includes the authority for health care, and you are considered incapable of informed consent, then a health-care provider will select one person to be your temporary substitute decision maker (TSDM). They will select the person – spouse, family member, close friend or in-law – according to the order listed in the *Health Care Consent and Care Facility Admission Act*.

A TSDM only has temporary authority. This means the person chosen from the list has authority to make health-care decisions only for the specific time a health-care provider needs consent. It does not allow the person to act as an advocate, like a representative appointed in a Representation Agreement can. There are also qualifications that a TSDM must meet. If a health-care provider disqualifies someone on the list, there is no way to appeal it. The Public Guardian and Trustee (a government official) is the last resort if no one else qualifies.

Your spouse, next of kin, friend or in-law has more authority and access to information as a representative (named in a Representation Agreement) than they do as a TSDM. You can be proactive by making a Representation Agreement.

Default for personal care

There is no separate default scheme in law to determine who may act on your behalf for personal care as there is for health care (TSDM). Consent is still required for personal-care matters but with no specific legislation it leaves more power in the hands of service providers. Only a Representation Agreement lets you give someone of your choosing the authority for personal-care decisions such as living arrangements, lifestyle preferences, diet, exercise and spiritual matters.

Default for health and personal care – Adult guardianship – Committee of person

Committee of person is rarely used. In this scheme, someone will hire a lawyer and apply to the B.C. Supreme Court to be appointed the adult’s committee (guardian) of person to take over the adult’s health-care and personal-care decisions. Someone might apply for this if the adult is in a permanent coma. (You can read more about committees under “Note” at the top of page 106.)

Default for financial and legal affairs – Adult guardianship – Committee of estate

Committee of estate becomes necessary if you are incapable of managing your financial and legal affairs and there is no EPA or RA7 with routine finances in place or the document is not sufficient.

Your financial and legal decision-making rights can be taken over in two different ways:

1. The Public Guardian and Trustee, a government official, can take over your affairs if a qualified health-care provider assesses you as incapable. You have 40 days to ask for a second assessment.
2. A spouse, family member or other person may apply to court for authority over your financial and legal affairs. The first step is for a judge to declare you mentally incompetent, and the second step is for the judge to decide who may act as your committee of estate (guardian).

NOTE: Court applications for committee of estate and/or committee of person generally take three to four months and cost \$5,000 - \$7,000. However, the greatest cost of adult guardianship is that an adult loses their civil rights: legally, they become a non-person.

86. LEGAL REQUIREMENTS FOR HEALTH-CARE CONSENT

What are the legal requirements for making health-care decisions?

Consent is a very important concept and must be done properly by health-care providers to comply with the law.

Legal authority to consent for health care matters

*YOU, if you are capable of informed consent. If not, then in this order.**

- 1. Your Representative** *authorized in a Representation Agreement, if no one*
- 2. An Advance Directive** *with applicable instructions, if none*
- 3. Temporary Substitute Decision Maker** *a person is selected by a health care provider to be your Temporary Substitute Decision Maker (TSDM), if no one*
- 4. The Public Guardian and Trustee** *a government official who acts as the last resort where no other authority is available.*

* Sometimes a spouse or family member might apply to BC Supreme Court to be appointed by a judge as your committee of person. Although this is rare, if a committee of person is appointed they would be at the top of the list to make health care decisions.

The *Health Care Consent and Care Facility Admission Act* spells out the requirements for health-care consent. It outlines the elements for informed consent and your right as a patient to give, refuse or withdraw (stop) consent. The law also spells out how consent is obtained if you are considered not capable of informed consent.

The third and fourth authorities on the list to the left are part of the default scheme.

You will notice that the living will, No-CPR/DNR order, the Medical Order for Scope of Treatment (MOST) form and the levels of care are not on the consent list. These forms were discussed previously at #3 under Frequently Asked Questions (page 103).

87. LEGAL REQUIREMENTS FOR FINANCIAL AUTHORITY

Legal authority to act for financial matters

YOU, if you are capable. If not, then one of the following:

- 1. Your Attorney** *appointed in an Enduring Power of Attorney.*
- 2. Your Representative** *authorized by a Representation Agreement Section 7 that includes routine finances.*
- 3. A Committee of Estate** *someone appointed by a judge (court order).*
- 4. The Public Guardian and Trustee** *as property guardian – based on assessment by a qualified health care provider.*

What is required for managing financial affairs?

Acting on someone's behalf for financial affairs is a big responsibility and the law spells out who has legal authority to do this.

The third and fourth authorities on the list to the left are part of the default scheme.

While a bank power of attorney gives someone authority to act an adult's behalf for finances it will only apply to the specific financial institution. It is not useful for planning.

