


METRO VANCOUVER

Family & Friend Caregivers

Information and Resource Handbook

2013/14



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



This directory of information and resources for family and friend (unpaid) caregivers is designed to connect you to community resources – government, non-profits, and businesses – for yourself and your elderly care recipient to reduce caregiver stress, reduce isolation, and improve quality of life for yourself and your loved one.



United Way
Lower Mainland

FOREWORD

United Way of the Lower Mainland is pleased to place this copy of the *Metro Vancouver Family and Friend Caregivers Information and Resource Handbook* 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 BC 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 BC – 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 Dr. Jean Kozak envisioned and advocated for in 2012. For family and friend caregivers and others at the community level, it should knit together the two health authorities in useful ways.

This Handbook is the work of Katherine Willett, a Lower Mainland-based gerontologist and elder caregiving consultant, whose extensive knowledge about caregivers and their needs – hence, the information and resources they're looking for – is based on more than 15 years' experience working closely with family and friend caregivers in the region. Katherine is also an I&R – or information and referral – specialist whose encyclopedic knowledge of caregivers and their needs has informed efforts to develop a provincial strategy for caregivers in BC. She represents the interests of seniors and caregivers in several formal advisory capacities in the region's public health and social service sectors. And she leads a popular, longstanding caregivers' education program in Burnaby noted for its successful outreach to multicultural caregivers.

We plan to update this Handbook on a regular basis. Please use the contact information provided on the last page to forward new information, revisions and corrections, as well as general comments. Your contributions will be appreciated.

Metro Vancouver Family and Friend Caregivers Information and Resource Handbook can be found on United Way's website at www.uwlm.ca/reports-and-resources.

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September 2013

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, assisted living or a residential care 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 bathing, cleaning, cooking, dental care, dressing, emotional support, exercising, feeding, finances, foot care, grocery shopping, grooming, home repairs, hospital visits, housing, laundry, legal issues, making the home safe, medications, pain management, socializing, toileting, transporting, spiritual care, end-of-life care, coordinating all these things...and more.

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 are also under 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 suffer.

Disclaimer: This guide is intended for information purposes only and is not intended as a substitute for competent financial, legal, medical or other professional counsel. No representation is made as to the accuracy of the information herein provided, as portions of the information contained in this guide may change from time to time. Information about organizations has been provided by the organizations or acquired from public sources. No endorsement of the organizations or their services is implied. Other information resources may also be available. Individuals using the information herein provided do so at their own risk and assume full liability for any damages or loss arising therefrom.

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Welcome to the *Metro Vancouver Family & Friends Caregivers Information and Resource Handbook* 2013-2014.

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 numerous challenges and significantly change your life. By understanding what government services are available to you and your care recipient, and by tapping into non-profit society and business community 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 four points:

1. TALK WITH THE FAMILY AND FRIENDS YOU ARE CARING FOR ABOUT PLANNING AHEAD AND THEIR WISHES FOR THEIR 'OLD AGE'

Many transformations – big and small – come with aging. Getting old is a normal part of the human life course; not something to be denied or ashamed of. Have conversations about topics in this Handbook.

2. CAREGIVING – DON'T TRY THIS ALONE!

This is the motto of the Family Caregivers Alliance. 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.

3. PRACTICE SELF CARE

Recall what the flight attendants tell us: put on your oxygen mask before helping another. This means eat well, exercise, socialize, get enough sleep, and practice stress management. "Protect your health" is a core message of the National Family Caregiver Association. **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.

4. DON'T WAIT FOR A CRISIS – THINK AND PLAN AHEAD

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. A great many programs and services have wait lists. Remember the old adage "Hope for the best, plan for the worst".

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...

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I. ABOUT THIS HANDBOOK

1. A HANDBOOK JUST FOR CAREGIVERS

When aging brings on difficult challenges, family members and friends, as well as the many services offered by government, non-profit societies and private businesses can all assist. But families and friends typically have to struggle to find the assistance they need. Even knowing the right questions to ask is difficult. And learning where to turn for services isn't easy either.

BC Ombudsperson Kim Carter recognized 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 and advice that caregivers need is scattered, if it is available at all.

This Handbook is offered in the hope of helping family and friend (unpaid) caregivers do a better job of taking 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 guide to understanding the range of services available, how services work, and how to contact service providers. It is based on the successful *Burnaby Family Caregivers' Resource Handbook*, which was developed in connection with the Burnaby Family Caregivers Project at Burnaby Seniors Outreach Services Society, and funded by UNITED WAY.

2. METRO VANCOUVER CAREGIVERS

This Handbook covers 21 cities and villages in the Metro Vancouver area. These communities fall within the territory served by Fraser Health Authority (FH) or Vancouver Coastal Health Authority (VCH). The health authority responsible for different communities is noted below. This is helpful to know since the health authorities provide important services to the aging population and to family caregivers. You will learn more about health authority services and how to request them, throughout this Handbook.

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

3. INFORMATION & REFFERAL (I&R) SERVICES

Many of the services and programs mentioned in this Handbook are available in many communities. Others 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, there are Information and Referral Services – known as I&R – you can contact to ask what is available in your community:

A) **DIAL 2-1-1 TO SPEAK WITH AN INFORMATION SPECIALIST**

Services are free, confidential, multilingual and available 24/7. The bc211 service, funded by UNITED WAY, is the largest I&R agency in Metro Vancouver, and has the largest database listing of **social services and government programs**. You can also search the bc211 database at www.bc211.ca bc211 also covers Fraser Valley and Squamish-Lillooet Regional Districts. Note bc211 does not refer to private business services.

B) **DIAL 8-1-1 HEALTHLINK BC**, a free 24/7 non-emergency health information line.

(If you are dealing with a health emergency call 9-1-1 for ambulance, fire and police service.) 8-1-1 is operated by HealthLink BC, a Ministry of Health service. A health services representative can help you find health information and services or connect you directly with a registered nurse (24/7), a registered dietitian (M - TH, 8am - 8pm; F, 8am - 5pm) or a pharmacist (5pm - 9am). 8-1-1 provides translation services on request in 130 languages. For deaf and hearing-impaired assistance (TTY), call 7-1-1. The HealthLink BC website also contains a great deal of health information at www.healthlinkbc.ca

C) **LOCAL COMMUNITY INFORMATION AND REFERRAL (I&R) SERVICES**

Some communities have a free local I&R service. While limited by the number of hours they operate – typically standard week day work hours – they sometimes know of small unique community services not listed in large Metro Vancouver databases. 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.

- **BURNABY**

Burnaby Community Connections, Information Services 604-299-5778 produces *The Community Resource Guide, Burnaby/New Westminster 2013* which lists resources for all ages www.burnabycommunityconnections.com/pdfs/2013_CRG.pdf

- **DELTA NORTH AND LADNER**

Deltassist Seniors' Office 604-946-9526, provides I&R on seniors services in Ladner and North Delta. It also publishes an 11 page *Seniors Services Handbook*. Provided through Deltassist Family & Community Services www.deltassist.com the Deltassist Seniors' Office is funded by UNITED WAY. E: inquiry@deltassist.com

- **LANGLEY**

Langley Senior Resources Society, Information & Referral Service 604 530 3020 x 302 or x 306, also funded by UNITED WAY, www.lsr.ca E: info@lsr.ca or outreach@lsr.ca

- **MAPLE RIDGE / PITT MEADOWS/KATZIE**

604-786-7404 has a *Seniors Resource Guide 2011* which is being updated by the Maple Ridge, Pitt Meadows, and Katzie Seniors Network. The 2011 guide can be found at www.comservice.bc.ca (then under 'Programs & Services', click on 'Seniors Services')

- **NEW WESTMINSTER**

Seniors Support Services, Assistance, Information & Referral for Seniors 604-520-6621, funded by UNITED WAY, offers phone or drop-in information. Also publishes the *New Westminister Directory of Seniors Services* available at www.seniorsservicessociety.ca/services/index.html

- NORTH SHORE
North Shore Community Resources, Seniors' One Stop Information Line
 604-983-3303 or 604-925-7474, funded by UNITED WAY, offers phone and drop-in service. They produce a *Seniors Directory* annually in partnership with The North Shore Outlook newspaper. The directory is available in print or at www.nscr.bc.ca/information/senior.html
 E: sosvolunteer@nscr.bc.ca

- RICHMOND
Volunteer Richmond Information Services (VRIS) Seniors Information Line
 604-279-7020, funded by UNITED WAY, trained volunteers help by phone or in person (by appointment) to provide information on resources for seniors, M - F, 9am - 4pm. Service is also available in Chinese, by appointment. Offered in collaboration with Vancouver Coastal Health-Richmond Health Services and in partnership with the City of Richmond, Senior Services. VRIS www.volunteerrichmond.ca also publishes the *Richmond Seniors Directory* in partnership with The Richmond Review newspaper. The listings in it can be found at the Richmond Public Library website www.yourlibrary.ca/findall/community/csd.cfm Type 'caregivers' or 'seniors' or in the search box. E: info@volunteerrichmond.ca

- SURREY
DIVERSEcity Community Resources (formally called Surrey Delta Immigrant Services) 604-597-0205 (www.dcrs.ca) funded by UNITED WAY offers information services for seniors in Hindi, Punjabi, and Urdu through the Seniors' Integration Program of the settlement and Community Programs Department. E: seniors@dcrs.ca

- SURREY/WHITE ROCK
Seniors Come Share Society Seniors Information & Referral Line
 604-531-9400 is answered by Senior Connector volunteers, M - F, 9am - 4pm. The society also publishes a *Seniors' Resource Directory* at www.comeshare.ca which covers Surrey and White Rock

- TRI-CITIES
Community Volunteer Services for Seniors, Information and Referral Program
 604-927-7919 funded by UNITED WAY, operates M - F, 8:30am - 3:30pm www.cvss.org
 E: cvssoutreach@yahoo.ca. There is also a *Tri-Cities Seniors Directory* produced annually by the Tri-city News newspaper, with information supplied from the local seniors centre. Check with local community centres for a copy.

- VANCOUVER
411 Seniors Centre Society, Information and Referral Services 604-684-8171 Volunteers offer a phone or drop-in service. If you require assistance in a language other than English, they have volunteers who speak Cantonese, Dutch, Mandarin, Punjabi, Spanish, and Swedish. Check with the service to inquire when multiple language volunteers are available.
www.411seniors.bc.ca E: contact411@411seniors.bc.ca

- VANCOUVER
Japanese Community Volunteers Association (Tonari Gumi) 604-687-2172 provides I&R in Japanese for seniors' issues www.tonarigumi.ca E: services@tonarigumi.ca

○ VANCOUVER

Jewish Seniors Alliance 604-732-1555 provides community resources information by phone and on their website www.jsalliance.org Information can be made available in French, Italian, Romanian, Russian, Spanish and Yiddish; call ahead to arrange. Alliance staff and volunteers help edit the privately published annual *Vancouver Jewish Seniors' Directory* available at www.jsalliance.org/portfolio/vancouver-jewish-seniors-directory/ E: office@jsalliance.org

○ VANCOUVER

South Granville Seniors Centre, Spanish Outreach Program at 604-732-0812, is funded by the City of Vancouver, and provides I&R services for Spanish speaking seniors and their families

○ VANCOUVER (Downtown East Side)

Vancouver Second Mile Society, Downtown Eastside Seniors Centre 604-254-2194 provides I&R to local seniors.

○ VANCOUVER (South)

South Vancouver Neighbourhood House, Seniors Information & Referral Program 604-324-6212, offers I&R in multiple languages E: svnh@southvan.org

○ VANCOUVER (West End)

West End Seniors Network, Kay's Place 604-669-7339, volunteers offer phone or drop-in I&R www.wesn.ca/information-referral E: kaysplace@wesn.ca

○ WHITE ROCK See Surrey/White Rock above

D) YOUR LOCAL LIBRARY

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 there, you can print out articles, forms, etc. for a small price per page.

PART II. EDUCATION AND SUPPORT FOR FAMILY CAREGIVERS

1. 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 supportive housing, assisted living or a long term care facility – because of age, injury, long term chronic illness or disability.

Education programs help caregivers gain knowledge about the problems they face. Caring is a journey that can develop slowly over time as in the case of a diagnosis of dementia, or come on suddenly when a loved one has 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 difficult job to do, and the painful feelings of loss related to seeing a loved one deteriorate. Support groups remind us that we are not alone on the caregiver journey, and offer a friendly, open and informal atmosphere of understanding to share emotions and experiences.

The programs below can help you pace yourself as you navigate the twists and turns of eldercare. They are FREE unless otherwise mentioned.

A) Burnaby – **Burnaby Family Caregivers Project** 604-291-2258, funded by UNITED WAY, is offered by Burnaby Seniors Outreach Services Society (BSOSS) www.bsoss.org Services include:

- Presentations such as *Burnaby Resources for Family Caregivers – Including How to Navigate Fraser Health Authority Services, Caring for an Older Person with Dementia, Demystifying Seniors Housing Options, Medications and the Elderly, Representation Agreements and Powers of Attorney...because a Will is not enough*, and more. We have offered presentations in Chinese, Hindi, Korean, and in 2014 will offer talks in Hindi/Punjabi
- Four Week Education Series offered three times a year for family and friend caregivers
- Information & Referral to community resources for family caregivers
- For caregivers or care recipients age 50 plus, BSOSS volunteer Senior Peer Counsellors are available to offer confidential one-to-one emotional support upon request
- Lunch ‘n Learn outreach presentations for employers, church groups, government offices, and community organizations. Phone us to arrange for a talk to your group
- Annual Family Caregivers Information Fair with speakers and information tables. Join us Saturday April 26th, 2014, 10am - 2pm, at Holiday Inn Metrotown Express. Drop in for awhile, or stay the whole day (many do, and we become a family caregivers community for the day!)
- The *Burnaby Family Caregivers’ Resource Handbook*
- Support group for sharing emotions and experiences, meets every other Saturday 10am - 12pm
- E: bsoss@telus.net

B) Delta (South – Ladner) – **South Delta Caregivers’ Education & Support Network** 604-943-3921 or 604-948-0660, meeting space contributed by Delta Hospice Society. Services include:

- Eight session education program once a week, \$25
- Support group for those who have completed the eight session education program, meets the 2nd Tuesday of each month, 12:30 - 2:30pm
- E: info@deltahospice.org

DELTA See also Surrey/Delta below

C) Langley – **Langley Caregivers Support Group** 778-328-2302 ext. 2, is offered by Langley Senior Centre www.lsr.ca Services include:

- Support group Thursdays, 1:15 - 2:30pm
- E: info@lsr.ca

D) North Shore – **Caregiver Support Program** 604-985-7138, is jointly funded by UNITED WAY and Vancouver Coastal Health SMART Fund, and is offered by North Shore Community Resources www.nscr.bc.ca/information/caregiver-families.html Services include:

- Education on a wide variety of caregiving topics
- Network groups to meet with other caregivers
- Strategies to cope with stress
- Self-care and relaxation
- Telephone consultation
- Information on healthcare and community services
- Resource library
- Bi-monthly newsletter
- Annual BC 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* (2012). Available as a pdf or hard print copy. (This is the same guide published by the Family Caregivers' Network Society in Greater Victoria, but the resources listed in the North Shore edition are North Shore specific)
- Support groups – Caregiver Network Groups meet monthly. Choose from the 2nd Wednesday morning or the 1st Thursday evening of each month, at North Shore Community Resources
- E: info@nscr.bc.ca

E) Richmond – **Caregivers Education and Support Program** 604-279-7020, funded by UNITED WAY, is offered by Volunteer Richmond Information Services (VRIS) www.volunteerrichmond.ca Services include:

- A series of five, once weekly education series to provide caregivers with the tools to support their loved one and, just as importantly, the skills to remain healthy and well themselves. Topics covered include stress management, navigating the health care system, communication, problem solving, and more. Offered in English, Cantonese and Mandarin.
- One-on-one support by phone, or in person by appointment
- Information & Referral
- Support group – Cantonese support group meets monthly
- E: info@volunteerrichmond.ca

F) Richmond – **Caregivers Drop-In Support Group** 604-271-3646, Fridays, 1 - 2pm, Rosewood Manor

G) Richmond – **Caregivers Support Group** 604-238-8450, offered by Minoru Place Activity Centre Mondays, 2 - 4pm. Centre facility pass (\$22.40 annual fee) required. No July/August meetings

H) Surrey – **Focus on Seniors and Their Caregivers** 604-501-5100 offers occasional family caregiver oriented programs, funded by the Union of BC Municipalities – Age Friendly Community Grant, and offered by the City of Surrey www.surrey.ca/seniors Services include:

- Caregiver workshops
- *Focus on Seniors Forums* for seniors and their caregivers offered in English and Punjabi

I) Surrey/Delta – **Caregivers Network Surrey/Delta** 604-686-3793, is volunteer-led. Services include:

- One-on-One support
- Information & Referral linking to needed resources
- Workshops

- Support groups –
 - (i) Delta: Northcrest Care Centre, 3rd Wednesday of month, 10am - 12:00pm
 - (ii) Delta (North): Kennedy Seniors Recreation Center, 3rd Wednesday of month, 6:30 - 8pm
 - (iii) Surrey: Fleetwood Villa, last Thursday of month, 10am - 12pm
 - (iv) Surrey (Newton): Come Share Society Newton, last Monday of month, 7 - 9pm

