

Toolkit for Employers



**Resources for Supporting Family
Caregivers in the Workplace**



Written and compiled by:
Barbara Small, Program Development Coordinator
Family Caregivers' Network Society

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Contact information:

Family Caregivers' Network Society

#6 - 3318 Oak Street

Victoria, BC V8X 1R1

Tel: 250-384-0408

Toll-free: 1-877-520-3267

Fax: 250-361-2660

caregiversupport@fcns.ca

www.familycaregiversnetwork.org



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Today there are over 1 million people providing care for family members or friends in British Columbia¹ and almost 70% of these family caregivers are trying to juggle the demands of employment and caregiving.²

The impact of this growing social and economic issue of concern on businesses includes:

- higher absenteeism rates, costing over \$1 billion per year in Canada
- lower productivity (distraction, distress and fatigue)
- quitting work or declining promotions

The **Family Caregivers' Network Society (FCNS)** has developed this **Toolkit for Employers: Resources for Supporting Family Caregivers** to provide both employers and employees with information and resources to help minimize the impact of caregiving on both the employee and the workplace. With the right information, support and education, employees can be healthier and more productive. It's good for everyone's bottom line.

This Toolkit is divided into two sections:

Section 1: Information for Employers - includes the impact of caregiving on your employees and your workplace, the cost of caregiving on your organization, the top workplace needs of employed family caregivers and workplace strategies to create a caregiver friendly workplace.

Section 2: Resources for Your Employees Who are Family Caregivers - includes community and healthcare resources available to support family caregivers, self-care handouts, how to develop a care plan, navigating the healthcare system and legal and financial considerations for family caregivers.

Section 1

Information for Employers



Definition of a family caregiver

A family caregiver is anyone who provides care and support for an adult family member or friend who is in poor health, frail, elderly or disabled. The care recipient can live either in their own home, with the family caregiver or in a care facility.

Although most people think of caring for elderly parents when they hear that someone is caring there are many other types of situations where caregiving is involved. A family caregiver could be caring for:

- an aging parent
- their 30-year old spouse with MS
- their sister with breast cancer
- an adult disabled child
- an aunt with dementia
- a friend or a neighbour

or....

“While caregiving implies the provision of unpaid care, it does come at a cost to Canadian businesses. In 2007, Canadian employers absorbed an estimated \$1.28 billion in lost productivity as a result of employees missing work and/or leaving their jobs because they had difficulties juggling their care responsibilities.”³



Impact of caregiving employees on the employer and the workplace

In addition to the personal, economic and social costs for family caregivers, caregiving affects the workplace in terms of:

- lost productivity, higher absenteeism rates and more lateness.
- employees may be present, but distracted and fatigued, therefore, high rates of presenteeism.
- attention on work is interrupted by telephone calls, appointments and emergencies that must be handled.

“According to a survey of over 32,000 employees in large and medium-sized Canadian workplaces in the public, private and non-profit sectors, 26% of employees reported experiencing high levels of caregiver strain. Caregiver strain is positively correlated with absenteeism due to eldercare problems and emotional, physical and mental fatigue.”⁴

- refusing promotions or not taking advantage of professional development opportunities.
- reduced work hours and caregiving employees are less able to work overtime or travel for work.
- leaving employment in order to caregive or taking early retirement. Early retirement may result in employers paying out pensions earlier.
- increased costs for recruitment and training of new employees. Loss of knowledge, skills and experience of current employees who are unable to balance caregiving and work.

“It is estimated that US business spends \$2.8 billion every year to replace employees who leave their jobs to care.”⁵

“According to a UK study, it may cost the equivalent of three-month’s salary to replace a low-skilled worker and more than a year’s salary to replace a professional, who quits their job in order to care.”⁶

“Whether the economic climate is good or bad, it does not change the fact that we have a rapidly aging population and that caring responsibilities are going to grow.”⁷

Calculating the costs of caregiving on your organization

This tool can help you find out *just how much* money your business is losing due to unaddressed caregiving needs.

The National Alliance for Caregiving and the MetLife Mature Market Institute have developed the eldercare calculator, an easy-to-use online program available at www.eldercarecalculator.org. Based on your company’s size, estimated number of employee caregivers and average hourly wage for employees, the calculator will project your business’s lost productivity costs.



Also, the National Caregiver Library provides a downloadable Caregiving Cost Tracking Form to measure the financial impact of working caregivers on your organization. Available at www.caregiverslibrary.org/Portals/0/Tracking_Sheet_NCL.pdf.

“As the demand to address family needs spills into the workplace, time spent on the phone at work and time one is distracted or preoccupied with eldercare concerns can also be counted as partial “absenteeism” even though it takes place at work. Additional invisible costs pertain to the added stress co-workers may experience, especially as their own workload or performance is affected by a colleague or team member’s difficulties in meeting unadjusted work demands or stress in trying to find or arrange home care, or other services.”⁸

Why is it important for employers to recognize and address this issue?

Caring for an adult is not the same as caring for a child. The care of an adult is usually more complex, involving many different services, professionals and family members. The need for care is often precipitated by a crisis, and is incremental making it difficult to predict the type, amount and duration of care required. Children usually become more independent, while an adult needing care will often become more dependent as time progresses.

According to a recent study on work-life balance conducted by an AON Consulting Group in partnership with the Royal Bank of Canada: *“Acknowledging people’s needs outside of work is the key driver to employee commitment – outranking compensation, benefits, training and job growth.”*⁹

Benefits of providing workplace support to employees who are family caregivers include:

- employee time saved.
- increased work performance.
- employee retention.
- stress reduction and healthcare cost prevention.
- reduced absenteeism.¹⁰

And by the numbers...