88. REGISTERING YOUR PERSONAL PLANNING DOCUMENTS

After you have completed your planning documents, you can register them with the online Personal Planning Registry™. The registry provides secure storage with 24/7 access.

The registry service lets you store important information and a copy of document(s) you made. You can register a Representation Agreement, Enduring Power of Attorney, Advance Directive, living will/advance care plan wishes, Notice of Revocation and more.

Go to www.nidus.ca/registry and click Online Registry in the right sidebar. Here is a screenshot of the Personal Planning Registry website home page with explanation.



1. Account holders access their registry account to view, update, or add registrations.
2. Individuals (account holders) can create their own registry account as self-registrants.
3. Not sure if mom or dad made any plans? Check to see if they might have a registry account.
4. Sign into Shared Access if an account holder gave you viewing access to their registration.
5. Authorized notaries public and lawyers can set up accounts and register documents for clients.
6. Third parties such as the Public Guardian and Trustee, financial institutions, health-care institutions and government agencies can be authorized to view information and documents.

When you fill out the registration forms, you can allow authorized third parties to search for your registration, e.g. hospital staff could search the registry if you were unconscious in order to get a copy of your document, if you stored one, and contact your representative.

There is a one-time fee of \$25 to register your first document. You can register additional documents for \$10 each. You can print wallet cards for free. Keep the card in your wallet and help others to know you are registered. The card contains your Nidus ID for easy reference.

89. TIPS FOR SAFEKEEPING AND USING PERSONAL PLANNING DOCUMENTS

The original of your document is proof of authority. You can make photocopies for others. Your representative or attorney may need to show the original.

Keep the original document in a safe but accessible place. Many people keep their original documents at home or with their representative or attorney. It is not advisable to keep your documents in a safety deposit box.

If an address or phone number changes, do not make this change on your original document. You can make changes on future photocopies. You can also update this information in the registry (there is no charge to update contact information in the registry).

Other resources you may need to use

Nidus has numerous resources you or those you appointed may need to use. Go to www.nidus.ca
> Information – select Resources under Representation Agreement or Enduring Power of Attorney.

- **Revoking/cancelling a personal planning document**
Making a new Representation Agreement or Enduring Power of Attorney does not automatically revoke (cancel) the previous one. Nidus has information and forms for making a Notice of Revocation.
- **Role of a representative and role of an attorney**
Those you appointed must keep records and follow other rules. Read about their responsibilities and rights and give them a copy of these fact sheets.
- **Lifespan of a Representation Agreement/Enduring Power of Attorney**
Learn about the circumstances when your document(s) will end.
- **Comparison chart for EPA and RA7 F+L**
Review this chart to learn about the key differences in what an EPA covers versus an RA7 F+L.
- **Resigning as a representative or attorney**
You can resign if you are a representative or alternative appointed in a Representation Agreement or an attorney or alternative appointed in an Enduring Power of Attorney. Nidus has information and forms.
- **Information in Chinese and Spanish**
Nidus has basic information on Representation Agreements and Enduring Power of Attorney in these languages.
- **Refusing Health Care: What are My Rights?**
This fact sheet is on the Nidus website in the Health-Care Consent Section. Go to www.nidus.ca > Information > Health Care Consent > Resources.

90. RESOURCES ON PERSONAL PLANNING

Nidus Personal Planning Resource Centre and Registry is a non-profit, charitable organization that has been educating British Columbians on the importance of personal planning since 1995. Nidus specializes in Representation Agreements.

Nidus provides resources for self-help through its website. See the chart on the next page on how to get started. Click on the button or heading that best fits your situation. You will find information and links to the Representation Agreement forms (RA9 and RA7) as they apply to the specific situation. You can also read about the difference between the Nidus RA forms and the government forms.

Get started by clicking on a heading below that best describes your situation.

Helping a Relative with a Disability

My mom is my legal representative

In British Columbia, personal planning is for all adults, based on their need for support not their competence. This is important for my son, who does not speak. As his legal representative I can help him be his own person and protect his rights. This provides an alternative to adult guardianship which would remove his rights and declare him a non-person.

I'm Planning for the Future

I'm not waiting for a crisis

Through personal planning you can make your own legally enforceable arrangements with those you trust. This prevents the government or others you would not want from becoming involved in your personal and private affairs. Personal planning lets you stay in control.

Caring for an Older Adult who Needs Your Help

It's about dignity and respect

Personal planning gives us peace of mind. As a caregiver, my main concern is to ensure quality-of-life to the end-of-life at home or in a facility. And if something happens to me, I need to know someone else can carry on with no disruption in care for my loved one.

Nidus is a Latin term for nest: a symbol of safety, support and self development.

Nidus also offers presentations. Sign up for one of its free webinars. These are held regularly each month. Go to www.nidus.ca > Self-Help > Presentations.