J) Surrey/White Rock – **Caregiver Support Program** 604-531-9400 ext. 4, funded by UNITED WAY, is offered by Seniors Come Share Society www.comeshare.ca Services include:

- Educational Sessions such as *Dealing with Emotions, Give Yourself a Break!, Letting Go, Overcoming Challenges, and Setting Boundaries*
- 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 & Referral about community and health care services
- Resource library
- Social activities
- Education forum held twice a year
- Website forum coming autumn 2013
- Direct one-on-one support for individuals and/or families
- Outreach to groups & organizations within the Community
- Direct one-on-one support in Punjabi
- Multicultural interpreters available in: Cantonese, German, Hindi, Korean, Mandarin, Polish, Tagalog, Ukrainian...with more to come.
- Support groups - Caregiver Support and Information Sessions - phone for information
- E: info@comeshare.ca

K) Tri-Cities (Anmore, Belcarra, Coquitlam, Port Coquitlam, Port Moody) – **The Tri-Cities Senior Caregiver Support Program** 778-789-1496, 604-927-6098, funded by UNITED WAY, is offered by Dogwood Pavilion Recreation Centre (for adults aged 50 years and older) www.coquitlam.ca/parks-recreation-and-culture Services include:

- 1-to-1 support in person or by telephone
- Drop-in information sessions
- 5 week caregiver education series once a week covering: *All about Caregiving (Overview), All about YOU the Caregiver (Guest speaker), All about them (Video), All about Making Plans (Guest speakers: Financial Planner, Notary, Funeral Planner), All about Making Connections (Guest Speaker)*
- Support groups – meet monthly at Dogwood Pavilion, Glen Pine Pavilion, Maillardville Community Centre, and Shaughnessy Care Centre
- E: seniorcaregiverprogram@gmail.com

L) Vancouver: **Caregiver Support Program** 604-709-6437, funded by Vancouver Coastal Health – Vancouver Community, and delivered in Vancouver through the health authority. The program addresses the five key elements to sustaining family and friend caregivers: recognition, information, education, support and respite. www.caregivers.vch.ca Services include:

- Education Workshop Series consists of a four - six session series of once a week workshops given two or three times per year in locations around Vancouver to help caregivers define and adjust to the numerous practical and emotional issues that their role and responsibilities presents.
- Information & Referral to health care and community resources
- *Caregiver Times* quarterly electronic newsletter covers various topics and provides updates on the Vancouver Caregiver Support Program events.
- *Take Care: A Handbook for Family Caregivers* (Revised May 2013) includes tips on coping with the challenges of caring for an aging or ill relative, managing different care needs such as

medication use and dementia, information on VCH Home Health services, and a detailed community resource section. (Note: resource listings refer to some services in Vancouver Coastal Health that are not the same as in Fraser Health Authority area.) To download a copy visit:

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

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

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

- Annual *Caregiver Forum ‘Celebrate the Caregivers’* every May in partnership with UNITED WAY and various other disease and illness community-based organizations that support family caregivers.
- Support Groups –
 - Vancouver (Central): Ravensong Health Centre, Wednesday evening, monthly
 - Vancouver (East Side): Renfrew Park Community Centre, Wednesday afternoon, monthly
 - Vancouver (West Side-Kerrisdale): Tuesday afternoon, monthly
- E: caregiversupport@vch.ca

M) Vancouver (East Side) – **Lion’s Den Caregiver Support Group** 604-718-5848, supported by Encourage Lion’s Den Adult Day Centre

- Support Group - 3rd Thursday of each month, 6 - 8pm, no July or August meetings

WHITE ROCK See Surrey/White Rock above

N) Canada – **Care-ring Voice Network** 1-866-396-2433 (toll-free) M - F, 9am - 5pm (EST) offers free tele-learning conferences to Canadian caregivers. Each free tele-learning conference can have 5 to 500 participants on the telephone. Facilitators ensure telephone 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, Life After Diagnosis*, etc. Preregistration required. Call the Care-Ring Voice Network or register on-line. Past workshop recordings are on the website to listen to any time www.careringvoice.com French sessions at www.reseauentraidants.com

2. DISEASE-SPECIFIC EDUCATION AND SUPPORT PROGRAMS

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

A) ALZHEIMER SOCIETY OF B.C. FAMILY CAREGIVER SUPPORT GROUPS

604-681-8651 or visit www.alzheimerbc.org

B) ALZHEIMER JAPANESE CAREGIVER SUPPORT GROUP

604-687-2172 at Tonari Gumi (Japanese Community Volunteers Association) meets in Japanese Wednesday, 1:30 - 3pm, monthly in Vancouver.

C) BC CANCER AGENCY CAREGIVERS WEBSITE

Contains links to many websites that specialize in information for family caregivers who are caring for someone with cancer. The list is compiled by BC Cancer Agency librarians www.bccancer.bc.ca/PPI/RecommendedLinks/coping/caregivers.htm

D) CANADIAN CANCER SOCIETY

604-253-8470

www.cancer.ca/en/cancer-information/cancer-journey/if-you-re-a-caregiver/?region=bc

E) MULTIPLE SCLEROSIS SOCIETY OF CANADA

604-689-3144 has some caregiver specific information at www.mssociety.ca/en/help/iAmaCaregiver.htm
French information at www.mssociety.ca/fr/aider/JeSuisLaidant_profil.htm

F) PARKINSON SOCIETY BRITISH COLUMBIA

604-662-3240 offers education and support for family caregivers
www.parkinson.bc.ca/Self-help-Support-Groups

G) STROKE RECOVERY ASSOCIATION OF BC

604-688-3603 support groups across the province include family caregivers
www.strokerecoverybc.ca/contact-us/branch-locations

3. CAREGIVER WEBSITES

These sites cover many caregiver topics. Some non-BC sites are listed because of their large variety of topics, but be careful when at a non-BC site. Websites from other provinces and the US will have information that is not applicable to BC 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.

A) CAREGIVER.COM, US www.caregiver.com Thousands of articles. Free weekly e-newsletter.

B) CAREGIVER ACTION NETWORK, US www.caregiveraction.org Formerly called the National Family Caregivers Association. Tip sheets and electronic Family Caregiver Forum where caregivers can post questions, receive support and communicate with others. Some [Spanish](#).

C) CARING FOR FAMILY by Saint Elizabeth Homecare non-profit society, offers a free printed or online guide *Caregiver Compass* to help know where to begin when taking on the responsibility of caring for someone. www.saintelizabeth.com/Caring-for-Family

D) DIAMOND GERIATRICS, BC www.diamondgeriatrics.com Many articles and tips by Lower Mainland geriatric social worker and private case manager Peter Silin. Free monthly BC e-newsletter.

E) FAMILY CAREGIVER ALLIANCE, US www.caregiver.org Includes some articles in [Chinese](#) (Simplified and Traditional) and [Spanish](#). Free webinars archived for viewing anytime.

F) FAMILY CAREGIVERS' NETWORK SOCIETY Greater Victoria, BC www.fcns-caregiving.org Articles relevant to BC family caregivers, including their book *Family Resource Guide for Family Caregivers*. Free bi-monthly e-newsletter. FCNS reminds us that “**Caregivers Need Care Too!**”

G) FAMILY CAREGIVERS UNITE, US www.familycaregiversunite.org Features hour-long radio programs on a variety of topics. Programs are archived so you can listen 24/7. Note the *Tools for Family Caregivers for Assessing Care Needs of their Family Members*, aired June 3, 2013.

H) *FOUR STAGES OF CAREGIVING* handbook, US Area Agency on Aging www.agingcarefl.org/for-caregivers-handbook-and-resource-guide 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.

I) *HANDBOOK FOR CAREGIVERS* (2005) by Fraser Health Authority covers: Being a Care-Receiver, Being a Caregiver, Managing the Caregiving, and Partners in Caring – You and the Home Health Care Team www.fraserhealth.ca/media/HandbookForCaregivers.pdf

J) NATIONAL CAREGIVERS LIBRARY, US www.caregiverslibrary.org is one of the largest sources of information and tools for caregivers and seniors in the U.S.

K) NORTH SHORE COMMUNITY RESOURCES CAREGIVER SUPPORT PROGRAM website is filled with BC-relevant information, including a *Resource Guide for Family Caregivers – North Shore Edition* (2012). It is the same guide as published by the Family Caregivers' Network Society, Greater Victoria, BC, but the resources have been revised to make them North Shore specific. This website also contains a section for employers about ways they can support their family caregiver employees.
www.nscr.bc.ca/information/caregiver.html

L) SENIORSBC - BC Ministry of Health www2.gov.bc.ca/ Type 'Caring for Seniors' in the search term box to see *Daily Care Tips and Advice*, *Building a Care Guide*, *Caring for the Caregiver*, and *Training and Caregiver Role Management Tools*. Under *Building a Care Guide* is *My Care Guide*, a tool provides an easy way to record and track medical information.

Under *Training and Caregiver Role Management Tools* in the *Communications* section, is an important article *How to Care: The Conversation*. The article addresses the importance of talking with your older family members about the challenges they face. www.howtocare.com/conversation.htm#know

M) *TAKE CARE: A HANDBOOK FOR FAMILY CAREGIVERS* (2013) by Vancouver Coastal Health Authority, has information applicable to all caregivers, up to page 52. However, the remaining pages refer to some services in Vancouver Coastal Health Authority area that are not relevant to the Fraser Health Authority area. The handbook is available in English:

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

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

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

N) VON CANADA www.caregiver-connect.ca Many practical resources on this English and French website, including *Developing a Care Plan* found under the 'Caregiver Tools' button. Free e-newsletter.

4. HEALTH AUTHORITY–BASED HOME AND COMMUNITY CARE SERVICES

Whether the person you are caring for lives in the areas served by Fraser Health (FH) or Vancouver Coastal Health (VCH), the health authorities offer Home and Community Care Services to assist both the care recipient and the family caregiver.

Take note how the BC government explains these services on the webpage *Home and Community Care* www2.gov.bc.ca/gov/topic.page?id=11D44209BCED4198ABD2E0DD3A0066D9&title=Home%20and%20Community%20Care%20-%20Home%20Page "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."

Some services are provided free of charge; others involve a cost which is dependent on your income.

To be eligible for subsidized home and community care services:

from www2.gov.bc.ca/gov/topic.page?id=E2ED536A29A6405ABDB7248AF8E81648

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 a resident of British Columbia for at least three months; and
- be 19 years of age or older.

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.

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 residential care facility.
- You have a life-limiting illness.

Needs Assessment Criteria - In addition to meeting the criteria described above, each service described below has its own needs assessment criteria that you must meet.

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).

If the person you are caring for is eligible for the services described below, call the Home and Community Care office which corresponds to the health authority area your care recipient lives in.

HOME AND COMMUNITY CARE OFFICES

Fraser Health Authority (FH) www.fraserhealth.ca

1-855-412-2121 toll-free, 7 days a week, 8:30am - 4:30pm

Vancouver Coastal Health Authority (VCH) www.vch.ca

VCH - North Shore 604-986-7111 M - F, 8am - 4:30pm

(After hours, leave a message)

VCH - Richmond 604-278-3361 M - F, 8:15am - 5pm

(After hours, leave a message)

VCH – Vancouver Community 604-263-7377 M - F, 8:30am - 5:30pm

(After hours, leave a message)

Services the health authorities provide in Home and Community Care include:

A) 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 health authorities' 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.

The case manager assigned to a client will: assess needs, determine eligibility for services, determine the costs for certain services, based on your 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 it is very important that seniors file their income tax on time each year), 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 residential care 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 health authority in the area where your care recipient lives (see phone numbers on 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 – 90 minute long 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.

Depending on the case manager's assessment, one or more of these services might be offered:

B) 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 (aka respite) for the primary caregiver. If home support assistance is recommended by your case manager, she/he 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 understand 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 (CHW's) 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.

Home Health does not provide banking, companions, driving to appointments, foot care, grocery shopping, house cleaning, laundry, meal preparation, or rehab equipments/aids, but intake staff or the case manager can assist in locating these types of services in your community.

C) ADULT DAY CENTRE PROGRAMS

These provide a break/respite 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 first assess the client and determine their need for this program. Programs generally run from 10am - 2pm 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.

D) 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. Health authority case managers can help you arrange three different kinds of respite: Respite may be **a few hours of service provided in the home** of the senior while the caregiver takes a break to renew energy. **Adult Day Centre Programs** (item C above) also provide respite. **Short-term admission to a residential care facility or hospice residence** for a person with complex care needs is another respite service. This gives caregivers a temporary rest from between four and thirty 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 respite.

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 health authority area where your care recipient lives.

E) GOVERNMENT-SUBSIDIZED ASSISTED LIVING AND RESIDENTIAL CARE

See the HOUSING parts of this Handbook to learn about the three levels of care in seniors housing – supportive housing, assisted living and residential care. You will also find an explanation of the three types of housing providers – public or government subsidized, non-profit societies and private businesses.

F) END-OF-LIFE PALLIATIVE/HOSPICE CARE

Home and Community Care also provides services that support family members and those nearing the end of their lives – at home, in assisted living, residential care, in a hospital hospice unit, or a dedicated hospice building. End-of-life care focuses on preserving the individual's comfort, dignity and quality of life, and offers on-going support for family/friend caregivers. 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.

Adapted from Ministry of Health and Fraser Health websites

Palliative care includes care coordination and consultation, pain and symptom management, community nursing services, community rehabilitation services, home support, respite for the caregiver, and residential hospice care.

N.B. In Canada, the terms Palliative and Hospice tend to be used interchangeably to refer to a specific approach to care for people who have a life-limiting illness or are terminally ill. See the END-OF-LIFE part of this handbook for more information about caring for a dying person.

Obtaining services not provided by the health authorities' Home and Community Care Services

If you want to add to the services offered by Home and Community Care Services, or are not eligible for those services, some of these 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 and home health services from private business agencies found in the Yellow Pages under *Home Support* or *Seniors*.

See PART III. Community Resources in this Handbook for more about Better At Home and Home Support Agencies.

5. COUNSELLING

A) SENIOR PEER COUNSELLING (SPC)

For caregivers who are over age 50, some seniors groups offer a free, confidential, one to one counselling service to those who are 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 senior 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 Association of Senior Peer Counsellors of BC. 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. Note that SPCs are also available to provide services to the senior you are caring for. The service is available in multiple languages at some centres.

B) LOW-COST COUNSELLING

Some social service organizations offer low-cost counselling, often based on a sliding fee scale. Expect wait lists in many cases.

Want to know if a service like one in this Handbook is available in your community?

Just dial **2-1-1** – it's a free information service. bc211 is funded by UNITED WAY.

bc211 can help you find social and government services.

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

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

TTY For Deaf/Hard of Hearing Callers: 604-875-0885

C) 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 counseling you examine the behaviors, 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 counselor will encourage your personal growth and development in ways that foster your interest and welfare.

Adapted from the American Counseling Association

If you are an employee, check to see if you might 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 **BC Association of Clinical Counsellors** 1-800-909-6303. www.bc-counsellors.org has a ‘find a counsellor’ search feature. **Counselling BC** 604-729-6059 also lists counsellors and psychologists in BC www.counsellingbc.com

6. FINANCIAL SUPPORT FOR CAREGIVERS

There is no program that pays family caregivers for the work they perform, but some financial relief may be provided through the following programs:

A) CANADA REVENUE AGENCY (CRA) DISABILITY TAX CREDITS FOR CARE RECIPIENTS

1-800-959-8281 toll-free. Caregivers should know their care recipients might be eligible for Disability Tax Credits (DTC), 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.

Publication Guide *RC4064 Medical and Disability – Related Information* explains more, and is available on the CRA website or by phoning. Note that Guide RC4064 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 (DTC) 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, www.cbc.ca/news/canada/story/2011/02/09/disability-tax-credit-revenue-agency-claims.html If you hire a company to help you with the form, choose the firm carefully.

B) CANADA REVENUE AGENCY (CRA) FAMILY CAREGIVER AMOUNT (FCA) TAX CREDIT

1-800-959-8281 The Family Caregiver Amount, a federal tax credit that began in 2012, 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

C) 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 the END-OF-LIFE part of this Handbook for more details.

D) HARDSHIP-REDUCED RATES FOR PUBLIC LONG-TERM CARE

As explained in the HOUSING –RESIDENTIAL CARE part of this Handbook, government-subsidized residential care costs 80% of an individual’s annual after-tax income, subject to a minimum rate of \$958.90 per month and a maximum rate of \$3,059 per month. This can be financially very 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% 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.

7. 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 that you can reduce and manage stress:

A) A LIST OF TECHNIQUES:

Acceptance (some things cannot be changed), aromatherapy, art, avoid people who drain you (energy vampires), bathe, breathe, comedy, dance, don’t ‘should’ on yourself, esthetic care (including hair care, nail care and spa treatments), eat out or order in, exercise, forgive, garden, healthy nutrition, journal/write, 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 pushed around by them, and without getting into a struggle with them), music, pet therapy, pick your battles carefully, pray, read, recreation programs at your local community/seniors centre, relaxation tapes, CD’s and DVD’s, time in nature, say ‘no’, sex, sleep, socialize, 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:

B) 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. If we do not accept their rights though, we cause ourselves unnecessary stress by trying to control the behaviour of our care recipient. Also, when we don't value another's autonomy and try to control their behavior, 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 <http://dsp-psd.pwgsc.gc.ca/Collection/H71-4-1-9-2E.pdf> or in [French](http://publications.gc.ca/collections/Collection/H71-4-1-9-2F.pdf) at <http://publications.gc.ca/collections/Collection/H71-4-1-9-2F.pdf>

C) BE MINDFUL OF THE CHALLENGES FACED BY THE PERSON YOU ARE 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 license, 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 behaviors 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 behaviors. 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 he/she can for himself/herself.
- 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, BC

8. CRISIS LINES

A) SENIORS’ DISTRESS LINE **604-872-1234** and THE CRISIS LINE **604-872-3311** provide confidential, free, 24/7 highly trained listeners to support you during a difficult moment 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 www.crisiscentre.bc.ca

B) PROVINCIAL SUICIDE HELPLINE **1-800-784-2433** (SUICIDE) toll-free, is a 24/7 source of help

C) FRASER HEALTH CRISIS LINE **604-951-8855** emotional support and resource information 24/7

D) S.U.C.C.E.S.S CHINESE HELP LINES Volunteers provide caring support to those in distress 10am - 10pm daily. **604-270-8233** (Cantonese), **604-270-8222** (Mandarin)

Remember the motto of the US 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?” With age, changes occur throughout our body systems, body functions slow down, and there is a higher risk of developing health problems.

With advances in technology and medications, many incurable health problems that used to be fatal are now seen as chronic, e.g. congestive heart failure, dementias, diabetes and stroke, so living longer can also mean living for a long time with multiple disease conditions. This is why it is often said that 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 you to begin preparing for expected changes, should you be helping someone with a progressive disease.

The health issues listings in this handbook begin with **the 3 D’s** – also known as **the 3 Geriatric Giants**. This refers to delirium, depression, and dementia. The three medical conditions can resemble each other in older people, i.e. some of the symptoms overlap, and it is vital to distinguish between the three. For example, a caregiver might assume that sudden confusion is ‘just dementia’, when it is actually delirium which needs to be attended to immediately. None of the 3 D’s are a ‘normal’ part of aging, but rather, are serious health threats in old age.

Here are the health issues that a very large percentage of family caregivers struggle with:

1. DELIRIUM

Delirium is a medical emergency. 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. It comes on suddenly and is commonly reversible with treatment – hence the need to seek medical care quickly. For more information google: Vancouver Island Health Authority *Delirium in the Older Person: A Medical Emergency (2006)*.

2. 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 marked by gradual deterioration and gets worse over time. Dementia is not a ‘normal’ part of the aging process, i.e. not everyone who ages develops a 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 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/caregiver/jsp/content_node.jsp?nodeid=2185

From US Family Caregiver Alliance website

A) 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.

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% 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% of those over the age of 85 have dementia. N.B. Early-onset Alzheimer's can strike people in their 40's and 50's.

Vascular dementia, the second most common form of dementia, is a broad term for dementias associated with problems of circulation of blood to the brain, and it includes **Multi-infarct dementia**.

Other types of dementia are **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's 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.

B) GETTING A DIAGNOSIS

The BC Medical Association and the BC Ministry of Health created guidelines and protocols for MD's 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 on the webpage www.alzheimerbc.org/Alzheimer-s-Disease-and-Dementia/Getting-a-Diagnosis.aspx:

“Getting a Diagnosis

Diagnosing dementia is a complex and difficult process, requiring the time and expertise of skilled practitioners. A dementia diagnosis can only be made after a systematic assessment that takes into account other possible causes for the symptoms. For example, symptoms that are associated with dementia could also be due to other conditions such as depression, thyroid or heart disease, infections,

drug interactions or alcohol abuse. Thus, there is no single test that can tell that someone has or does not have Alzheimer's or another dementia. It is important to see a doctor as soon as you suspect problems.

Benefits of Getting a Diagnosis

Early detection and diagnosis of Alzheimer's disease or another dementia is critical to ensuring proper support, care and treatment of the illness. It is also important because it allows people with the disease and their families to make key financial and care decisions while they are still functioning at the highest possible level.

The diagnosis of dementia often comes as a complete shock. However, many people feel relieved once they have identified the source of their worries after a diagnosis has been made. Getting an early diagnosis will help you to move forward and gain more control over your life by taking the necessary steps to live better with the disease. Receiving an early diagnosis allows a person to:

- Understand the symptoms they are experiencing, and the changes that they can expect
- Gain access to information, resources and support
- Benefit from and explore treatment options
- Plan for the future
- Develop and engage support networks
- Maximize their quality of life.

Visiting your Doctor: What to expect

When seeking a diagnosis, the doctor may begin by asking you some general questions about your overall health:

- What kind of symptoms have you noticed?
- When did they begin?
- How often do they happen?
- Have they gotten worse?
- What other medical conditions exist?

They will look for problems with memory, reasoning ability, language and judgment, and how these affect day-to-day function.

The doctor may use the words "probable Alzheimer's disease".

Many doctors who make this diagnosis are accurate 80 to 90 percent of the time. The doctor may refer you to another specialist such as a psychologist, psychiatrist, neurologist, geriatrician, nurse, or a social worker.

Medical History

A doctor will ask you and possibly your family members about your medical history, including current and past illnesses. The doctor will also look at your family history of medical conditions. It may be helpful for you to bring a list of current medications that you are taking.

Mental Status Tests

Mental status testing helps give the doctor a general idea of your mental functioning. One of the most common is the Mini-Mental State Examination (MMSE). This part of the process tests things such as your sense of time and place, as well as your ability to remember things 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 and Diagnostic Tests

A physical exam is helpful in ruling out other causes for the symptoms you are experiencing. 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 Exams

If necessary, the doctor may request that further testing be done. This can include laboratory testing such as blood tests, x-rays, brain imaging or scanning.”

Specialty Seniors Health Clinics are another way to get a comprehensive assessment. See section 8 of this part of the Handbook for a description. (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 BC. The Clinic provides assessment and diagnosis of Alzheimer disease and related disorders for patients including care and support for the affected individual and his or her 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.

C) DEMENTIA MEDICATIONS

There is no cure for dementia, but there are medications to help with symptoms and slow down the progress of the disease for some people for a period of time – though not indefinitely. Not all medications work for all people. When they do work, they help buy time for sufferers to plan ahead, be with their loved ones and stay independent longer.

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), Reminyl® (galantamine) and Exelon® (rivastigmine). A commonly used medication for the treatment of moderate to severe Alzheimer dementia 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.

D) DEMENTIA INFORMATION AND SUPPORT

(i) The **Alzheimer Society of B.C.** 604-681-8651 (Lower Mainland) or 1-800-936-6033 toll-free, www.alzheimerbc.org 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, Dementia Helpline, Information Bulletins, Dementia Education, Tele-Workshops, Support Groups, Individual Support, First Link®*, and *Minds in Motion®*. From July 2013 *Programs and Services* brochure. In Vancouver and Richmond, education in Cantonese and Mandarin is available at the Chinese Resource Centre 604-279-7120

If your family member or friend with dementia wanders, you can inquire about the *MedicAlert® Safely Home® and Wandering* program at 1-855-581-3794 www.alzheimerbc.org/wandering.aspx

(ii) **Multilingual information** on dementia can be found at:

- *Alzheimer’s Disease International* www.alz.co.uk/other-languages (50 languages)
- Chinese, Farsi, French, Japanese, Korean, Persian and Punjabi information about Alzheimer Society of B.C .services is at www.alzheimerbc.org/We-Can-Help/Resources-and-Information/Non-English-Resources.aspx

(iii) The **Mayo Clinic** in the US offers a website with information, podcasts and a free e-newsletter for caregivers of people with dementia at www.mayoclinic.com Enter ‘caregivers’ in the search box.

E) DEMENTIA ADVOCACY

- **Alzheimer Society of B.C.** is seeking action from the provincial government to develop and implement a comprehensive, funded dementia plan for BC www.alzheimerbc.org/We-Can-Help/Advocacy.aspx
- **UNITED WAY**, Alzheimer Society of BC, City of Vancouver, FH, SFU, Social Planning and Research Council of BC (SPARC BC), UBC, and VCH are collaborating on a project *Creating Dementia-friendly Communities in the Region – A Call to Action*. The summary report of their June 2013 dementia-friendly workshop will be on the UNITED WAY website www.uwlm.ca/reports-and-resources

3. 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 2 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 in care recipients has benefits that extend to the family members on whom patients depend, i.e. the family caregivers.

12 Depression Busters for Seniors offers more insight and tips on depression and the elderly. The article is available at 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 US 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 the three best strategies used for managing depression.

4. 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 Authority.

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 4 women and 1 in 8 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, 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 damn 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 6-8 glasses of fluids a day - preferably water. Concentrated urine is very irritating to the bladder so that 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 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 2 hours) to take to 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 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 BC there are increasingly more nurse continence advisors. 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. Vancouver Coastal Health Authority, Providence Health Care, Fraser Health Authority, Vancouver Island Health Authority and Interior Health Authority 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 on-line resources to look at. Physiotherapists who specialize in the pelvic floor muscle are another excellent resource.

5. MENTAL HEALTH

A) FH AND VCH GERIATRIC MENTAL HEALTH SERVICES

FH **Geriatric Psychiatry Services** offer a specialized outreach service for seniors affected by dementia, major affective disorder, 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 supportive housing, or in residential care. The teams operate out of local mental health centres www.fraserhealth.ca/find_us/services/our_services?program_id=10674

FH **After Hours Emergency Mental Health Program** 1-877-384-8062 offers professional mental health staff available via phone M – F, 4:30 – 11pm, and 1pm – 11pm on weekends.

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

B) CANADIAN MENTAL HEALTH ASSOCIATION (CMHA) - BC DIVISION

604-688-3234 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 video providing practical tips on managing mood and healthy living, 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 for family caregivers.
- *Chinese Mental Health Services Resource List* is available for the Chinese community.

Adapted from www.cmha.bc.ca

C) MOOD DISORDERS ASSOCIATION OF BC (MDABC)

604-873-0103 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. It is vitally important that family members take time to learn how to best help someone experiencing mental health issues—not only to ensure that support is beneficial to the person receiving it, but also that support-givers maintain their own health. They offer a support group for caregivers. MDABC with BC Partners for Mental Health and Addictions, have published a 91 page resource manual, *Family Self-Care and Recovery From Mental Illness*, available as a PDF. It offers a wealth of practical guidance for families dealing with mental illness. A mental health resources list in Punjabi is also available. *Adapted from www.mdabc.net*

6. STROKE

Stroke is a medical emergency; it is 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.

Every ten minutes a person in Canada has a stroke. Recognizing and responding **immediately** to the warning signs of stroke by calling 9-1-1 or your local emergency number can significantly improve survival and recovery as “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 2 million brain cells per minute. That is why it we need to recognize these **5 warning signs of stroke** and immediately call 9-1-1:

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

From the Heart and Stroke Foundation of Canada website

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 education and support groups all over BC for caregivers and people recovering from stroke. www.strokerecoverybc.ca

7. SUBSTANCE ABUSE

A) AL-ANON FAMILY GROUPS

604-688-1716 are support and education groups 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 who attends meetings and what is said at meetings is held in strict confidence. There are no dues or fees.

Based on the Twelve Steps used in Alcoholics Anonymous (AA), Al-Anon groups meet throughout North America. Phone for meetings in your area, or google ‘Al-Anon and BC’. They can also refer you to Twelve Step groups for friends and families of people who abuse drugs (prescriptions, over-the-counter, and street drugs).

B) OLDER ADULT ADDICTION SERVICES

Programs are offered by each of the health authorities for older persons suffering with addictions.

**Want to know about HEALTH SERVICES like the ones in this Handbook
available in your community?**

Just dial 8-1-1

a free 24/7 non-emergency health information line operated by HealthLink BC, a Ministry of Health service. A health services representative can help you find health information and services or connect you directly with a registered nurse (24/7), a registered dietitian (M - TH, 8am - 8pm; F, 8am - 5pm) or a pharmacist (5pm - 9am). 8-1-1 provides translation services on request in more than 130 languages. For deaf and hearing-impaired assistance (TTY), call 7-1-1. The HealthLink BC website also contains a great deal of health information www.healthlinkbc.ca

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

You can also email them your question at help@bc211.ca

TTY For Deaf/Hard of Hearing Callers: 604-875-0885

8. 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% of the Canadian population but take over 30% of prescription drugs. Older bodies do not handle meds as easily as younger ones and polypharmacy (the use of many, i.e. four or more medications) puts older people 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% of all admissions of the elderly to hospital are related to adverse drug reactions or incorrect drug use.

A) BC MEDICATION REVIEW SERVICES PROGRAM

Not everyone knows their pharmacist can perform a free medication review. This is designed to increase communication between patient and pharmacist to promote safe and effective medication use and improve health.

The review is provided as an in-person appointment with a pharmacist. Eligible patients are BC 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.

B) MEDICATION REMINDERS

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

9. WHEN UNCERTAIN ABOUT WHAT AILS YOUR CARE RECIPIENT

A) SPECIALTY SENIORS HEALTH CLINICS

If the family physician of your care recipient 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. Some are located in hospital buildings; others are separate stand alone clinics. In FH, these clinics are called *Specialized Geriatric Clinics*; in VCH, they are given various names depending on the location. They serve 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 and
- the help of a clinic social worker, e.g. when a caregiver is overwhelmed with providing care to a loved one.

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 of several weeks to months. If you are able to transport your loved one to a clinic further 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 – 2 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 also.

10. THE HOSPITAL JOURNEY

The hospital journey can be alarming for care recipients and their 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 Fraser Health Authority 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.”

There are a number of hospital-based elderly friendly programs for frail seniors. Not all hospitals have all programs.

A) 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, behavior 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, providing information regarding health services and community resources.

B) 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. 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, there is free interpretation or written translation service provided through a provincial program. If you will require the use of language services, please inform the hospital. They will do their best to provide a trained interpreter.

C) ACUTE CARE OF THE ELDERLY (ACE)

ACE is a unit in some hospitals that provides specialty care to admitted seniors with a number of serious medical problems, and who 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 to their loved ones, and to prevent or delay their admission to residential care.

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 illness, 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.

D) DISCHARGE PLANS

If you have an older family member in the hospital, note that evidence shows leaving hospital as soon as possible and recuperating at home with home supports and community services is better than waiting in hospital to fully regain strength before returning home. Hospital environments can be very disruptive, new routines can cause confusion making it difficult to think as well as at home, noise makes sleeping difficult, mobility is severely restricted causing rapid loss of general muscle tone, strength and energy, falls occur more often in unfamiliar settings, the food is 'strange', and immune systems weakened by age make seniors more vulnerable to bacterial and viral infections.

BC 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, care at another hospital, 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 philosophy that **Home is Best** as the place to recover from illness and injury, and manage chronic conditions.

If you are concerned about how a loved one who is recuperating will manage at home when leaving the hospital, speak to a member of the health care team on your ward and she or he will relay your concerns to a hospital coordinator called a Home Health Liaison or Quick Response Case Manager who understand how to match patient needs to resources in the community.

(It is interesting to note that at Vancouver General Hospital, care teams give patients a 2-page document *My Discharge Plan* which summarizes their hospital stay, any follow-up tests or appointments, medication information, contact information for community health providers, and any signs or symptoms of their condition, and patient transition (discharge) instructions.)

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

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/restarted? 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

E) PATIENT and FAMILY EDUCATION CENTRES

These are places, found in many hospitals, where patients and their family caregivers can get information about health-related topics and health authority services. Patients and family caregivers can also have time-limited access to onsite computers offering internet and email access, access online government forms, and for research needs, and can ask the information staff or volunteers to assist with health-related inquiries.

11. HEALTHLINK BC / 8-1-1

This service provides trusted health information with just a free phone call; dial **8-1-1** or go to www.healthlinkbc.ca for easy access to non-emergency health information and services. **Speak with a nurse 24/7** about your symptoms; **consult with a pharmacist** from 5pm - 9am every day when your community pharmacist may not be available to answer your medication-related questions; **get nutritional information from a registered dietitian** (formerly known as Dial-A-Dietitian service), M - F, 9am - 5pm. HealthLinkBC can also help you find local health services. Translation services are available in over 130 languages on request. For deaf and hearing-impaired assistance (TTY), call 7-1-1.

The free *BC HealthGuide Handbook* is also available from your pharmacist in Chinese, English, French and Punjabi. *Chapter 3: Healthy Aging* of the handbook has a section called *Caregiver Tips* in the Chinese, English and Punjabi editions. The *BC First Nations Health Handbook*, an online companion document to the *BC HealthGuide*, is also available at the HealthLink website or by phoning for a copy.

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

When considering the housing options open to them as they get older, many decide to ‘age in place’, i.e. stay at home (apartment, co-op, condo, house, trailer) in their communities, and use locally-available services to assist with any health challenges. 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 help might be necessary for the older adult you are caring for include problems with addictions (alcohol and drugs including over the counter and prescription medications), cognitive health (forgetting, personality changes), 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 including bathing, medication management, mobility (including falling), money management (paying bills on time, falling prey to scams, gambling problems), social isolation, and transportation (difficulty driving, problems using public transit).

Services in the community may be offered by public or government-subsidized programs, non-profit societies, and/or private for-profit businesses.

Want to know if a service like one in this Handbook is available in your community?

Just dial **2-1-1** – it’s a free information service. bc211 is funded by UNITED WAY.

bc211 can help you find social and government services.

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

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

TTY For Deaf/Hard of Hearing Callers: 604-875-0885

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

1. ADAPTIVE CLOTHING

Clothing is available on the market that simplifies the dressing process for people with arthritis, dementia, MS, Parkinson’s and stroke, and 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.debrallynncreations
- *Neway Adaptive Clothing* 604-940-9871. www.newayadaptiveclothing.com
- *Silvert’s Speciality Clothing* 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.