You can access personal help from Nidus by appointments in person or phone. Go to www.nidus.ca > click on BOOK NOW in the right sidebar. Anyone can book the appointment for you.

The B.C. Ministry of Health has a great deal of information and resources on its website (www.gov.bc.ca/advancecare) to promote advance care planning, including information in Chinese (Simplified) and Punjabi and for First Nations communities.

The Public Guardian and Trustee of British Columbia has a booklet on adult guardianship (also called committeeship): *It's Your Choice – Personal Planning Tools* available in English, Chinese (Traditional), Filipino, Punjabi, Spanish and Vietnamese at www.trustee.bc.ca/reports-and-publications/Pages/default.aspx#Adult_Guardianship.

Legal professionals (lawyers and notaries) can offer advice. To locate a lawyer, contact the Lawyer Referral Service (604-687-3221). Lawyers who practice in the areas of wills and estates will be familiar with the Enduring Power of Attorney. To find a notary public near you, phone 604-681-4516 or search www.notaries.bc.ca.

Access ProBono (604-424-9600) operates a free legal clinic for personal planning documents for terminally ill adults and low-income seniors. E: willsclinic@accessprobono.ca

PART XI. END-OF-LIFE CARE

One of the most difficult times for anyone is when a loved one is dying. A number of services are available to support the family caregiver during this difficult time as well as the dying person to ensure they have the kind of death consistent with their values.

91. B.C. MINISTRY OF HEALTH – END-OF-LIFE CARE SERVICES

As stated at www2.gov.bc.ca/gov/content/health/accessing-health-care/home-community-care/care-options-and-cost/end-of-life-care-and-palliative-care:

End-of-life care is supportive and compassionate care that focuses on comfort, quality of life, respect for personal health-care treatment decisions, support for the family, and psychological, cultural and spiritual concerns for dying people and their families. Palliative care is specialized medical care for people with serious illness – whatever the diagnosis. Care can be provided wherever the client is living, whether at home, in hospice, an assisted living residence or a residential care facility.

End-of-life and palliative care services aim to preserve an individual’s comfort, dignity and quality of life as their needs change, and to offer ongoing support for family and friends. These services include the following: care coordination and consultation; pain and symptom management; community nursing services; community rehabilitation services; home support; respite for the caregiver; and residential hospice care.

End-of-life care may also be called supportive care, palliative care or symptom management.

In VCH, the Nancy Chan Ambulatory Clinic through the home hospice team in Vancouver offers psychosocial and spiritual support to clients and loved ones in Vancouver. A caregiver education series aims to support caregivers providing care to loved ones living with a life-limiting illness. Sessions have a focus on issues specific to end-of-life care. A mindfulness group to cope with stress is available for clients and caregivers connected with palliative care in Vancouver. Mindfulness meditation can be a useful resource for clients and caregivers by providing a space to quiet the mind and foster a sense of peace. Individual and group bereavement services are also provided to loved ones who have experienced a death from illness. This includes bereavement information evenings that are one-time sessions open to all grieving loved ones residing in Vancouver. Additionally, a bereavement clinic offers grief support for individuals whose loved ones received palliative home care and have an increased bereavement risk for complicated grief responses.

How do I arrange for end-of-life care services?

If you know someone in need of these services, you can contact the Home and Community Care office of their HA (see 8a for phone numbers). Alternatively you can have the health-care professional of the dying person, e.g. home-care nurse or doctor, make the referral.

More about end-of-life care from 2014 www.fraserhealth.ca/your_care/hospice_palliative_care:

Are palliative and hospice care the same thing?

It depends; the terminology is a bit confusing. In Canada, we tend to use the terms interchangeably and together to refer to a specific approach to care for people who have a life-limiting illness or are terminally ill. Hospice/palliative care offers services to help relieve suffering and improve quality of

life for people with a life-limiting illness or those grieving a loved one. Hospice/palliative care becomes appropriate when treatment no longer supports quality of life. This approach involves a focus on pain and symptom management, care and understanding, and comfort and caregiver support to enhance the quality of both living and dying.

One reason the terminology is confusing is that hospices are places (a unit set aside in a hospital or a dedicated building) where hospice/palliative care is practiced. Sometimes end-of-life care at home may not always be possible. If you require publicly subsidized residential hospice palliative care, you will pay a fixed daily rate of \$32.50 per day. If payment of the fixed daily rate would cause you or your family serious financial hardship, or means you (or your spouse, if applicable) would be unable to maintain the family home or unit, you may be eligible for a reduced rate. For more on costs or eligibility for short-term residential care services (which includes residential hospice palliative care), see www2.gov.bc.ca/gov/content/health/accessing-health-care/home-community-care/care-options-and-cost/short-term-residential-care.