2. AIDS TO DAILY LIVING

From small things like button fasteners to large things like hospital-style beds, many items are available to aid in daily living activities and 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. A number of stores sell these items; some also rent equipment.

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

1-877-952-3818 toll-free. 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 or by phoning. For a pdf copy go to www.gov.bc.ca/seniorsguide

4. CANADIAN RED CROSS SOCIETY HEALTH EQUIPMENT LOAN PROGRAMS (HELP)

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 are no longer using, consider donating it to the Canadian Red Cross Society HELP program.

5. CATS FOR SENIORS PROGRAM

604-724-7652 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 up for fostering. Their 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, so in that case Action for Animals takes the cat back. www.actionforanimals.net

6. CHRONIC DISEASE SELF-MANAGEMENT PROGRAMS

604-940-1273 These peer-led patient education programs are offered for adults experiencing chronic health conditions (e.g. arthritis, heart disease, hypertension, lung disease, stroke, etc.), their family members, friends and caregivers. The programs, which are all led by a trained facilitator, provide information and teach practical skills on managing chronic health problems, giving people the confidence and motivation they need to live full lives despite the challenges of chronic health conditions. 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 are free programs organized by the University of Victoria – Centre on Aging, offered throughout BC. For locations and dates of workshops visit www.selfmanagementbc.ca

Online Chronic Disease Self-Management Program follows the same information and process as the in-person CDSMP (above), i.e. they are peer-led with a trained facilitator, but participants log-on at their convenience two to three times a week for two hours per week. The program is accessible to those with all levels of computer experience.

Chronic Pain Self-Management Program (CPSMP) is adapted from the Chronic Disease and Arthritis Self-Management Programs, which is to say it is peer-led, and follows the same time-frame and group facilitation process. The program is targeted to adults experiencing chronic musculoskeletal pain,

whiplash injuries, chronic regional pain syndromes, repetitive strain injury, chronic pelvic pain, post-surgical pain that lasts beyond 6 months, neuropathic pain (often caused by trauma), or neuralgias (such as post herpetic pain, and trigeminal neuralgia), and post-stroke and central pain. It may also be appropriate for those with conditions such as persistent headache, Crohn's disease, irritable bowel syndrome, persons with diabetes who have neuropathy, and those who have severe muscular pain due to conditions such as MS.

Diabetes Self-Management Program (DSMP) follows the same time-frame and group facilitation process as the Chronic Disease and Chronic Pain programs, but is targeted to those with Type 2 diabetes. It is also peer-led. The program teaches the skills needed for the day-to-day management of diabetes and related symptoms. It is available in selected communities.

Arthritis/Fibromyalgia Self-Management Program (AFSMP) follows the same time-frame and group facilitation process as the Chronic Disease Self-Management Program, but is targeted to adults living with different types of rheumatic diseases, such as osteoarthritis, rheumatoid arthritis, fibromyalgia, and lupus, and their family members, friends and caregivers. In the same peer-led fashion as the others, the program teaches the skills needed for day-to-day management of arthritis and/or fibromyalgia and related symptoms. This was the first program developed by the Stanford Patient Education and Research Center and was the prototype for subsequent programs. Available in selected communities.

7. CNIB

(Canadian National Institute for the Blind) 604-431-2121 CNIB helps not only those who are blind, but also those who are living with deteriorating vision. As we age, the incidence of eye diseases increases, hence the importance of regular eye exams. The CNIB offers support, information and training to those with low vision. Their library service has an extensive list of talking books. The CNIB store and catalogue offer products designed to help make life easier for people who are blind, partially sighted or have age-related vision loss. www.cnib.ca

Make the most of the sight you have

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 you make the most of your sight so you or your loved one can live life to the fullest. Assessments with low-vision specialists are offered by appointment.

8. ELDERPOST.COM

This is a BC-based website where you can find, give away or sell equipment for seniors. Things like wheelchairs, ROHO mattresses, aids to daily living, lifts, walkers, etc. www.elderpost.com

Note: If you have unused equipment, in good shape, that others can use, **please consider donating it** to the Canadian Red Cross Society Health Equipment Loan Programs (HELP) described in this Handbook.

9. FALLS

One in three adults over the age of 65 falls at least once a year. Falling can cause injury, loss of mobility and independence, and it 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 falling 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 assisted living facilities, and in residential facilities.

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

- *Have a regular exercise program* to make you stronger and help you feel better. Exercises that improve balance and coordination (like Tai Chi) 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.
- *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 PART II of this Handbook for more about Medication Reviews.)
- *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.
- *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 light-weight 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

10. 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 your perfectionism too: sometimes a caregiver becomes convinced that she/he is the only person who can do anything for the care recipient.

The refusal to accept help from family, friends and members of your faith community adds to the risk of the caregiving situation. A caregiver who won’t accept help can end up burnt-out and more ill than the care recipient. As well, a harried caregiver means a care recipient is at greater risk of neglect and abuse.

Instead, come to see accepting help as an affirmation of strength and wisdom.

11. FOOD

A) 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 cost-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 them.

Dairyland Home Service 604-421-4663 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 www.morethanmilk.ca

B) 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-\$6.00 per meal. In some communities, both Meals on Wheels and similar style programs offer more than one style of food – e.g. Chinese style, Japanese style, Kosher food, and Western style.

- Burnaby – **Burnaby MOW** (Chinese and Western Food) 604-299-5754
- Burnaby – **Tonari Gumi** (Japanese Food) 604-687-2172
- Delta – **Delta MOW** 604-946-9526
- Delta (North) – **Surrey-North Delta MOW** 604-588-6325
- 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** (Glatt Kosher Food) 604-257-5151
- North Shore – **North Shore MOW** 604-922-3414
- Richmond – **Health and Home Care Society of BC, MOW**(Chinese and Western food) 604-732-7638
- Richmond – **Kosher MOW** (Glatt Kosher Food) 604-257-5151
- Richmond – **S.U.C.C.E.S.S. Multi-Level Care Society, MOW** (Chinese Food) 604-292-7200
- 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 BC, MOW**(Chinese and Western food)604-732-7638
- Vancouver – **Kosher MOW** (Glatt Kosher Food) 604-257-5151
- Vancouver – **S.U.C.C.E.S.S. Multi-Level Care Society, MOW** (Chinese Food) 604-292-7200
- Vancouver – **Tonari Gumi** (Japanese Food) 604-687-2172
- White Rock – **White Rock MOW** 604-541-6325

Want to know if a service like one in this Handbook is available in your community?

Just dial **2-1-1** – it's a free information service. bc211 is funded by UNITED WAY.

bc211 can help you find social and government services.

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

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

TTY For Deaf/Hard of Hearing Callers: 604-875-0885

There are also private business meal delivery services such as **Better Meals** 604-299-1877. This company offers frozen Regular Complete Dinner Menus (\$6.00), snack, breakfast & lunch items, diabetes and weight control menus, bland low-sodium menus and pureed menus. A \$25.00 minimum order yields a free delivery. www.bettermeals.ca

Gold Card Catering 604-594-5520 is another company that delivers frozen meals. There is a minimum order of \$30 per week plus \$2 delivery fee, but no delivery fee for orders over \$50. www.goldcardcatering.com

C) 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.

D) NUTRITION

Remember – if you have dietary concerns related to your health condition, you can speak with a registered dietitian (M - Th, 8am - 8pm; F, 8am - 5pm), by dialing 8-1-1, the free HealthLink BC non-emergency health information line. 8-1-1 provides translation services on request in more than 130 languages. For deaf and hearing-impaired assistance (TTY), call 7-1-1.

12. FOOT CARE

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 BC Podiatric Medical Association 604-985-3338 or go to 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*, in this part of the Handbook. Some foot-care nurses offer home services, but there is no association that lists them.

13. FORMS

Filling out government, medical and other kinds of 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.

14. 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'. Home owners 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 down-sizing to liberate some money, taking out a conventional mortgage or line of credit, using existing cash from investments, or getting a reverse mortgage.

Home owners 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 home owners can qualify for these types of loans – a certain level of income and good credit rating are important. 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 contains a great deal of information about reverse mortgages including comparative information about the various ways of tapping into home equity www.chip.ca

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 bi-weekly) 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) continue 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, BC (2005) so that you understand the risks involved. It is at <http://bcli.org/ccel/publications/consultation-paper-reverse-mortgages>

15. HOME MODIFICATION – FINANCIAL ASSISTANCE FOR LOW-INCOME SENIORS WHO RENT OR OWN THEIR HOMES

A) HOME ADAPTATIONS FOR INDEPENDENCE (HAFI) program, administered by BC Housing 604-646-7055, provides financial assistance to help eligible low-income seniors and people with disabilities in BC to 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 is having difficulty performing day-to-day activities independently and safely – the HAFI program may be able to help. Phone or go to www.bchousing.org/Options/Home_Renovations for details about eligible adaptations and application information. The HAFI brochure is also available in Chinese and Punjabi. N.B. This program used to be called HASI and was formerly administered by CMHC.

B) HOMEOWNER RESIDENTIAL REHABILITATION ASSISTANCE PROGRAM (HOMEOWNER RRAP) 1-800-668-2642 Canada Mortgage and Housing Corporation (CMHC) offers financial assistance to low-income homeowners for mandatory home repairs that will preserve the quality of affordable housing. The program helps people who live in substandard dwellings and cannot afford to pay for necessary repairs to their home. www.cmhc-schl.gc.ca/en/co/prfinas/prfinas_001.cfm

C) RESIDENTIAL REHABILITATION ASSISTANCE PROGRAM FOR PERSONS WITH DISABILITIES (RRAP - DISABILITIES) 1-800-668-2642 Canada Mortgage and Housing Corporation (CMHC) offers financial assistance to allow homeowners and landlords to pay for modifications to make their property more accessible to persons with disabilities. These modifications are intended to eliminate

physical barriers, imminent safety risks and improve the ability to meet the demands of daily living within the home. www.cmhc-schl.gc.ca/en/co/prfinas/prfinas_003.cfm

D) RESIDENTIAL REHABILITATION ASSISTANCE PROGRAM (RRAP - SECONDARY/ GARDEN SUITE) 1-800-668-2642 Canada Mortgage and Housing Corporation (CMHC) 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. This means there are full kitchen and bath facilities as well as 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 an 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. www.cmhc-schl.gc.ca/en/co/prfinas/prfinas_002.cfm

16. HOME SUPPORT AND HOME HEALTH CARE SERVICES – GOVERNMENT-SUBSIDIZED

See PART II., section 4 of this Handbook for the explanation about health authority based Home and Community Care services offered by Fraser Health and Vancouver Coastal Health authorities.

17. HOME SUPPORT SERVICES – NON-PROFIT SOCIETIES

A) BETTER AT HOME (B@H)

This is a new low-cost (free in some cases) non-profit home support services program that will operate in up to 68 communities across BC. It assists seniors with simple day-to-day non-medical tasks like help with housekeeping, so that they can continue to live independently in their own homes and remain connected to their communities. B@H services are designed to complement - not replace - existing community supports, such as the medical/personal care home health services offered by the health authorities Home and Community Care Services.

The BC Ministry of Health has provided \$20 million in funding for the B@H program until the end of 2015. UNITED WAY manages the program, oversees the community-development process involved, and contracts with local non-profit organizations to provide B@H services in their local community. This is consistent with United Way’s mandate to support programs that help seniors live independently and age with dignity. UNITED WAY will seek ongoing funding support for B@H.

What services are provided?

Each community-based B@H provider is asked to offer two services out of a list (or ‘basket’) of possible B@H services which includes: friendly visiting, grocery shopping, light housekeeping, light yard work, minor home repairs, snow shoveling, and transportation. If you have a B@H program in your community, the two services offered will be determined through a consultation process that involves seniors and services providers in the chosen community. This explains why B@H services can differ from community to community.

Who does the work?

A mix of volunteers and paid staff, and the mix will vary from community to community.

Who is eligible? If you are a senior living in a community that has a B@H program, you may be eligible. You can apply by contacting your local B@H service provider. A program representative will speak with you, assess your needs, and suggest services that may be of interest to you.

Cost of services

In order to ensure B@H services are available to all seniors, regardless of income, the program operates on a sliding-scale fee model which is usually based on the after tax income of the client. Some services may be free.

Adapted from the B@H website www.betterathome.ca

Communities with operating B@H programs, as of August 2013:

- Burnaby - In development
- Delta - In development
- **Langley Senior Resources Society** 604-530-3020 E: info@lsrs.ca
- **Maple Ridge/Pitt Meadows Community Services Society** 604-467-6911
- **New Westminster Seniors Services Society** 604-520-6621 E: info@seniorsservicessociety.ca
- **North Shore Community Resources Society** 604-985-7138
- **Richmond Volunteer Richmond Information Services** 604-279-7021
- **South Surrey/White Rock) Seniors Come Share Society** 604-531-2502 E: info@comeshare.ca
- **Surrey (Newton) DIVERSECity Community Resources** 604-507-2266
E: betterathomewest@dcrcs.ca
- **Surrey (Whalley) Progressive Intercultural Community Services Society (PICS) and S.U.C.C.E.S.S.** 604-596-7722
- **Tri-Cities SHARE Family and Community Services Society** 604-936-3900
- Vancouver (Eastside) - In development
- Vancouver (Hastings) - In development
- Vancouver (Kerrisdale Oakridge) - In development
- Vancouver (Kitsilano) - In development
- Vancouver (Mt. Pleasant) - In development
- Vancouver (Renfrew-Collingwood) **Collingwood Neighbourhood House** 604-435-0323
- Vancouver (South) - In development
- Vancouver (West-End) **West End Seniors' Network Society (WESN)** 604-669-5051 E: info@wesn.ca

In the case of programs marked 'In development' in this list, please contact the B@H provincial project office for updates on program development 604-268-1312 www.betterathome.ca
E: info@betterathome.ca

B) In addition to the Better at Home program, 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.

Want to know if a service like one in this Handbook is available in your community?

Just dial **2-1-1** – it’s a free information service. bc211 is funded by UNITED WAY.

bc211 can help you find social and government services.

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

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

TTY For Deaf/Hard of Hearing Callers: 604-875-0885

18. 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 \$22 per hour 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 BC, 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, you might also want to ask if the agency runs staff through ICBC driver-record checks.

19. 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 BC Income Assistance (also known as welfare, and not the same as Employment Insurance) based on your income, assets and other factors. Call the BC Ministry of Social Development. 1-866-866-0800 (press 3 + 1)

20. INCOME TAX CLINICS FOR LOW-INCOME SENIORS

1-800-959-8281 held each March and April at seniors’ centres. Senior citizen volunteers trained by Canada Revenue Agency (CRA) offer help with income tax forms for people 55 or older, or individuals who receive a disability pension. A few other criteria apply: your annual income must be less than \$25,000/ individual or \$35,000/couple; you must have a simple tax return, i.e. no returns involving rental income, self-employment income, complex stocks, bonds or dividends; and your annual investment income must be less than \$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 services 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.

21. ISOLATED SENIORS

Many seniors have huge challenges getting out of their homes, becoming house-bound. UNITED WAY estimates that social isolation affects at least ten percent of seniors in the Lower Mainland. The following kinds of services offered by some non-profit agencies 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, I&R, 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.

22. 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 Daisy disc.

23. 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:

A) 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 to first 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 so 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

B) 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.

C) 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 West Coast Domestic Workers Association 604-669-4482 exists to protect the rights of live-in caregivers and families, and warn them about malpractice in this business. Both live-ins and employers can contact CCA to get the information and support they need www.cdwcr.org

D) PRIVATE HOME SUPPORT AGENCIES

These agencies also supply workers, for a fee, who live-in on a short- or long-term basis. See HOME SUPPORT SERVICES in the Yellow Pages for a list of agencies.

E) 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.

24. 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 backgrounds, 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 call the **Music Therapy Association of BC** 604-924-0046 or visit their website. *Adapted from www.mtabc.com*

25. 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 he/she remains 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.

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.

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.

26. PREVENTING 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 ill from the heat include: make sure the person stays cool using air conditioning or fans, or spend time in a cool place such as a community centre, mall, or big box store; keep hydrated – because of a reduced sense of thirst, seniors need to drink BEFORE they get thirsty; wear loose, breathable fabrics such as cotton and linen; have a cool shower or bath; block out the sun in the house; eat food with a high water content; and check on your family member or friend a few times a day (once is not enough when it is very hot).

You can find more information on this topic 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

27. PROPERTY TAX DEFERMENT PROGRAM

604-660-2421 This program helps older people who are struggling financially to stay in the house or condo 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 BC 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 your deferment account at a rate not greater than 2% below the bank prime rate.
www.sbr.gov.bc.ca/individuals/property_taxes/property_tax_deferment/about.htm

28. SECOND-HAND THRIFT STORES

For those helping an older family member de-clutter their home or downsize after years and years of accumulating things, it is good to know that second-hand stores will take your donations. Note that 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 pick-ups because of high gas prices.

29. SENIOR PEER COUNSELLORS

Part I Section 5 of this Handbook suggests that family caregivers who are age 50 plus and feeling stressed might want to consider the free Senior Peer Counsellor service available in some communities. These counsellors are also helpful for care recipients who are struggling with the challenging changes of aging. Note that Seniors Peer Counsellors can come to you. See Part I Section 5 for more information about this outreach service.