Transitioning to hospice/palliative care, regardless of where it occurs, can be extremely difficult. An ill person and their family may have spent many months or years concentrating on curative treatment. Now your attention turns to a different kind of treatment.

What is hospice/palliative care?

People who choose hospice/palliative care have made the decision with their doctor and family to move away from unsuccessful attempts at getting better to palliative, or comfort, care.

Hospice/palliative care:

- Does not hasten death.
- Does not delay death.
- Improves the quality life by offering comfort and dignity.
- Offers comfort, emotional and spiritual supports to the person and family.
- Allows people to continue receiving treatments that slow the progress of the disease and reduce uncomfortable symptoms.
- Provides a variety of services designed to provide care and comfort.

Medical intervention is confined to symptom management, including pain control, as opposed to trying to cure, which, of course, is not always possible.

Many people mistakenly associate hospice/palliative care only with sorrow. However, most people's experiences of this stage of life and dying include times of joy, peace and heart-warming closeness. People often comment that hospice experiences, although involving a death, give them a deeper understanding of life.

92. B.C. PALLIATIVE CARE BENEFITS PROGRAM

The B.C. Palliative Care Benefits Program supports B.C. residents of any age who have reached the end stage of a life-threatening illness and want to receive medically appropriate palliative care at home. "Home" is wherever the person is living, whether in their own home, with family or friends, in a supportive or AL residence or hospice that is not a licensed RC facility covered under PharmaCare Plan B.

The intent of the B.C. Palliative Care Benefits Program is to allow patients to receive palliative care at home rather than be admitted to hospital; it gives palliative patients access to the same drug

benefits they would receive if they were in hospital, and some medical supplies and equipment from their HA. The B.C. Palliative Care Benefits Program includes full coverage of approved medications (PharmaCare B.C. Palliative Care Drug Plan P) and equipment and supplies (upon referral to and assessment by the local HA of the dying person).

B.C. residents who are enrolled in the Medical Services Plan (MSP) can request that their physician assess their eligibility for the program and submit an application on their behalf. A reply should come quickly.

93. CAREGIVER'S GUIDE: A HANDBOOK ABOUT END-OF-LIFE CARE

This 130-page guide provides family caregivers with medical and nursing information they can use to support their loved ones in clear, easily understood language. It also helps them understand the journey upon which a dying person has embarked and to become an effective, informed member of the palliative care team providing essential physical, spiritual, and emotional support. The guide is co-published by The Canadian Hospice Palliative Care Association and The Military and Hospitaller Order of St. Lazarus of Jerusalem.

You can download the English edition at:

67.227.227.84/~st1a2013/images/lazarus_pdf/caregivers_guide.pdf or order paper copies of the guide in English, [French](#), [Inuktitut](#) and [Chinese](#) by emailing info@chpca.net, online at www.market-marche.chpca.net or from the Canadian Hospice Palliative Care Association (toll free: 1-800-668-2785 x 221).

94. HOSPICE SOCIETIES

Across B.C. there are many local hospice societies that offer a variety of caring and compassionate services to individuals who are dying and their family and friends. They also offer bereavement support for after death. A list of the local groups can be found on the website of the BC Hospice Palliative Care Association (604-267-7024): www.bchpca.org/directory-of-members/.

95. CANADIAN VIRTUAL HOSPICE

This website (www.virtualhospice.ca) has information on all aspects of caregiving to a dying loved one, from the day-to-day practicalities to the spiritual challenges. It includes discussion forums, videos, and an Ask the Professional section. The website was created with palliative care in mind, but much of the information is also useful when caring for people who are elderly or who have been diagnosed with a serious, chronic or life-limiting health condition. This website was created by palliative care leaders to address some of the gaps in palliative care information in Canada. It is funded by the Winnipeg Regional HA and CancerCare Manitoba and has been ranked as one of the best health websites in Canada by the Canadian Association of Health.

96. CANADA EMPLOYMENT INSURANCE (EI) COMPASSIONATE CARE BENEFITS

Compassionate Care Benefits (toll free: 1-800-0-Canada) are EI benefits paid to persons who have to be away from work temporarily to provide care/support to a family member who is gravely ill and who has a significant risk of death within 26 weeks (six months). Up until January 2, 2016, a maximum of six weeks of compassionate care benefits may be paid to eligible people. Good news: as of January 3, 2016, a new enhanced benefit will allow claimants to extend the duration of compassionate care benefits from the current six weeks to 26 weeks (six months). The benefits can

also be taken within an expanded period of 52 weeks (up from 26 weeks) and can be shared between family members as per <http://news.gc.ca/web/article-en.do?nid=973699>.