30. SENIORS ABUSE AND INFORMATION LINE

(SAIL; formerly called the Seniors Advocacy and Information Line) 604-437-1940 1-866-437-1940 toll-free, is a safe place 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. Daily, 8am – 8pm (except holidays) www.bcceas.ca

31. SENIORS BC

This provincial program offers a website with information and resources for planning and living a healthy and active life. Included on the website are sections on benefits, caring for seniors, finances, health care, housing, transportation and more. The website is maintained by the Seniors' Directorate.

SeniorsBC also publishes the *BC Seniors' Guide* and the *BC Healthy Eating for Seniors Guide* and operates the **Seniors Health Care Support Line**.

32. SENIORS HEALTH CARE SUPPORT LINE

1-877-952-3181, M – F, 8:30am – 4:30pm BC provides seniors and their families with support when it comes to resolving health-care issues that may be related to seniors' often complex needs and the complexity of the health-care system. The support is offered by telephone so that seniors who are not computer savvy can get help, and it is meant to supplement already-existing resolution mechanisms. The Support Line is intended to be a simple, accessible way to report concerns about health care and have them handled in a respectful and timely fashion. That intention is a key component of the Province's *Improving Care for BC Seniors: An Action Plan* released in February 2012. See the part of this Handbook on Advocacy for more information about the Action Plan.

33. SERVICE BC

(formerly Enquiry BC) 604-660-2421 call centre provides information on provincial services and programs www.servicebc.gov.bc.ca

34. SERVICE CANADA

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

35. 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 he/she is able to leave the home; they may also be of interest to you, the caregiver, for social, educational, and leisure activities.

36. SPCA PET SURVIVOR CARE PROGRAM

604-681-7271 This SPCA program addresses the concern "What will happen to my pet/s when I 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 to put in your Will. There are several types of plans to choose from.

How does it work? After receiving a call from your executor, the BC SPCA will accept custody and assume ownership of your pet, provide it with care and attention in one of their facilities and arrange for a new adoptive home. They guarantee 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, "Should I become ill or incapacitated, what will happen to my pet/s?" If you enroll a small animal at the Silver or Gold Plan levels of the program, they will help you to keep your pet in the event you become temporarily hospitalized or incapacitated. The BC SPCA 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

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

Offers information and referral as well as emotional phone support to the Chinese community 10am - 10pm, in Cantonese 604-270-8233, and Mandarin 604-270-8222

38. TRANSPORTATION

A) 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. They are part of the overall discussions you will want to have about their aging, and their wishes and plans for the future should the day come when their functional and cognitive abilities decline. In regards to driving, SeniorsBC notes that "Typically, older adults live 7 – 10 years beyond their driving ability." It's 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 (OSMV) 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 because their range of motion is limited
- 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, cars stopped in front of them, or
- 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/road-safety/seniors.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. We all 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:

(i) **BCAA Road Safety Foundation** 604-298-5107 offers information on age changes and driving behavior 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. There is 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.bcaaroadsafety.com/drivers/older-drivers

(ii) The **Canadian Association of Occupational Therapists (CAOT)** created the national blueprint for older-driver education when they published *Older Drivers in Canada and Their Families* and launched the Injury Prevention in Older Drivers program. In both, 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 Driver's Safety website 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
www.olderdriversafety.ca

(iii) 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. They 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 requirement for all BC driver's license holders over the age of 80 – who hold a Class 5 driver's license – to have a Driver Medical Examination Report completed every two years, if they wish to renew their driver's license. 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 her/his ability to drive safely, the senior may be referred for a DriveABLE assessment. 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*

(iv) **DriveABLE** 1-888-475-4666 toll-free. Has the person you are caring for been referred for a DriveABLE assessment? A short video about BC'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/driveable

Note: In the spring of 2012, the *Office of the Superintendent of Motor Vehicles (OSMV)* initiated a review of the Driver Fitness Program and the DriveABLE program. There may be changes coming to these programs to ensure that seniors can keep driving for as long as it is safe to do so, while ensuring decisions on their ability to drive are done in the fairest and most respectful ways possible.

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

- *DriveABLE Cognitive Assessment Tool (DCAT)*, a touch screen software solution for identifying 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 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 province 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

(v) **Unsolicited Driver Fitness Reports**, Office of the Superintendent of Motor Vehicles (OSMV) 1-855-387-7747 toll-free. 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 (FOIPPA). 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 actions it has 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/shareddocs/factsheet-unsolicited-driver-reports.pdf*

B) TRANSPORTATION ALTERNATIVES TO DRIVING

(i) **TransLink** provides buses, SkyTrain, SeaBus and West Coast Express for public transit users in Metro Vancouver. A helpful trip planner service is available at 604-953-3333 (press 0 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. Low-income seniors and persons with disabilities are eligible for a reduced cost annual pass for travel on bus, SkyTrain and SeaBus. 1-866-866-0800, press extension 4, and then press extension 3, M – F, 9am – 4pm
www.seniorsbc.ca/transportation

(ii) **Family and Friends** can sometimes help drive someone. Faith communities often connect driving members to those who have trouble traveling to their church, synagogue or temple services and events.

(iii) **Community Seniors Transportation Programs** Some communities have small programs to assist seniors with transportation. As an example, in North Vancouver, the *North Shore Seniors Go Bus Program* transports seniors to malls, medical buildings, and recreation centres. You can look into what is available in your area.

(iv) **Better at Home (B@H)** is a low-cost non-profit seniors' services program that will be available shortly in up to 68 communities across BC. Some B@H communities offer some transportation services – usually drives to medical appointments. For much more on the B@H program, see the full Better at Home listing in this part of the Handbook.

(v) **Store Delivery Service** by grocers, pharmacists, and others is sometimes available. Let your local businesses know if this is important to you.

(vi) **Private Driving Businesses** Sometimes people who have driven for many years hesitate to use a private driving service because of the cost involved. It may 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** 1-877-613-2479 toll-free, 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 ¼ hour, minimum charge of typically 1/2 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 community or that of your care recipient, visit www.drivingmissdaisy.net

- **Home James - Opening Doors for Seniors** 604-928-7789 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, hair cuts, 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 Health Identification cards accepted for Veterans. Cost is \$50/hour; services are pro-rated to the ¼ hour, minimum charge of 1/2 hour. Gift certificates available. To see if this Metro Vancouver-based company operates in your area www.homejamesforseniors.ca E: mike@HomeJamesForSeniors.ca

○ **Private Home Support and Home Health Care Services** Some private home support agencies also 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 2-3 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* listing in this part of the Handbook for a description of the variety of services these businesses offer.

○ **SNTransport** 1-800-768-0044 Special Needs Transport 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 has received extensive training in transporting those with mobility impairments. Their hospital transfers service also offers non-emergency bed-to-bed transportation by wheelchair or stretcher. www.SNTransport.ca

○ **Taxis** Your local taxi company can provide you with an estimated cost of a trip. Also, **taxime.ca** is a website that uses Google Maps to estimate how much your cab fare will cost. Enter your start and finish address at www.taxime.ca

Note that those with physical or cognitive disabilities who have a HandyCard - more on HandyCard on the following page - are eligible for the Taxi Saver program which provides some subsidized taxi coupons.

○ **Cancer Car Program** 604-872-2034 The Freemasons of BC provide free transportation with volunteer drivers who pick patients up from their home and drive them to cancer treatments and back again. Out-of-town patients can be picked up at the airport, ferry terminal or bus depot. In Metro Vancouver the program covers Burnaby, New Westminister, Richmond and Vancouver.

(vii) TransLink Access Transit program services *Information adapted from www.translink.ca :*

○ **HandyDART** 778-452-2860 (to register to become a HandyDART user) DART stands for Dial A Ride Transportation. This door-to-door, shared-ride service uses specially-equipped vehicles designed to carry passengers with physical or cognitive disabilities who need assistance to use public transit. 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 (type in '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 and reservations are on a first come first serve basis, so book as many days in advance as possible. If you are unable to book your ride upon your initial call, call again as space may become available as other customers may cancel their rides.

Note that ‘*subscription trips*’ – that is, the regular same day/same time trips for travel to destinations such as adult day programs and 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.

Cost of HandyDART Regular ‘adult’ TransLink zone fares apply regardless of age. HandyDART does not accept any concession tickets. As well, the BC Ministry of Housing and Social Development discounted yearly bus pass is NOT accepted on HandyDART. To travel with HandyDART you can pay with cash, full fare FareSaver tickets, or full fare monthly FareCards.

- **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 lets 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 her/him, that person can ride 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 to apply to be a HandyDART user, plus you must submit two hardcopy photographs or one digital photograph with your application, and it takes four to six weeks to receive your non-transferable photo ID HandyCard.

- **Taxi Saver** 778-452-2860 is a program available for people with permanent disabilities. It provides the opportunity for spontaneous travel when HandyDART cannot accommodate their 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% subsidy toward the cost of taxi rides. Passengers use coupons that are pre-purchased through the Taxi Saver program. An eligible customer may purchase a maximum of 2 booklets each month. Each booklet costs the customer \$25 and is worth \$50 of taxi vouchers. To purchase Taxi Saver coupons you must have a HandyCard (see item ii above for how to apply for a HandyCard.) To purchase Taxi Saver coupons you must have a HandyCard (see item ii 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.

C) TRANSPORTATION ADVOCACY

- COSCO (Council of Senior Citizens Organizations of British Columbia), a large federation of BC 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.
- STAR (Seniors Transportation Access and Resources) 604-669-2860 www.starcanada.ca partially funded by UNITED WAY, is a province-wide coordinating initiative that works to assist urban, rural and remote agencies in helping seniors to age in place. STAR develops programs and provides information for active living, transitioning from driving, and new transportation resources that assist people to remain in their neighbourhoods. STAR also makes transportation available, accessible, predictable, convenient and affordable for seniors by working with agencies that provide these services. STAR provides technical and financial support for agencies wishing to provide transportation services to seniors. The STAR program is an initiative of *BEST (Better Environmentally Sound Transportation)* www.best.bc.ca

Note: In the spring of 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.

39. TYZE ONLINE PERSONAL NETWORK

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. www.tyze.com Should you decide to become a network member, there is a fee to join Tyze. It is also available through the Victoria-based Family Caregivers Network Society free-of-charge for the first year (\$129 value), limited quantities available. For more details on this trial, visit www.familycaregiversnetwork.org

40. VETERANS AFFAIRS CANADA

1-866-522-2122 For information on pension benefits plus VAC case management services for seniors that can help them manage aging in place. You must have the Veteran's service number available in order to talk with an agent. www.veterans.gc.ca

41. WESTERN INSTITUTE FOR THE DEAF AND HARD OF HEARING (WIDHH)

604-736-7391 This non-profit has clinicians who are dually registered as audiologists and hearing instrument practitioners under the College of Speech and Hearing Health Professionals of BC. They provide hearing assessments and hearing aids from all major brands. WIDHH also offers recycled hearing aids, a hearing-aid loaner program, as well as a social recreational program called Happy Hands funded by UNITED WAY. www.widhh.com

42. WHEN I'M 64

This classic made-in-BC handbook for seniors was revised in 2012 and has been republished as three separate booklets by People's Law School and BC Centre for Elder Advocacy and Support (BC CEAS):

(i) *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.

(ii) *When I'm 64: Services* lists services available to seniors in health care, housing, transportation, and recreation.

(iii) *When I'm 64: Controlling Your Affairs* contains information about planning for the future. It covers Power of Attorney, Representation Agreement, Wills, staying safe and secure, and protection from frauds and scams.

Availability: Find the booklets at seniors' centres or at:
www.publiclegaled.bc.ca/product/when-im-64-benefits
www.publiclegaled.bc.ca/product/when-im-64-controlling-your-affairs
www.publiclegaled.bc.ca/product/when-im-64-services

There are only four kinds of people in the world –
those who have been caregivers,
those who are currently caregivers,
those who will be caregivers,
and those who will need caregivers.

Rosalynn Carter

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

You will know that, no matter how many community supports are in place, the day may come when your care recipient is just no longer able to remain living at home. It may be the need for 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 one looms large – and is upsetting. ‘Home’ is filled with so many meanings and memories.

The changes in behaviour, mood, and health that can accompany the moving process are so widespread they have a name - *Relocation Stress Syndrome*. So expect to find yourself tired and confused and sorting through many feelings – including anger, guilt, helplessness, a lot of sadness, even relief since your loved one will have others to help him or her, relieving you of some caregiving duties. And know that your care recipient will be experiencing a flood of emotions, poor sleep and so on. Brace yourself as you prepare to manage the plethora of practical issues related to moving a loved one.

1. PREPARING TO MOVE

Start early. Don’t wait until a crisis hits to begin a conversation with a loved one about the 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, 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, however, there is very little time to prepare. The sudden onset of an illness (a bad stroke, for example) or a fall that results in a broken hip (when home is a place with many stairs) can necessitate a change in housing with almost no notice at all.

The time between notification of a vacancy for a place where a senior is on a wait list and 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 you rent, make sure you know your obligations to your landlord about proper vacancy notice procedures; if you own, 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 including BC Medical Services Plan, bank, insurance company and social organizations; 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 www.fraserhealth.ca/your_care/residential_care

Throughout the moving process, remember that there are services available to support family caregivers and care receivers with the turmoil and challenges of moving house late in life. See PART II.

EDUCATION AND SUPPORT RESOURCES FOR FAMILY CAREGIVERS about counselling services and crisis lines.

The following pages describe the types of housing for seniors who are no longer able to live independently at home, as well as the types of housing providers found in the Metro Vancouver area, and where, the regulations that apply, the costs of the different housing types, and how to apply for a bed, room or suite.

2. THREE TYPES OF SENIORS' HOUSING

Aside from the option of housing your loved one in the home of an adult child, there are three types of seniors' housing available: Supportive Housing, Assisted Living and Residential Care. These are part of what's known as 'the continuum of care', a continuum that ranges from low- through medium- to high-levels of care. In some cases, more than one type of housing is available in a given housing development – e.g. on different floors of a building or in different buildings on the site. This situation, which makes future moves from one level of care to another much simpler, is referred to as 'a campus of care.'

This Handbook has parts on each of Supportive Housing, Assisted Living and Residential Care. See below.

3. THREE TYPES OF SENIORS' HOUSING PROVIDERS

These are government-subsidized housing providers, non-profit society housing providers and private housing providers.

4. WAIT LISTS

Regardless of the type of housing or the type of service provider, wait lists are common. Housing that is government-subsidized (the least expensive type) has the longest wait lists. Non-profit society-operated housing has long wait lists too, and seniors' housing run by the private sector often has wait lists as well. Never assume that a space will be available on demand. This is one of the many reasons this Handbook stresses **DON'T WAIT UNTIL THE LAST MINUTE OR FOR A CRISIS – THINK AND PLAN AHEAD.**

5. WHERE ARE SENIORS' HOUSING COMPLEXES LOCATED?

The Ministry of Health lists all registered Assisted Living complexes in BC at www.health.gov.bc.ca/assisted/locator/index.php/displayhealthauthority/index

Fraser Health Authority www.fraserhealth.ca and Vancouver Coastal Health Authority www.vch.ca websites list all the government-subsidized Assisted Living and Residential Care buildings in each of the communities they serve.

The following also keep lists of housing providers across the continuum of care. Note it is challenging to keep housing information current, so never rely on just one database:

- **Seniors Services Society** 604-520-6621 (formerly Seniors' Housing Information Program or SHIP) publishes the *Seniors Housing Directory of BC* on their website at www.seniorsservicesociety.ca The website lists seniors' housing complexes across BC – from independent living all the way to residential care – provided by all types of housing providers.
- **Senior Living Magazine**, a free business publication from Victoria, offers a web-based *Housing Directory* of seniors housing in BC at www.seniorlivingmag.com/housingdirectory
- **The Care Guide** is a free booklet about seniors' housing and providers. Published by a Toronto business, there is a BC edition. To request a copy, go to www.thecareguide.com
- The names of **Housing Providers** and **Buildings** can also be googled in a search.
- **Your Public Library** reference librarians can also help you find seniors' housing information.

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

1. WHAT IS SUPPORTIVE HOUSING AND WHO IS IT FOR?

If needs are relatively simple, Supportive Housing (SH) will be sufficient - it includes a number of basic supports in the monthly fee. SH provides a private suite with locked door, at least one meal daily – and 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.

SH does not offer personal health care services such as bathing and help with getting dressed and taking medications as part of their monthly rent fee. 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 health authority Home and Community Care Services or, alternatively, a home support service that you hire privately. Sometimes a SH-provider offers its own support service program which you can purchase separately in addition to your regular monthly services fee.

2. WHO REGULATES SUPPORTIVE HOUSING?

The BC Residential Tenancy Act regulates the rental portion of SH, just as it regulates rental apartments. But the services portion (i.e. meals, activities and housekeeping) are not regulated at this time.

3. WHO OFFERS SUPPORTIVE HOUSING?

A) GOVERNMENT-SUBSIDIZED SUPPORTIVE HOUSING does not offer personal health care, and so it is not subsidized by the BC Ministry of Health.

B). NON-PROFIT SOCIETY SUPPORTIVE HOUSING

To Apply to SH units offered by non-profit societies, contact the building providers directly.

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

List of Buildings See the information at the end of PART V. of this Handbook for how you can find a list of SH buildings.

C). PRIVATE/BUSINESS SUPPORTIVE HOUSING

To Apply to SH units offered by businesses, contact the buildings directly.

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

List of Buildings See the information at the end of PART V. of this Handbook for how you can find a list of SH buildings.

PART VII. HOUSING OPTIONS – ASSISTED LIVING

Some of the information in this part of the Handbook has been cut and paste or adapted from the BC Ministry of Health webpages at www.health.gov.bc.ca/assisted

1. WHAT IS ASSISTED LIVING AND WHO IS IT FOR?

The next service level on the care continuum of seniors' housing – an option if more assistance is required than Supportive Housing provides - is called Assisted Living (AL). AL is semi-independent housing for those who are cognitively able to make their own decisions about day-to-day activities (unless they are living with a spouse who can make decisions on their behalf). 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 assisted living, they must move to a setting that offers more oversight, care and protection, such as residential care.

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

A) 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.

B) HOSPITALITY SERVICES

By law, AL operators must offer five hospitality services:

- (i) Meals – one to three meals 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; and appropriate professional advice (e.g. from a registered dietitian) is obtained for the menu plan and when preparing meals in accordance with special and/or therapeutic diets
- (ii) Housekeeping – light housekeeping is provided at a frequency to meet residents' health and safety needs
- (iii) Laundry – laundering of flat linens (sheets and towels, whether supplied by the resident or the operator) once a week
- (iv) Social and recreational opportunities
- (v) 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 more information about the services offered in private-pay assisted living, ask the operator directly. For government-subsidized AL, ask your health authority case manager. Operators provide hospitality services through their own staff or through a contract with third parties.

The UNITED WAY-managed *Better at Home* non-medical home support program is available in some BC communities, with more planned. It offers extra services that can help residents living in AL. Read more about the Better at Home program in the HOUSING-AGING IN PLACE AT HOME USING COMMUNITY SERVICES part of this Handbook.

C) PERSONAL ASSISTANCE SERVICES

AL is modeled 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 two of these **personal assistance** areas (to provide personal assistance to seniors beyond these two areas would contravene the Assisted Living regulations):

- (i) *Regular assistance with activities of daily living, including eating, mobility, dressing, grooming, bathing and personal hygiene, and/or*
- (ii) *Central storage of medication, distribution of medication, administering or monitoring the taking of medication.*

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 the private home's 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.

AL operators must not house people who cannot make decisions on their own behalf (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' to transfer the resident to other accommodation. 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 an AL residence, 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.

2. WHO REGULATES ASSISTED LIVING?

In BC, AL services are regulated under Bill 73 (2002), the *Community Care and Assisted Living Act* through the Assisted Living Registrar 1-866-714-3378, toll-free. The Registrars' role is to protect the health and safety of AL residents in government-subsidized, non-profit, and private business AL residences. The Registrar administers the AL provisions of the Act, which require all AL operators to register their residences 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.

Adapted from the Ministry of Health website www.health.gov.bc.ca/assisted E: info@alregistrar.bc.ca

3. WHO OFFERS ASSISTED LIVING?

A) GOVERNMENT-SUBSIDIZED ASSISTED LIVING

To Apply

The person needing assistance must go through an assessment by a local health authority office case

manager, and be assessed as requiring AL. Do not contact the housing provider directly regarding subsidized AL units – they will only refer you back to your local health authority office.

Cost

Government-subsidized AL costs 70% of after-tax/net income for rent, hospitality services and personal assistance services, subject to a minimum and a maximum cost set annually by the Ministry of Health. Funding from a government-subsidized AL program is not transferable to a private pay AL community.

List of Buildings

Government-subsidized AL buildings list can be found at www.health.gov.bc.ca/assisted/locator/index.php/displayhealthauthority/index The list is broken down first by health authority 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 private business) units in the building are noted. The case manager will also provide you with a list of government-subsidized buildings in your area.

B) NON-PROFIT SOCIETY ASSISTED LIVING

To Apply

For AL units offered by non-profit societies, contact the buildings directly.

Cost

Rates begin at approximately \$1,750/month but can be much higher and can differ among buildings.

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, BC Housing 604-433-2218 subsidizes the Shelter Aid for Elderly Renters (SAFER) program which sometimes helps make rents – including the rent portion of supportive housing costs – affordable for BC seniors www.bchousing.org/Initiatives/Providing/SAFER

List of Buildings offering non-profit society AL can be found at www.health.gov.bc.ca/assisted/locator/index.php/displayhealthauthority/index The list is broken down first by health authority 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.

C) PRIVATE/BUSINESS ASSISTED LIVING

To Apply

For AL units offered by private businesses, contact the businesses directly.

Cost

Each private business sets its own price and residents must pay all costs. Private-pay 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 \$1,800 - \$6,000/m. Remember - for people aged 60 or older with low to moderate income, BC Housing 604-433-2218 subsidizes the Shelter Aid for Elderly Renters (SAFER) program which sometimes helps make rents – including the rent portion of supportive housing costs – affordable for BC seniors www.bchousing.org/Initiatives/Providing/SAFER

List of Buildings offering private/business AL can be found at www.health.gov.bc.ca/assisted/locator/index.php/displayhealthauthority/index The list is broken down first by health authority, 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.

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

1. WHAT IS RESIDENTIAL CARE AND WHO IS IT FOR?

RC, which is known by many names (see the title bar above) 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. The recent introduction of the Ministry of Health's *Home is Best* initiative means that there may be options to RC that are more suitable for your loved one. Speak with the health care providers to explore the options.

Note that RC provides dementia care; this is because a large proportion of residential care residents have dementia. A few facilities also have a 'special care unit' (SCU), but a facility does not need to have an SCU to care for people with dementia.

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, 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 government-subsidized 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 get used 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 government-subsidized or a private pay (i.e. either a non-profit or private/business) facility, you can 'add on' 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 a long-term service you wish to have.

2. WHO REGULATES RESIDENTIAL CARE?

RC facilities are licensed under the BC *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 BC. They 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 (Residential Care Regulation). During inspections, licensing staff look for items typically divided into ten broad categories to determine if they meet the minimum requirements to ensure the health, safety and well being of persons in care. The ten categories are: 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.

Health Authority 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 Reports for RC facilities in 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 another Act - the Hospital Act. You can ask any facility that you are considering for a copy of their latest Licensed Residential Care Facility Inspection Report. Note that, after every inspection, the facility will have a report that identifies any 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. The information provided on the website is not enough to determine if a facility is the best one for your loved one or you.

What will the Health Authority 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 inspections. You are encouraged to visit each facility that is being considered before making a choice. Call ahead to make an appointment.

Adapted from www.health.gov.bc.ca/ccf/facility-inspection-reports.html

The **Vancouver Sun newspaper's Facility Inspection Database** explains how to probe more deeply into problems at a particular long-term care residence.

www.docstoc.com/docs/2552448/How-To-Use-The-Vancouver-Suns-Facility-Inspection-Databases-www-

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 health authority 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 1-877-880-8823 (FHA) or 1-877-993-9199 (VCHA). The Ministry of Health states that: Once a complaint has been investigated and is substantiated, a summary of the complaint is posted on the health authority 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 Board. Lastly, you can call the Seniors Health Care Support Line 1-877-952-3181 which provides seniors and their families with support for health care-related issues that they may have had

trouble resolving due to the intricacy of the health-care system. This line supplements existing resolution mechanisms available to support seniors with complex needs who have concerns about their health care.

If the above processes do not resolve your concern, you can contact the Office of the Ombudsperson 1-800-567-3247 www.ombudsman.bc.ca to see if that office can help you. See also the Advocacy part of this Handbook for information about advocating for residential care residents.

3. WHO OFFERS RESIDENTIAL CARE?

A) GOVERNMENT-SUBSIDIZED RESIDENTIAL CARE

To Apply

For placement in a government-subsidized residential care bed, do not contact the facility (or the housing provider) directly. They can only refer you back to your local health authority office. For a government-subsidized long-term care bed your first step is to see that your care recipient is assessed by the local health authority 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 has:

- (i) complex care needs that require continuous care;
- (ii) care needs that cannot be met safely by community-based resources; and
- (iii) an immediate need for residential care (although it could take some weeks to get a bed).

The case manager will provide a list of RC facilities and you will be asked to state a preferred or first-choice facility. Then your name will be forwarded for the **first available and appropriate bed** vacancy. Wherever possible, the health authority will do its best to offer you a bed in your preferred place. However it cannot guarantee that you will be placed in any particular facility. The expectation is that you will move into the first appropriate residential care bed offered to you, within either 24 or 48 hours, depending on the location.

This is how the government explains the placement process in their webpage on Long-Term Residential Care at www2.gov.bc.ca/gov/topic.page?id=4FEC0F570BC04692810548267D09577E “Once eligibility has been determined, access to long-term residential care services is on a priority basis, considering client needs, existing supports, and urgency of the response required. Priority placement is given in the facility that has an appropriate bed available*. As the goal is to find a residential care facility that meets the care needs for people at risk as quickly as possible, sometimes individuals are not placed in the facility that is their first choice.” In that case, a request can be made to have the elder’s name put on a transfer list.

*Note that the language here – ‘first appropriate residential care bed’ and ‘priority placement’ - refer to the Ministry of Health’s *Priority Access Program* policy implemented in 2002 which was designed to significantly cut wait lists.

At times, the health authorities experience shortages in residential care 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 residential care 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 his or her 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 you move in, an orientation to the facility will be provided by staff. The orientation will offer an opportunity to answer specific questions related to daily routines and care personnel. Ask for a facility orientation booklet.

Once you (or your care recipient) have moved into the bed you have been given, you can ask for your name to go on a transfer list for your preferred residential care facility. (This might be in your health authority area or the geographical area of another health authority, e.g. for Victoria, under Victoria Island Health Authority). When a vacancy arises at the place you wanted to be transferred to, you have the choice of accepting that new bed or declining to move again.

The above was adapted from *First Appropriate Bed...Patients/Clients Being Cared for in the Most Appropriate Setting*, by Fraser Health Authority, November 2011

Cost

In government-subsidized care, the health authorities 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 (from www2.gov.bc.ca/gov/topic.page?id=4FEC0F570BC04692810548267D09577E):

“You will pay up to 80% of your after tax income on a monthly basis to cover the cost of housing and hospitality services including meals, routine laundry and housekeeping, subject to a minimum and maximum monthly rate. Your monthly client rate for long-term residential care services is determined as follows:

- (i) If your income is less than \$19,500 (Formula A):
 - annual after tax income less \$3,900 (\$325 multiplied by 12), divided by 12.
- (ii) If your income is equal to or greater than \$19,500 (Formula B):
 - annual after tax income multiplied by 80%, divided by 12.

The minimum monthly rate for a client receiving residential care services is \$958.90 per month. The minimum rate is adjusted annually based on changes to the Old Age Security/Guaranteed Income Supplement rate as of July 1 of the previous year.

The minimum monthly rate for spouses receiving residential care services and sharing a room, where the couple is in receipt of the Guaranteed Income Supplement at the married rate, is \$709.90 per month.

The maximum monthly rate for a client receiving residential care services is \$3,059.00 per month. The maximum client rate is adjusted annually based on changes to the Consumer Price Index.

If payment of your assessed monthly rate would cause you or your family serious financial hardship, you may apply to your health authority 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.”

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, ask to have your name put on the wait list, after you have been admitted.

List of Buildings

For a list of government-subsidized 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/

B) NON-PROFIT SOCIETY RESIDENTIAL CARE

To Apply

Because you or your loved one would not be in a government-subsidized bed, and you will be paying 100% of the cost of housing and care, you can apply to any non-profit residential care facility. You 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 health authority home health staff is **not** needed for admission to a non-profit residential facility.

Cost

Rates begin at approximately \$3,000/month but can be much higher and can differ from one building to the next.

List of Buildings

The following websites contain listings of all RC facilities in BC – government-subsidized, non-profit and private/business – 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

C) PRIVATE/BUSINESS RESIDENTIAL CARE

To Apply

For-profit businesses also offer residential facilities where rooms and services are paid for by the resident and are not subsidized by the health authorities. Depending on individual financial circumstances, a private/business 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/business facility. An assessment by health authority case management staff is **not** needed for admission to a private pay residential facility. Contact these facilities directly for detailed information about availability, costs and services. Be mindful of the fact that private/business facilities often have wait lists too.

Note: Some long-term care facilities provide both health authority 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 \$3,300 to \$7,500/month depending on the building and level of care available. Residents are responsible for 100% of all costs.

List of Buildings

The following websites contain listings of all RC facilities in BC – government-subsidized, non-profit and private/business – 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

4. OTHER IMPORTANT ISSUES IN RESIDENTIAL CARE

A) RESIDENTS' BILL OF RIGHTS

The BC 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.”

From www.health.gov.bc.ca/ccf/pdf/adultcare_bill_of_rights.pdf

B) ANTIPSYCHOTIC DRUG USE IN RESIDENTIAL CARE

As explained in the BC Ministry of Health report, *A Review of the Use of Antipsychotic Drugs in British Columbia Residential Care Facilities* (2011), antipsychotic drugs were originally developed to treat schizophrenia and other psychoses, but have increasingly been used to treat the 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 dementias might experience symptoms including delusions, hallucinations, verbal outbursts, agitation and physical aggression. This can create 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 BC guidelines.

For more information on the issue: The **BC Patient Safety and Quality Council** has launched a Call for Less Antipsychotics in Residential Care (CLeAR) and is working towards reducing the number of residents on antipsychotic medications by 50% across BC by the end of 2014. www.bcpsqc.ca/clinical-improvement/clear/ **Advocates for Care Reform** has a fact sheet *Antipsychotic Medications In Long Term Care* (2012) with guidelines on *What You Can Do As An Involved Family Member* www.acrbc.ca

C) 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*, available as a pdf at www2.gov.bc.ca/gov/topic.page?id=96139325762343BB9F289A0C0F73D868

Advocates for Care Reform (ACR), a non-profit society dedicated to improving the quality of care and quality of life for people living in residential care in BC, 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 residential care through advocacy and education. In October 2012, the non-profit voted to dissolve the organization but members have decided to keep information and materials on the ACR website www.acrbc.ca

Find more information on Residential Care 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. Google 'Planning for Your Care Needs'
- Visit <http://www2.gov.bc.ca/> and type 'Long-term Residential Care' in the search box

PART IX. LEGAL ISSUES IN FAMILY CAREGIVING – ABUSE

The information below has been adapted from HealthLink BC, and is also available in Chinese (Traditional), French, Punjabi, Spanish, and Vietnamese at www.healthlinkbc.ca/healthfiles/hfile93b.stm

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 occurs, even when a family member means well but becomes overstressed. In many cases, the person who is abusive is a spouse or partner, another family member or someone else a care recipient relies upon or 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.

Most people do not intend to become abusive or neglectful. They 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 similar way.

Family caregivers 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 problems. This may mean that it is more difficult for them to safely offer hands-on caregiving.

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

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 8-1-1 BC HealthLink to speak with a health professional for information and advice. 24/7 multilingual service available
- The Seniors Abuse and Information Line (SAIL) 604-437-1940 or 1-866-437-1940 toll-free, 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, or to receive information about elder abuse prevention. Daily, 8am – 8pm (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; in the future, it is likely that someone will be a caregiver 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.)*

1. PERSONAL PLANNING – MAKING ARRANGEMENTS IN CASE OF INCAPABILITY

What is personal planning?

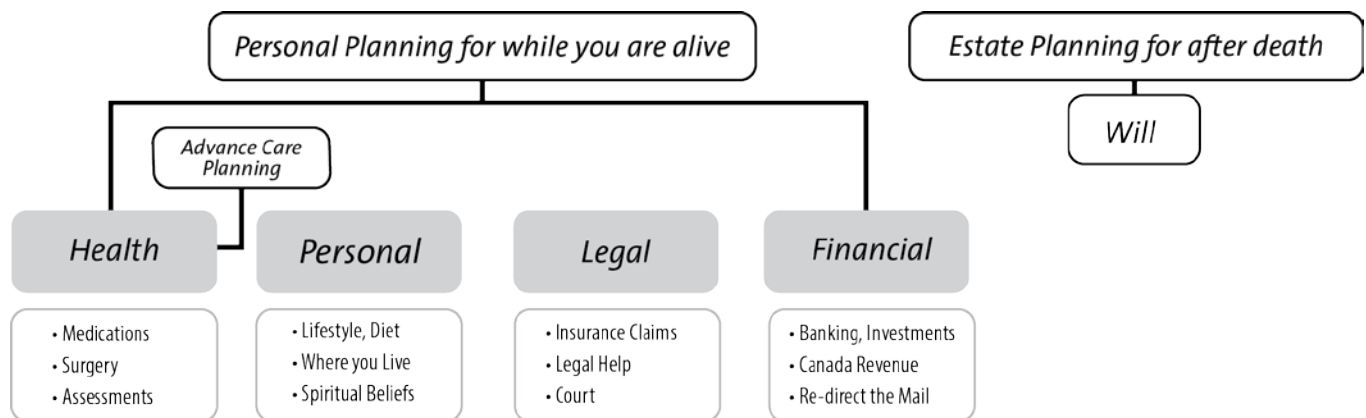
We are all familiar with estate planning, which is about making arrangements for after we die. A Will is the legal document people use to give legal authority to someone (an executor) to settle their estate. The term *personal planning* is about making arrangements in case you need help managing your affairs during your lifetime due to illness, injury, or disability. The key document for personal planning is the 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 and allows us to stay in control.

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?