If you are unemployed and already receiving EI benefits, you can also apply. To be eligible for compassionate care benefits, you must show that your regular weekly earnings from work have decreased by more than 40 per cent and that you have accumulated 600 insured hours of work in the last 52 weeks, or since the start of your last claim (this period is called the qualifying period). Self-employed Canadians can also apply for EI special benefits if they are registered for access to the EI program.

Adapted from www.servicecanada.gc.ca/eng/sc/ei/benefits/compassionate.shtml

97. CANADA BEREAVEMENT LEAVE

An employee is entitled to up to three days of unpaid leave on the death of a member of the employee's immediate family, as per the Canada Labour Code. This leave may be for purposes other than to attend a funeral: www.labour.gc.ca/eng/standards_equity/st/pubs_st/berereavement.shtml.

98. HELPFUL INFORMATION ABOUT FUNERALS

The Funeral Services Association of BC (toll free: 1-800-665-3899; www.bcfunerals.com) provides a free booklet called *Helpful Information About Funerals*. The association also offers a great deal of information on issues related to after a person dies, such as what steps to take when a death occurs, death certificates, burial and cremation, funeral homes, planning a meaningful service, being an executor, and more. The booklet is not available on their website; phone for a free copy.

99. BEREAVEMENT

99a) COPING WITH GRIEF

The reactions to a loss are referred to collectively as grief. To grieve or mourn is to experience a process which unfolds over a length of time. Upon learning of the death of a loved one, each of us embarks on a journey of healing. Although at first it is characterized by painful feelings, once the realization of the death comes, the therapeutic process of bereavement begins. Shock and denial will overwhelm the bereaved individual before he or she begins what is usually called the "grief work."

Grief is highly complex, but an absolutely normal reaction to a death. It affects each person differently. As their relationship was unique with the person who passed away, so too will be the way in which they grieve. Because grief is something that is so personal, it cannot be avoided by ignoring it or by frenetic activity. The grieving process must occur as there is no way around it; grieving is nature's way of healing.

Symptoms of grief include overwhelming sadness, inability to sleep, changes in appetite, quick to cry, lack of desire to do anything, confusion, feeling like you are going "crazy," forgetfulness, depression, irritability, inability to concentrate, and more.

How to ease grief: allow yourself to mourn; realize your grief is unique; talk about your grief; expect to feel a multitude of emotions; allow for numbness; be tolerant of your physical and emotional limits; develop a support system; make use of ritual; embrace your spirituality; allow a search for meaning; treasure your memories.

Adapted from www.bcbereavementhelpline.com/grief

99b) BC BEREAVEMENT HELPLINE (BCBH)

604-738-9950

This free, confidential service connects you to grief support services throughout B.C. BCBH assists the bereaved and their caregivers in coping and managing grief. Your call is answered by a caring, compassionate volunteer familiar with grieving and grief support groups in B.C.

Bereavement support groups provide a safe place for participants to share and support each other. Facilitators provide information about grief and encourage individuals to speak about their loss as they feel comfortable. Ask about the ones in your community.

One of its brochures, *Ten Things to Know About Grief*, is also available in Chinese, Farsi, Korean, Punjabi, Spanish, Tagalog and Vietnamese at www.bcbereavementhelpline.com/resources.

99c) CENTER FOR LOSS & LIFE TRANSITION

www.centerforloss.com

Headed by Dr. Alan Wolfelt, a world-renowned thanatologist (a specialist in study of the medical, psychological, and sociological aspects of death and the ways in which people deal with it), this U.S. centre has a website with information for those dealing with loss and grief.

99d) HOSPICE SOCIETIES

Across B.C. there are local hospice societies that, in addition to the services they offer to individuals who are dying and their family and friends, also offer bereavement support. See item 94 for more information.

99e) LIVING THROUGH LOSS COUNSELLING SOCIETY OF B.C.

604-873-5013 www.ltlc.bc.ca

This society offers individual and group loss counselling in Vancouver. There are also articles about grief on its website.

99f) LOWER MAINLAND GRIEF RECOVERY ASSOCIATION

604-696-1060 www.lmgr.ca

This association organizes grief support groups in Vancouver and the North Shore.

At some time, in some way, we must all face the end of life.
And most of us share a common hope: that when death comes
to us or to a loved one, it will be peaceful and dignified.

We hope to be surrounded by those we love,
feeling safe, comfortable and cared for.

Taken from the 2012 Burnaby Hospice Society website

PART XII. ADVOCACY GROUPS

While information and referral services exist to inform and refer people to services, advocacy groups work to help people receive services to which they are entitled, but for some reason cannot access. They also work to change public policy to improve the quality of life for older people. Advocacy groups working hard on behalf of seniors and their unpaid caregivers include: BC Health Coalition; Canadian Caregiver Coalition; Canadian Centre for Policy Alternatives – Seniors Care Project; CARP; Council of Senior Citizens Organizations of British Columbia; Seniors Community Planning Tables; Municipal Seniors Advisory Committees; and many more.

If you need help advocating for the person receiving your care, these groups might be able to help.

100. MLAs AND MPs

Having problems accessing provincial services? Contact your MLA who you find through www.leg.bc.ca/mla or call Service B.C. (604-660-2421) for your MLA's phone number.

For problems accessing federal programs, contact your local MP's office via www.parl.gc.ca/Parliamentarians/en/members or call Service Canada (toll free: 1-800-622-6232) for your MP's phone number.

101. OFFICE OF THE OMBUDSPERSON

1-800-567-3247 www.bcombudsperson.ca

The B.C. Ombudsperson is an officer of the provincial legislature, independent of government and political parties, and responsible for ensuring administrative practices and services of public agencies are fair, reasonable, appropriate and equitable.

If you think a provincial government ministry or public agency (e.g. a HA or hospital, ICBC, MSP, the Ministry of Health, Pharmacare, or the Public Guardian and Trustee), has treated you unfairly, the B.C. Ombudsperson may be able to help. The role of the office is to impartially investigate complaints to determine whether public agencies have acted fairly and reasonably, and whether their actions and decisions were consistent with relevant legislation, policies and procedures. The office also investigates complaints regarding the failure of HAs to enforce standards of care in RC facilities. Services are free.

You should first try to resolve your complaint directly with the public agency involved. Many public agencies have an internal process for handling complaints. If you've tried resolving the problem and still feel that you've been treated unfairly, contact the Office of the Ombudsperson by phone weekdays; 8:30 a.m. - 4:30 p.m., or use the online complaint form: www.bcombudsperson.ca/complaints/make-online-complaint.

Note: As the result of receiving a high number of complaints, past B.C. Ombudsperson Kim Carter issued two reports investigating the care of seniors in the province:

Part 1 of *The Best of Care: Getting it Right for Seniors in British Columbia (December 2009)* contains three findings and ten recommendations on rights for seniors in RC, access to information

about RC and the role of resident and family councils. Some of the points in the report can help point out what constitutes good care and can assist you in creating a list of considerations.

Part 2 of *The Best of Care: Getting it Right for Seniors in British Columbia (February 2012)* has 143 findings, 176 recommendations, and focuses on home and community care issues, home support services, AL and RC, including adequacy of information available, access to services, standards of care, complaint processes, monitoring and enforcement.

The reports were presented to the Ministry of Health, Ministry Responsible for Housing and the five regional HAs in B.C. (These are FH, Interior Health, Northern Health, VCH, and Island Health.)

Both reports are at www.bcombudsperson.ca/seniors. Translated extracts of the seniors' reports are available in Punjabi and Chinese (Simplified and Traditional).

Note: Shortly after the release of Kim Carter's second (2012) report, B.C.'s Ministry of Health issued *Improving Care for B.C. Seniors: An Action Plan* (www.gov.bc.ca/seniorsactionplan). It outlines the ministry's actions focused on addressing many of the ombudsperson's findings and recommendations. The plan for improving the home and community care system has six themes that address system-wide change through key actions: Concerns and Complaints; Information; Standards and Quality Management; Protection; Flexible Services; and Modernization. The *Seniors Action Plan Progress Report* can be found at the above website under What We've Done.

102. OFFICE OF THE SENIORS ADVOCATE

Toll free: 1-877-952-3181 www.seniorsadvocatebc.ca

For years various groups called for a provincial seniors advocate; in her February 2012 report, Former B.C. Ombudsperson Kim Carter also recommended the appointment of a B.C. advocate for seniors. Following consultations with the public and stakeholders across the province, the B.C. government introduced the *Seniors Advocate Act* in March 2013, making B.C. the first province in Canada to pass legislation to create an Office of the Seniors Advocate: www.leg.bc.ca/39th5th/3rd_read/gov10-3.htm.

Some suggest the *Act* is weak as it limits the independence of the office since "...it is part of government rather than independent of government like the B.C. Ombudsperson, or the Representative for Children and Youth. Both those positions are independent of government and report to the B.C. Legislative Assembly directly" according to a February 20, 2013 news release issued by the Hospital Employees' Union. At the same time, the B.C. Health Coalition expressed its frustration that the legislation "...will not create an advocate that is independent of government..." and the advocate will be limited to serving at the discretion of government and this will hamper the watchdog role it ought to have.

In March 2014, Isobel Mackenzie was appointed as B.C. Seniors' Advocate, Canada's first person to have that provincial role. Like B.C.'s representative for children and youth (Mary Ellen Turpel-Lafond), Mackenzie is expected to keep an eye on the government care system, but for seniors.