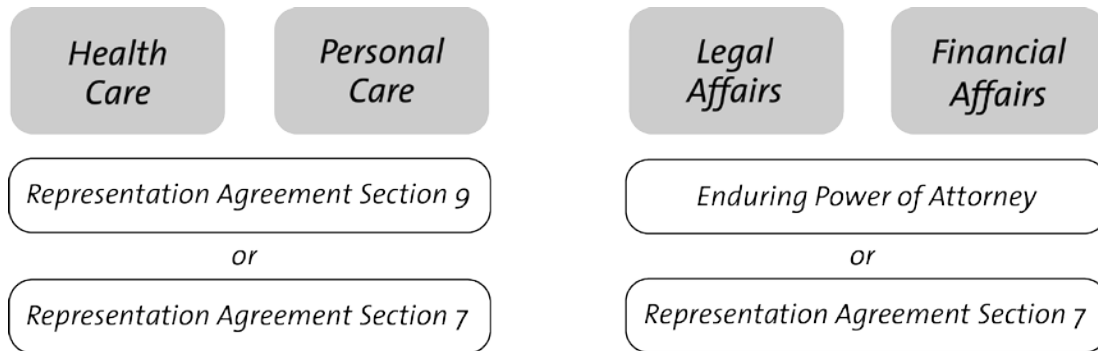
- It makes things easier on your family and friends.
- It avoids the need for the government to be involved in your personal and private affairs.
- It lets you stay in control of your life by ensuring that those you trust can advocate for you and carry out your wishes, if you need help speaking up for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

What if I do not plan?

Planning is voluntary, but if you become incapable and do not have a plan in place, other laws or the courts will determine who can make decisions for you. More on the ‘default scheme’ further down.

2. LEGAL DOCUMENTS FOR PERSONAL PLANNING IN BC

There are four legal documents available for personal planning: Representation Agreement Section 7 (RA7), Representation Agreement Section 9 (RA9), Enduring Power of Attorney (EPA), and the Advance Directive (AD). The Advance Directive is discussed later under Frequently Asked Questions.



Which document(s) do I make?

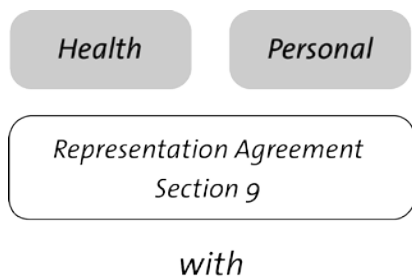
Read the example of John and Mary and learn about the legal documents for people, like John, who are planning for the future, or people like Mary, who need help today with managing their affairs.

EXAMPLE: John and Mary are 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, so if something happens, people will know what to do for him and for Mary.

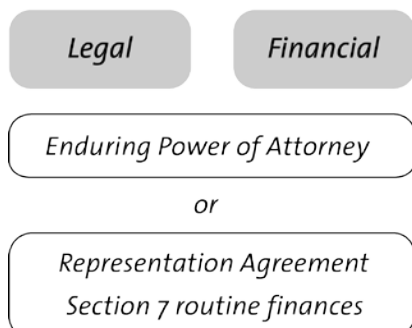
Are you planning for the future like John?

John is capable of making his own decisions and wants to plan for the future. If you are planning for the future, like John, you will make two documents to cover all areas of authority: you will make the RA9 for health and personal care, and you will make an EPA or an RA7 to cover financial and legal affairs.

PLANNING FOR THE FUTURE



John makes the **RA9** for health and personal care matters. The RA9 requires that John understand he is planning for the future in case he becomes incapable of making health or personal care decisions. He appoints his daughter as his representative and his son as the alternate. The RA9 gives John's representative the authority to act on his behalf for major and minor health care matters, including the final say to refuse life support, and for personal care such as living arrangements.



John chooses between two documents to cover financial and legal affairs: the EPA or the RA7. The EPA covers more than the RA7. For example, the EPA covers dealing with real estate but the RA7 does not. John and Mary downsized their house several years ago and do not intend to sell. John makes an **EPA** appointing his daughter and his son, just in case they ever need to sell the house on his behalf, before his death. John is able to make an EPA because he meets the capability requirements, which include understanding what he owns, its value, and his legal obligations.

EXAMPLES OF AUTHORITIES/POWERS – RA9 with EPA or RA7

Health & Personal Care		Legal & Financial Affairs	
RA9	EPA	RA7	
Minor Health Care - medications, routine tests, end-of-life comfort care	Settling an insurance claim, hiring a lawyer, representing in court	✓	<i>OR</i>
Major Health Care - surgery, kidney dialysis, procedures requiring anesthetic	Banking, managing existing loans, insurance investments	✓	
Final say to refuse life support	Selling a vehicle, re-directing the mail	✓	
Diet, exercise, activities, spiritual beliefs	Canada Revenue	✓	
Living arrangements	Dealing with real estate	✗	
Move or manage you, even against your objections	Acting on your behalf of a corporation you own or serve on	✗	

Are you helping someone like Mary who needs help today?

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. However, Mary may make an **RA7**. The RA7 looks at capability differently. The RA7 presumes Mary is capable. The law 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. Mary will be treated with respect and dignity. This is referred to as supported decision making.

WHEN YOU NEED HELP TODAY

Health
Personal
Legal
Financial

Mary makes an RA7 to cover all life areas. The Representation Agreement Act says Mary may make this legal document even if she cannot manage her own finances or make her health care decisions independently.

Representation Agreement
Section 7

John is her representative, their daughter is the alternate, 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 and legal affairs. There are also a number of practical things he can do under routine finances including selling their jointly owned motorhome.

EXAMPLES OF AUTHORITIES/POWERS – RA7

Health & Personal Care	Legal & Routine Financial Affairs
<i>Representation Agreement Section 7</i>	
Minor Health Care - medications, routine tests, end-of-life comfort care	Settling an insurance claim, hiring a lawyer, representing in court
Major Health Care - surgery, kidney dialysis, procedures requiring anesthetic	Banking, managing existing loans, insurance investments
Living arrangements	Selling a vehicle, re-directing the mail
Diet, exercise, activities, spiritual beliefs	Canada Revenue

Who can I appoint in my documents?

Most people appoint their spouse, a family member or a friend. Those appointed must be 19 years or older; they do not have to live in BC. 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, unless they are your spouse, parent or adult child. For example, you cannot appoint your doctor or a paid caregiver.
- An employee of a facility where you live and that provides health care or personal care services to you, unless they are your spouse, parent or adult child. For example, if you live in an assisted living residence, you cannot appoint the administrator, the cook or other staff.

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 appoint:

- Representative: One or more person(s) 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.
- Alternate: One or more person(s) who is a back-up in case the representative is not available.
- 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:

- Attorney: One or more person(s) 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.
- Alternate attorney: One or more person(s) who is a back-up 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. There are forms for Representation Agreements because the law does not require a legal professional. If you need to make an EPA, a legal professional will draft the document for you.

REPRESENTATION AGREEMENT FORMS

Nidus provides RA9 and RA7 forms through its website. Nidus forms are based on legal requirements as well as practical needs. Nidus 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 Advance Care Planning Guide. These 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.

A key difference between the Nidus and the government forms is that the Nidus RA forms include wording to allow the alternate to act on a temporary basis to provide relief for a representative, which reflects real life situations (especially those of caregivers). The government forms only allow the alternate to step up if the representative is permanently unavailable. Also, the wording in the government form requires that the alternate provide a Statutory Declaration signed by a lawyer or notary to prove

they can act. This is an extra cost and not practical in health care situations, which can be urgent. Nidus' long term experience helping caregivers alerted us to ensuring that RA forms allow for flexibility.

ENDURING POWER OF ATTORNEY 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. Nidus has fact sheets and other information about the EPA that you can use to prepare for your meeting with the legal professional, who will draft your EPA document.

Frequently Asked Questions

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

No. In BC, 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.

If I have a living will, do I need a Representation Agreement?

Yes. A living will is not a legal document under BC 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.

What is Advance Care Planning?

Advance care planning focuses on planning for health care, in case you become incapable. Personal planning is a broader term as it refers to the process of planning for all life areas.

The Ministry of Health produced a Guide called *My Voice: Expressing My Wishes for Future Health Care Treatment*. It includes a section with blank boxes to fill in your wishes, beliefs and values. This is referred to as an advance care plan – another term for living will. You give a copy to your representative.

My Voice also includes the government forms for Representation Agreements. See the previous section and the question “Where do I obtain the legal forms?”

What is an Advance Directive?

An Advance Directive (AD) is a legal document under BC 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. Generally, someone who is capable of making an RA9 would be capable of making 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.

An AD is not equivalent to 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. If you have a representative, they are able to have a discussion with the health care provider to clarify the meaning of your instruction and say when it must be applied. If you make an AD, you can give it to your representative, appointed in your RA9.

An Advance Directive form is provided by the Ministry of Health on page 50 of their *My Voice* Guide. See “Resources on Personal Planning” below to locate the Guide.

Is my Bank Power of Attorney enough?

No. A Bank EPA is not enough. You still need a general EPA or an RA7. A Bank EPA only covers dealing with accounts at that institution. It will not help with other financial affairs such as dealing with Canada Revenue, renewing car insurance, re-directing the mail and much more.

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. 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 in order to sell it if your spouse is incapable.

3. 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 courts 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 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 (government official) is the last resort if no one else qualifies.

Default for Personal Care

There is no separate default scheme in law to determine who can act on your behalf for personal care – as there is for health care (TSDM). This 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 as adult guardianship is intended to be the last resort. In this scheme, someone will hire a lawyer and apply to Court to be appointed the adult’s Committee (guardian) of Person to take over the adult’s health and personal care decisions. You can read more about Committeeship under the next heading.

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 in place or these documents are not sufficient.

Your financial and legal decision making rights can be taken over in two different ways:

1. The Public Guardian and Trustee (PGT), a government official, can take over your affairs if a designated health care provider assesses you as incapable and submits a Certificate of Incapability to Manage Finances to the PGT. There is no hearing or appeal in this process; or
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 Person generally takes 4-5 months and costs \$5,000 - \$7,000. However, the greatest cost of adult guardianship is that you lose your civil rights: legally, you become a non-person.

4. AFTER YOU MAKE YOUR PERSONAL PLANNING DOCUMENTS

Registering with the Nidus Personal Planning Registry www.nidus.ca/registry

You can register any personal planning document with the Nidus Personal Planning Registry™. The registry service lets you store information and a copy of your document(s) including Representation Agreement, Enduring Power of Attorney, Living Will, Advance Care Plan, Revocation and more.

When you fill out the registration forms, you can allow authorized third parties to search for your registration – for example, 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 \$25.00 to set up your Registry Account and register one document. You can register additional documents for \$10.00 each. You will receive a Registry Wallet Card with your Nidus ID once your initial registration is processed.

Safekeeping Your Original Personal Planning Document(s)

The original document is proof of your representative's or attorney's authority. 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.

Using the Representation Agreement and/or Enduring Power of Attorney

Read the Nidus fact sheet on Access to Information. It explains how to introduce the legal document to third parties – financial institution, hospital, government agency and others – and how to use it.

Resigning as a Representative or Attorney

You can resign if you are a representative or alternate appointed in a Representation Agreement or an attorney or alternate appointed in an Enduring Power of Attorney. Nidus has information and forms.

Revoking/Cancelling a Personal Planning Document

Each type of document has requirements for how to legally revoke/cancel it. In the case of a Representation Agreement or Enduring Power of Attorney, you must put your revocation in writing.

Making a new document does not automatically revoke the previous RA or EPA. Nidus has information and forms for making a Notice of Revocation. Read the Nidus fact sheet on Advance Directives to learn the requirements for revoking an AD.

5. RESOURCES ON PERSONAL PLANNING

Nidus Personal Planning Resource Centre and Registry

Nidus 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 below on where to find help.

You can access personal help from Nidus by appointment: in-person or phone. You need to book in advance through the website. Nidus also offers training as we want to enable community groups to provide information and assistance with personal planning at the local level.

Nidus Personal Planning Resource Centre and Registry

Visit these highlighted areas on the Nidus website for helpful information and tools. Use the tabs and side-bar to access these resources.

Information	Self-Help	Featured
<ul style="list-style-type: none">RA Fact SheetRA Resources<ul style="list-style-type: none">• Roles and Duties• Access to InformationEPA Fact SheetEPA ResourcesHealth Care Consent	<ul style="list-style-type: none">Forms<ul style="list-style-type: none">• Making RA7• Making RA9Tools<ul style="list-style-type: none">• Personal Information Record• Values/Beliefs Discussion GuidePresentations<ul style="list-style-type: none">• Online Webinar• In-person	<ul style="list-style-type: none">Subscribe to our newsAppointments<ul style="list-style-type: none">BOOK NOW• In-person• Over-the-phoneQ&A - Ask Joanne

www.nidus.ca

BC Ministry of Health

The Ministry of Health has information and resources on its website to promote advance care planning, including information in Chinese and Punjabi and for the First Nations community. The Ministry also has other useful resources of interest to seniors and caregivers.

<http://www.gov.bc.ca/health/> - click on SeniorsBC in the left margin.

The Public Guardian and Trustee

The Public Guardian and Trustee has information on adult guardianship (Committeeship) as well as a booklet on personal planning tools in BC.

http://www.trustee.bc.ca/reports_publications/index.html – scroll down to Adult Guardianship – click on Its Your Choice – Personal Planning Tools

Legal Professionals – Lawyers and Notaries

To locate a lawyer, contact the Lawyer Referral Service at 604-687-3221 or 1-800-6631919 toll-free. 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 1-800-663-0343 or search www.notaries.bc.ca

PART XI. END-OF-LIFE

One of the most difficult times for anyone is when a loved one is dying. A number of services are available to support the dying person have a kind of death consistent with their values, and also support the family caregivers.

1. BC MINISTRY OF HEALTH – END-OF-LIFE CARE SERVICES

End-of-life care is supportive and compassionate care that improves the quality of life for dying people and their families. (It may also be called supportive care, palliative care or symptom management.) Care at the end of life addresses physical, psychological, and spiritual needs of the dying person and focuses on comfort and symptom management, respect for decisions, and support for the dying person and their family. Care can be provided wherever the client is living, whether in their home, an assisted living residence, a residential care facility, or a hospice (a building or a hospital ward for people who are dying).

Adapted from the End-of-Life Care website

<http://www2.gov.bc.ca/gov/topic.page?id=CC1FF2DFADD34BEC85869ECBA40A27AA&title=End-of-Life%20Care>

As explained in Part II., section 4 of this Handbook, end-of-life care services aim to preserve an individual's comfort, dignity and quality of life as their needs change, and offer on-going support for family/friend caregivers. These services include care coordination and consultation, pain and symptom management, community nursing services, community rehabilitation services, home support, respite for the caregiver and residential hospice care.

How do I arrange for end-of-life care services?

If you know someone who might be in need of these services, you can contact the Home and Community Care office of their health authority (see phone numbers in the box below). Alternatively you can have the dying person's health care professional, e.g. home care nurse or doctor, make a referral.

HOME AND COMMUNITY CARE OFFICES

Fraser Health Authority (FH) www.fraserhealth.ca

1-855-412-2121 toll-free, 7 days a week, 8:30am - 4:30pm

Vancouver Coastal Health Authority (VCH) www.vch.ca

VCH - North Shore 604-986-7111 M - F, 8am - 4:30pm

(After hours, leave a message)

VCH - Richmond 604-278-3361 M - F, 8:15am - 5pm

(After hours, leave a message)

VCH – Vancouver Community 604-263-7377 M - F, 8:30am - 5:30pm

(After hours, leave a message)

A little more about end-of-life care (from www.fraserhealth.ca/your_care/hospice_palliative_care):

Are palliative and hospice care the same thing?

Yes, and the terminology is a bit confusing. In Canada, we tend to use the terms both 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, comfort and caregiver support, to enhance the quality of both living and dying.

Making the transition to hospice/palliative care can be difficult. You and your family may have spent many months or years concentrating on a cure. 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 or 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 and
- provides a variety of services designed to provide care and comfort.

Medical intervention is confined to symptom management, including pain control.

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.

2. BC PALLIATIVE CARE BENEFITS PROGRAM

The **BC Palliative Care Benefits Program** supports BC 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 assisted living residence or hospice that is not a licensed residential care facility covered under PharmaCare Plan B.

The intent of BC Palliative Care Benefits Program is to allow patients to receive palliative care at home rather than be admitted to hospital. The program 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 health authority. The BC Palliative Care Benefits Program includes full coverage of approved medications (PharmaCare BC Palliative Care Drug Plan P) and equipment and supplies (upon referral to, and assessment by the local health authority of the dying person).

BC 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.

www.health.gov.bc.ca/pharmacare/outgoing/palliative.html

3. CAREGIVER'S GUIDE: A HANDBOOK ABOUT END-OF-LIFE CARE

This 130-page guide provides family caregivers with the 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 their loved one has embarked and to become an effective, informed member of the palliative care team providing essential physical, spiritual, and emotional support. Co-published by The Canadian Hospice Palliative Care Association and The Military and Hospitalier Order of St. Lazarus of Jerusalem.