The Office of the Seniors Advocate (it is the only office of its kind in Canada) monitors seniors' services, promotes awareness of seniors' issues and works collaboratively with seniors, families, policymakers, service providers and others to identify solutions, and makes recommendations to government about system-wide issues facing seniors in five key areas: health care; personal care; housing; transportation; and income support.

The Office is also a go-to resource for seniors' information and referral.

Since the appointment of Isobel Mackenzie, these reports have been published:

- October 2014: *The Journey Begins, Together We can Do Better*
- March 2015: Seniors Advocate Survey Results *Bridging the Gaps*
- April 2015: *Placement, Drugs, Therapy Report*
- May 2015: *Seniors' Housing in B.C., Affordable, Appropriate, Available*
- August 2015: *2014-15 Annual Report of the Office of the Seniors Advocate*
- September 2015: *Caregivers in Distress: More Respite Needed*

PICK YOUR BATTLES

Expect numerous challenges – big and small – will come your way as you help to care for a person with growing frailty. You won't solve every problem – so choose your battles carefully as you decide what to devote energy to.

PART XIII. LIST OF WHERE IMPORTANT INFORMATION / PAPERS ARE KEPT

A great gift in a family caregiving situation is to have important papers in order before any critical news or emergency (e.g. falling and breaking a hip, a heart attack, a stroke, a diagnosis of cancer or dementia) occurs. Accordion file organizers hold a lot of papers and easily expand; if there are not a lot of documents, you may prefer a binder. Whatever your system, the important thing is to have a record of important information, and list where important papers are kept. Be sure those close to you know where your file organizer or binder is kept.

Throughout this document you have read about the importance of having certain information at your fingertips. Below is a beginning of the kind of information records that could be extremely helpful.

I. PERSONAL INFORMATION

1. Full legal name, birth certificate or date and place of birth
2. Social Insurance Number
3. BC CareCard number (also known as the “Gold Card” for seniors)
4. Full legal name of spouse and marriage license /separation/ divorce papers
5. Primary caregiver name and contact information
6. Other family members
7. Friends and nearby neighbours
8. Faith group
9. Military history, affiliations and papers (including discharge papers)
10. Other personal information

II. HEALTH / MEDICAL INFORMATION

11. Primary care, also known as family physician and medical specialists
12. Specialist physicians
13. Medical records noting allergies, illnesses, hospitalizations, surgeries, immunizations
14. Medications list (prescription, over-the-counter, vitamins, herbs, tonics). Note the name of each medication, dosage, when and how it is taken, reason for taking, date it was started (and, if use has stopped, the end date), notes on any side effects; who it was prescribed by, and the pharmacy it comes from.
15. Dentist and/or denturist and other dental specialists, e.g. hygienist, periodontist
16. Local health authority Home and Community Care office, and case manager name
17. Public (government-subsidized) home support contact
18. Private home support agency
19. HandyDART client number
20. Other health/medical information

III. HOUSING INFORMATION

21. Full address of home, and contact information for who has house keys
22. Mortgage papers (if owned); or rental agreements and landlord/building manager contacts
23. Insurance policies and carriers
24. Utility companies (gas, electric, phone, cable and Internet)
25. Home alarm contacts including personal emergency response systems, e.g. Lifeline

26. Property taxes statements
27. Lawn and garden care and snow removal personnel
28. Safe location and combination/keys
29. Other housing information

IV. FINANCIAL INFORMATION

30. Accountant
31. Bank accounts with bank locations, types of accounts, account numbers
32. Canada Revenue Agency: most recent tax return and notice of assessment
33. Credit card information including 1-800 numbers
34. Financial advisors
35. Insurance records for health, home, life, long-term care, vehicle: companies and contact information; policy numbers; beneficiaries as stated on the policies
36. Investments (certificates of deposit, stock certificates, bonds, notes, savings bonds)
37. Government pensions (OAS, CPP, GIS, BC Supplement)
38. Private pensions
39. Safety deposit boxes: contents; locations; location of keys
40. Other financial information

V. LEGAL INFORMATION

41. Lawyer or notary
42. Citizenship papers
43. Vehicle registration
44. Deed and titles to all property
45. Loan/lien information (who holds them and if there are any death provisions)
46. Trusts
47. Personal planning documents (as explained in Part X. Legal Issues in Family Caregiving)
48. Will
49. Other legal information

VI. IN THE EVENT OF DEATH

50. Instructions for funeral services and burial (if prearrangements have been made, name and location of funeral home, cemetery and plot information)
51. Up-to-date will in a safe place (inform executor and family where the will is located; you don't need to disclose contents)
52. Other in event of death information

**In the ordinariness of your caregiving lies
something more: sacredness.**

James E. Miller

HUMONGOUS THANKS FROM THE HANDBOOK COORDINATOR!