You can download the English edition at www.stlazarus.ca/english/news_pages/caregiversguide.html or you can order the guide in [Chinese](#) or [French](#) (the English copies have sold out) from the Canadian Hospice Palliative Care Association 1-800-668-2785 x 221 at www.market-marche.chpca.net/a-caregivers-guide

4. HOSPICE SOCIETIES

Across BC there are 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/membership/our-program-members.html E: office@bchpca.org

5. CANADIAN VIRTUAL HOSPICE

This website has information on all aspects of caregiving to a dying loved one, from the day-to-day practicalities to the spiritual challenges. 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 Health Authority and CancerCare Manitoba. www.virtualhospice.ca

6. EMPLOYMENT INSURANCE (EI) COMPASSIONATE CARE BENEFITS

Compassionate Care Benefits 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). A maximum of six weeks of compassionate care benefits may be paid to eligible people.

If you are unemployed and already receiving EI benefits, you can also apply. To be eligible for compassionate care benefits, you must be able to show that your regular weekly earnings from work have decreased by more than 40 percent; and 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

7. HELPFUL INFORMATION ABOUT FUNERALS

The **Funeral Services Association of BC** 1-800-665-3899 toll-free, 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 www.bcfunerals.com

8. BEREAVEMENT

A) COPING WITH GRIEF

Adapted from www.bcbereavementhelpline.com/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.

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.

B) BC BEREAVEMENT HELPLINE (BCBH)

604-738-9950 This free, confidential service connects you to grief support services throughout BC. The 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 BC.

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 their brochures *Ten Things to Know About Grief* is also available in Chinese, Farsi, Korean, Punjabi, Spanish, Tagalog and Vietnamese at www.bcbereavementhelpline.com/resources

C) CENTER FOR LOSS AND LIFE TRANSITION

Headed by Dr. Alan Wolfelt, world renowned thanatologist (specialist in the study of the medical, psychological, and sociological aspects of death and the ways in which people deal with it) this centre has a website rich with information for those dealing with loss and grief. This is a US website.

www.centerforloss.com

D) HOSPICE SOCIETIES

Across BC 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. A list of the local groups can be found on the website of their BC association group, the BC Hospice Palliative Care Association 604-267-7024, 1-877-410-6297 toll-free www.bchpca.org/membership/our-program-members.html

E: office@bchpca.org

E) LIVING THROUGH LOSS COUNSELLING SOCIETY OF BC

604-873-5013, partially funded by UNITED WAY, offers individual and group loss counselling in Vancouver. There are also articles about grief on their website www.ltbc.ca

F) LOWER MAINLAND GRIEF RECOVERY ASSOCIATION

604-696-1060 organizes grief support groups in Vancouver and the North Shore www.lmgr.ca
E: lmgr@lmgr.ca

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 (I&R) 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. These are some advocacy groups which support some of the work that family caregivers do:

1. BC HEALTH COALITION

604-681-7945 is a network of volunteer health care advocates in the province who champion the protection and expansion of a universal public health care system. The coalition believes: 1) health care is a right – everyone must have the right to high quality, responsive and appropriate health care which is publicly funded, publicly accountable and publicly controlled; 2) access to health care must be equitable – regardless of an individual’s income, level of ability, age, cultural heritage, sex, sexual orientation or geographical location; and 3) issues that are basic to good health must be addressed - food, education, income, housing, social support and personal safety determine an individual's ability to achieve and maintain good health. *Adapted from www.bchealthcoalition.ca*

2. CANADIAN CAREGIVER COALITION (CCC)

This national voice for the needs and interests of family caregivers is a bilingual, not-for-profit organization made up of caregivers, caregiver support groups, national stakeholder organizations and researchers.

CCC believes it is time for a Caregiving Strategy in Canada that provides a framework to guide our collective and individual response to family caregivers – by government, non-profit societies and the private/business sectors. A Canadian Caregiver Strategy will help to raise awareness and serve as a catalyst for action so that families who are asking for help are supported with reasonable options. An important aspect of the Coalition's work is identifying and developing key areas of policy in consultation with caregivers and others. Through policy research, including a series of policy papers, they are working to ensure that there are programs and services for caregivers, and to raise awareness of caregiving issues among Canadians.

The CCC believes that one of the most important activities the federal government can undertake is to actively promote the interests of family caregivers. It recommends that the following actions be undertaken by the federal government at this time: announce the establishment of a national caregiver strategy; enhance current tax credits; and protect caregivers’ employment income status. *Adapted from www.ccc-ccan.ca*

3. CANADIAN CENTRE FOR POLICY ALTERNATIVES (CCPA)-SENIORS CARE PROJECT

604-801-5121, CCPA is an independent, non-partisan research institute concerned with issues of social and economic justice. The Seniors Care Project works for policy changes to ensure BC seniors can age and die with dignity, and improve conditions for family members and health care workers. Their current formal research agenda focuses on solutions that can improve seniors’ quality of life and health outcomes while reducing cost pressures in acute care.

The CCPA BC office research paper *An Uncertain Future for Seniors: BC’s Restructuring of Home and Community Health Care* provides detailed concerns raised by the BC Auditor General, the BC Medical Association and the BC Care Providers Association about the deteriorating state of seniors’ care in BC.

The Remaining Light, a documentary film available on a free DVD, journeys through an often invisible part of Canada's health care system - the community-based services that provide care to seniors as they age and die. The film features the stories of seniors and their families, and explores themes of dignity, preventing illness and social isolation, and keeping health care costs under control as the boomer generation ages. It is set in BC, where the province's Ombudsperson has carried out investigations into a fragmented and underfunded system of seniors' care. The film's themes and stories will resonate with people who worry that we are not providing seniors with the dignity and respect, or the services they deserve. It is a resource for community-based discussions on the quality of seniors' care, and to advocate for better home and community services for BC seniors. You can also watch the 28-minute film at www.policyalternatives.ca/projects/seniors-care or order the free DVD. It has optional subtitles in Chinese (Simplified and Traditional), Punjabi, Spanish, and Vietnamese.

Adapted from www.policyalternatives.ca

4. CARP - A NEW VISION OF AGING FOR CANADA

Formerly called the Canadian Association of Retired Persons, CARP advocates for issues important to aging Canadians, including caregiver support. www.carp.ca

5. COUNCIL OF SENIOR CITIZENS ORGANIZATIONS OF BRITISH COLUMBIA (COSCO)

COSCO is a large federation of BC seniors' organizations. It works to assemble, co-ordinate and advance proposals and resolutions concerned with the welfare of elder citizens, and submit them to the appropriate government bodies; and to advance the social and physical welfare of all BC elder citizens.

From www.coscobc.ca

COSCO offers their Seniors' Health and Wellness Institute's 604 684-9720 health promotion workshops free of charge to any seniors' group. Several workshop topics address the needs of caregivers, including Dealing with Stress, Falls Prevention, Live without Driving, Medication Awareness and Staying fit at Home.

6. MLA'S AND MP'S

If you have problems accessing provincial services, you can contact your local MLA who you can locate the service you need through www.leg.bc.ca/mla or call Service BC 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/MembersOfParliament or call Service Canada 1-800-622-6232 for your MP's phone number.

7. OFFICE OF THE OMBUDSPERSON

1-800-567-3247 The BC 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 health region or hospital, ICBC, the Medical Services Plan, the Ministry of Health, Pharmacare, or the Public Guardian and Trustee), has treated you unfairly, the BC 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 health authorities to enforce standards of care in residential care 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 Ombudsperson's office by phone Mon – Fri, 8:30 – 4:30, or use the online complaint form at www.ombudsman.bc.ca/how-to-make-a-complaint

Note: As the result of receiving a high number of complaints, BC Ombudsperson, Kim Carter has issued two reports investigating the care of seniors in the province. These are:

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 residential care, access to information about residential care and the role of resident and family councils. Some of the points in the report can help point out what constitutes good care and 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) contains 143 findings, 176 recommendations, and focuses on home and community care issues, home support services, Assisted Living and Residential Care, 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 health authorities in BC. (These are Fraser Health, Interior Health, Northern Health, Vancouver Coastal Health, and Vancouver Island Health.) Both reports are at www.ombudsman.bc.ca/seniors

Translated extracts of the seniors' reports are available in Punjabi and Chinese (Simplified and Traditional) at www.ombudsman.bc.ca

BC's Ministry of Health issued *Improving Care for BC Seniors: An Action Plan*, shortly after the release of Kim Carter's second report. The Ministry plan outlines numerous actions focused on addressing many of the Ombudsperson's findings and recommendations. It promises to improve services by providing the information people need to access services in a timely and informed way, to ensure consistent and fair delivery of care, and to protect vulnerable seniors from abuse and neglect. A Seniors' Advocate is due to be appointed in 2013 to assist and protect seniors receiving public and private community and health care services, and ensure complaints are resolved. The 12-page action plan can be found at www.seniorsbc.ca/documents/pdf/SeniorsActionPlan.pdf

8. SENIORS ACTION NETWORK - SENIORS COMMUNITY PLANNING TABLES

UNITED WAY introduced funding for Seniors Community Planning Tables in 2008. Table objectives are to support the work of seniors and senior-serving agencies in Lower Mainland communities towards two important goals: improving local service coordination and addressing seniors' issues. Each Seniors Community Planning Table meets almost monthly and has sub-committees that work on specific projects, e.g. advocacy, outreach, transportation - it varies from community to community.

UNITED WAY strongly supports the idea of seniors planning for seniors. The Seniors Planning Tables (or Action Networks as some prefer to be called) are seniors-led, volunteer-based, inclusive and representative of the local seniors' population www.uwlm.ca/seniors-action-network There are ten Seniors Community Planning Tables and for each one, a local non-profit serves as the Host Agency for the Table in each community, providing supports of various kinds:

○ Burnaby: *Voices of Burnaby Seniors* (VOBS) 604-515-1718
E: manage@mariamlarson.com
Host Agency: Burnaby Community Services 604-299-5778

- Delta: *Delta Seniors Planning Team, A Voice for Seniors* 604-818-3290 or 604-596-2149
www.deltassist.com/deltaseniorsplanning.html
Host Agency: *deltassist* Family & Community Services 604-594-3455
- Langley: *Langley Seniors Community Action Table (LSCAT)* 604-818-3290
www.langley.ca/Partnershiphome/SeniorsTaskGroup.aspx E: llyscat@gmail.com
Host Agency: Langley Seniors Resource and Recreation Society 604-530-3020
- Maple Ridge/Pitt Meadows/Katzie: *Maple Ridge-Pitt Meadows-Katzie Seniors Network*
604-786-7404 E: htrleaven@shaw.ca
Host Agency: Ridge Meadows Seniors Society 604-467-4993
- New Westminster: *Seniors Planning & Action Network (SPAN)* 604-515-1718
www.seniorsservicessociety.ca/ausstf.htm E: manage@mariamlarson.com
Host Agency: Seniors Services Society 604-520-6621
- North Shore: *North Shore Seniors Action Table* 604-985-3852
www.lionsviewseniorsplanning.com E: lions_view@telus.net
Host Agency: Lionsview Seniors' Planning Society 604-985-3852
- Richmond: *Richmond Seniors Network (RSN)* 604-271-8512
E: richmondseiniorsnetwork@shaw.ca
Host Agency: Volunteer Richmond Information Services (VRIS) 604-279-7020
- South Surrey/White Rock: *Semiahmoo Peninsula Seniors Planning Table* 778-891-8948
www.sourcesbc.ca (click on 'Seniors') E: deirdre@teamplayconsulting.com
Host Agency: Sources Community Resource Centres 604-531-6226
- Surrey: *Surrey Seniors Community Planning Table* 604-671-7761
E: jmcbride@mcgi.ca
Host Agency: DIVERSEcity Community Resources Society 604-597-0205 x 1202
- Vancouver (West End): *Seniors Community Planning Table West End* 604-683-2554
<http://gordonhouse.org/programs/elders/> E: isaaksharon@gmail.com
Host Agency: Gordon Neighbourhood House 604-683-2554

9. TRI-CITIES SENIORS NETWORK

604-529-5139 Funded by The Vancouver Foundation, this network is offered through Community Volunteer Connections. While the network is not a United Way funded Seniors Community Planning Table, like the ten planning tables listed above, the network uses similar principles – bringing seniors and local service providers together to work to improve quality of life for seniors in the community.

10. MUNICIPAL SENIORS ADVISORY COMMITTEES

Several municipalities have a special committee for seniors which is advisory to city council. Seniors and others work with city staff to enhance services for older citizens in:

- Delta: Corporation of Delta Seniors Advisory Committee 604-946-4141
www.corp.delta.bc.ca/EN/main/mayor/346/seniors_advisory_committee.html

- Langley: Township of Langley Seniors Advisory Committee 604-532-7517
www.tol.ca/About-the-Township/Municipal-Government/Divisions-and-Committees/Seniors-Advisory-Committee
- Port Moody: City of Port Moody Community Care Committee 604-469-4500
www.portmoody.ca (click on ‘Committees’)
- Richmond: City of Richmond Seniors Advisory Committee 604-276-4390
www.richmondseiorsadvisory.ca
- Surrey: City of Surrey Seniors Advisory & Accessibility Committee 604-591-4132
www.surrey.ca/city-government Click on ‘Committees’
- Vancouver: City of Vancouver Seniors Advisory Committee 604-873-7789
www.vancouver.ca/your-government/seniors-advisory-committee.aspx

PICK YOUR BATTLES

Expect numerous challenges – big and small – will come your way as you help to care for an older 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. A LIST - WHERE IMPORTANT INFORMATION AND 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. Whatever your system, the important thing is to have a record of important names, contact numbers, and record where important papers are. Be sure those close to you know where your list of important contact information is kept.

1. PERSONAL INFORMATION

- A) Full legal name, birth certificate or date and place of birth
- B) Social Insurance Number
- C) BC CareCard number (aka 'Gold Card' for seniors)
- D) Full legal name of spouse and marriage license or divorce papers
- E) Primary caregiver name and contact information
- F) Other family members
- G) Friends
- H) Faith group
- I) Case Manager at local Health Authority Home Health Office
- J) Private home support agency
- K) HandyDART client number
- L) Military history, affiliations and papers (including discharge papers)

2. MEDICAL INFORMATION

- A) Physician and medical specialists
- B) Medical records noting illnesses, allergies, surgeries, immunizations
- C) Pharmacy and list of all medications (prescription, over-the-counter, vitamins, herbs, tonics)
- D) Dentist and denturist

3. FINANCIAL INFORMATION

- A) All bank accounts, account numbers and types of accounts and the bank locations and credit cards
- B) Pension records (OAS, CPP, GIS, Private pensions)
- C) Investments (certificates of deposit, stock certificates, bonds, notes, savings bonds)
- D) Canada Revenue Agency most recent tax return and notice of assessment
- E) Financial Advisor
- F) Insurance records: companies, policy numbers, beneficiaries as stated on the policies and type of insurance (health, life, long term care, automobile, etc.)
- G) Safety deposit boxes – contents, locations, location of keys

4. LEGAL INFORMATION

- A) Lawyer or Notary
- B) Citizenship papers
- C) Vehicle registration
- D) Rental agreements, mortgage papers, property tax statements
- E) Deed and titles to all property
- F) Loan/lien information, who holds them and if there are any death provisions
- G) Trusts
- H) Advance Care Plan which expresses your health care wishes should you become incapacitated
- I) Advance Directive or Representation Agreement appropriate to your province
- J) Enduring Power of Attorney appropriate to your province

5. IN THE EVENT OF DEATH

- A) Instructions for funeral services and burial (if prearrangements have been made, name and location of funeral home, cemetery and plot information)
- B) Up-to-date Will in a safe place (inform executor and family where the will is located; you don't need to disclose contents)

In the ordinariness of your caregiving lies
something more: sacredness.

James E. Miller

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

Email: MetroVanCaregiversHandbook@yahoo.ca

Canada Post: Metro Vancouver Caregivers Handbook,
c/o United Way of the Lower Mainland, 4543 Canada Way, Burnaby, BC V5G 4T4

Sorry, but we cannot reply to mail at these addresses.

Service Providers: Please include the name of your agency in your feedback to us.

**This Handbook can also be found on the UNITED WAY website at
www.uwlm.ca/reports-and-resources**



Being a Family Caregiver

Caregiving is loving and rewarding and can bring family members and friends closer together. Caring for an adult family member – while juggling all the other obligations in our time deprived world – also puts caregivers at risk for isolation, ill health, depression and burnout from prolonged stress. Act preventatively to avoid exhaustion and burnout. When you take good care of yourself, your care recipient also benefits.

Consider this renowned Caregiver Bill of Rights:

I have the right

- To take care of myself. This is not an act of selfishness. It will enable me to take better care of my loved one.
- To seek help from others even though my loved one may object. I recognize the limits of my own endurance and strength.
- To maintain facets of my own life that do not include the person I care for, just as I would if he or she were healthy. I know that I do everything that I reasonably can for this person, and I have the right to do some things for myself.
- To get angry, be depressed and express other difficult emotions occasionally.
- To reject any attempt by my loved one (either conscious or unconscious) to manipulate me through guilt, anger or depression.
- To receive consideration, affection, forgiveness and acceptance from my loved one for as long as I offer these qualities in return.
- To take pride in what I am accomplishing and to applaud the courage it sometimes takes to meet the needs of my loved one.
- To protect my individuality and my right to make a life for myself that will sustain me when my loved one no longer needs my full-time help.
- To expect and demand that as new strides are made in finding resources to aid physically and mentally impaired persons in our country, similar strides will be made toward aiding and supporting caregivers.

Adapted from the book *CareGiving: Helping an Aging Loved One*, by Jo Horne published in 1985 by the American Association of Retired Persons-AARP.