A publication like this could never be written and distributed throughout the Lower Mainland by just me. I am hugely indebted to the following who supported the editions with their encouragement, help with fact checking, and assistance with distribution, so family caregivers of the frail elderly could have access to it. First debt is to United Way of the Lower Mainland which has supported many Family Caregiver programs in various forms over the years. Next debt is to my fellow gerontologist Linda Comba, who supervised me the six years that I coordinated the Burnaby Seniors Outreach Services Society (BSOSS) Family Caregiver Program, funded by the United Way. Linda took a risk when I told her in 2008 that I wanted to do a bit of a “mind dump;” she okayed my writing what became an annual Burnaby Family Caregivers Handbook. The first issue was a big 24 pages! This Lower Mainland edition in your hands now came into being when in 2012, the then Planner, Strategic Initiatives (Seniors) for United Way – Beverley Pitman, PhD, asked if I might write a larger publication with a wider geographic scope. It was successful beyond our dreams and we hope this second edition – kindly funded by an anonymous United Way donor - will meet unmet needs.

I am also indebted to: Barb Maclean, Family Caregivers of British Columbia; Barbara Lindsay, Dorothy Leclair, Lori Kelly and Rebecca Morris, Alzheimer Society of BC; Carol Dickson, Volunteer Richmond; Carolline Thindal, FH Delta & White Rock/South Surrey Community Geriatric Mental Health Services; Charito Gailling, past VCH VC Seniors Community Developer; Cheri Rauser, Virtual Health Librarian; Cheryl Nagle, Steveston MD; Evan Kellett, Macdonalds Home Health Care; FH Burnaby Home and Community Care office; Frances Thomson, Community Librarian Fraser Valley Regional Library; Geriatric Emergency Nurse Clinicians Cathy Sendeki, Maureen Chant, and Wendy Magnusson; Heather Treleaven, Seniors Network Coordinator, Ridge Meadows Seniors Society; Hospital Social Workers Alex Harper, Gerry Diccico, Elisse Tan, Jasmin Painchaud, and Naoko Watanabe; Joanne Roemer, Community Services, City of Port Moody; Joanne Taylor, Nidus Personal Planning Resource Centre and Registry; Julie Shaver, B.C. Ministry of Health; Judith McBride, Surrey Community Seniors Planning Table; Kara-Leigh Bloch, Seniors Services Society; Karyn Davies, North Shore Community Resources; Kay Dennison, Delta Seniors Planning Team; Krista James, Canadian Centre for Elder Law; Leona Cullen, Burnaby Division of Family Practice; Linda Western, Tri-Cities; Lisa Duong, VCH VC Geriatric Rapid Access Clinic; Lisa McCune, Provincial Survivorship Program, B.C. Cancer Agency; Louise Ghoussoub and Ruth Marzetti at bc211; Mary Ong and Sue Uremovich, Community Volunteer Services for Seniors; Miriam Larson, Gerontologist; Nicole Smith, 8-1-1 Taxonomist; Renee Strong, Capilano Community Services; Robyn McGuinness, Lionsview Seniors Planning Society; Sarah Galuska, VCH VC Family Caregiver Program; Shihori Scott-Moncrieff, Tomari Gumi; Sepia Sharma, FH Delta; Susan Burns, Westside Seniors Working Group; Suzanne Taylor, Seniors Come Share Society; Tasha Lorenzen-Ewing, Gerontologist; VCH Community Engagement Advisory Network staff Belinda Boyd and Saori Yamamoto; VCH Integrated Primary & Community Care staff Cheryl Rivard and Joanne Douglas; VCH’s Richmond IPCC Steering Committee (chair, Dr. Robert McKenzie) members.

On a very personal note... While writing this I developed my own team/circle of friend (unpaid) caregivers when I was diagnosed with thyroid cancer that has metastasized to my lungs and some lymph nodes (a slow growing non-killer cancer that “will have to be managed”). My friends immediately stepped up to the plate with offers to help and I can’t say thank you enough to Anthony Kupferschmidt, Cheri Rauser, Diane Ballash, Joanne Taylor, Isabell Doucette, Merrily Tan and Tasha Lorenzen-Ewing, for all their kind offers of help at a distressing time. I also have to thank my professional carers: Dr. Tong Vi Lam, Emergency M.D.; and R.N. Mike (human companion to canine Raj) at VGH Emergency Department; VGH staff on 12B Respiratory; and Dr. Daniel Worsley, Nuclear Medicine Specialist; B.C. Cancer Agency’s Survivorship Nurse Practitioner Kristina Morrison; and last but certainly not least my “most responsible physician” Dr. Mira Keyes, Radiation Oncologist and the team at B.C. Cancer Agency.



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