- productivity increases by about 20% after companies implement work-life balance programs.
- staff turnover falls by up to 50% when employees are offered benefits such as child-care subsidies, elder-care programs and flexible hours.
- the cost of losing and replacing an employee can range from 50% to 150% of his or her annual salary.¹¹

*“There is a strong reason for employers to get on-board now with helping their employees to balance their paid work with their unpaid caregiving responsibilities. In just a few years, employees will have no other choice. Demographic changes will mean that more employees than ever will have caregiving responsibilities. Balancing caregiving with employment will be as common tomorrow as working mothers of young children are today.”*¹²

How does being a family caregiver impact your employees?

Below is a list of the challenges and issues of concern that are experienced by your caregiving employees. It is beneficial for managers, supervisors and human resource staff to be aware of and be able to recognize these red flags so that employees receive the support they need therefore minimizing the negative impact of caregiving on their health and work productivity. Supporting your caregiving employees is an important way for employers to retain experienced employees.

- **Overload and exhaustion** caused by trying to balance caregiving responsibilities with other demands in their daily life, such as work, family and the caregiver's own wellness. Often there is no advance notice before caregiving begins and it can suddenly take over a large amount of time and energy from what may have already been a busy and demanding life.
- **Not asking for help:** Asking for help can be difficult because family caregivers may not know what they need, they are fearful of being a bother, or they feel guilty that they are not able to do it all themselves. Beliefs such as "no one can do this as well as I can," or "no one should do this but me" can also be obstacles to asking for help. Sometimes the care recipient will reinforce this by being resistant to having a "stranger" or anyone but the primary caregiver take care of them.
- **Isolation:** Caregivers can feel that they are the only person in this situation even though there are approximately 1 million family caregivers across BC. They don't expect anyone else to understand their situation including their supervisors and co-workers.
- **Lack of a support network:** Other family members may live in another city or province and may only offer help from a distance. Friends and co-workers may not understand if they have not had the experience themselves. Family caregivers may not be aware of the various resources or support groups available in their community.
- **Not setting limits and boundaries:** Caregivers often have difficulty saying "no" to additional requests whether from the care recipient, healthcare providers or employers. They keep stretching their "limit".

- **Overwhelming emotions** of guilt, anger, resentment, grief, worry, frustration, and anxiety are common and impact all decisions that the family caregiver makes both at home and at work.
- **Navigating the healthcare system:** What services are available and how do I access them? Who do I call if I have a concern? What is the cost? The healthcare system can seem very overwhelming to someone that has not had to navigate it before and who at the moment is already feeling overwhelmed and stressed.
- **Poor self-care** (diet, exercise, sleep) leads to the family caregiver developing health problems. “Forty-five percent of those providing care for three or more years report a stress-related illness such as hypertension, depression, frequent colds and flu, back injuries, body pain, headaches, insomnia, recent weight loss or gain, fibromyalgia and chronic fatigue.”²⁰ Family caregivers tend to neglect their own health and postpone seeking medical attention for themselves.
- **Finding sources of respite:** Respite is a chance for family caregivers to be relieved of their caregiving responsibilities for a few hours, days, or weeks, so that they can refresh and replenish their energy. There are many creative ways of arranging respite. A friend or neighbour can pop over for a couple of hours while the family caregiver goes out. The care recipient might attend an Adult Day program. A Community Health Worker might come to their home overnight to look after their aging parent so they can catch up on sleep, or during the day for a few hours to stay with their disabled spouse so that they can attend a business meeting. The care recipient can also stay in a designated respite bed at a local care facility. Respite can be any activity where the family caregiver feels that they are taking a break.
- There can be many **financial concerns** that can be created by the caregiving situation, such as reduced income, additional costs for care, adaptations to the home, travelling for long-distance caregiving and handling the care recipient’s financial issues.

- **The impact on the family:** Past family dynamics can come to the forefront again once the dynamics of caregiving begin. A strain is put on other family relationships, including relationships with spouses, children and siblings. Family roles can feel like they are reversed now that adult children are taking care of their parents or the more dominant spouse is now ill.
- **Ongoing losses:** Facing ongoing loss is one of the most challenging issues that family caregivers encounter as they adjust to changes in their family member's health. With each change that occurs, the caregiver can experience feelings of loss. These losses can include a loss of independence, privacy, plans for the future, financial security, changes in their relationship, loss of their social life and loss of their job. The grief experienced by the family caregiver can manifest itself in many ways including guilt, anxiety, helplessness, irritability, anger or frustration. All of which impact the family caregiver's productivity and attentiveness at work.

Supporting Your Caregiving Employees



The top four needs that employed family caregivers have identified are important to them include:

Time: Flexibility to schedule work and caregiving activities in ways that allow effective management of the two sets of responsibilities along with respite time that offers a break from both work and caregiving responsibilities

Information: Access to accurate, up-to-date information about community-based services and resources, as well as legal and financial issues

Financial Assistance: The ability to pay for services needed to appropriately care for older adult relatives; payment may require combining the financial resources of the elder, the working caregiver, other family members and government or private-sector programs

Emotional Support: An understanding and caring support network that includes family members, friends, co-workers, supervisors and advisory professionals.¹³

The Importance of "Culture"

"The key factor between success and failure when implementing new caregiving and eldercare programs is whether one makes improving the culture a priority. Employees must feel sufficient corporate level support for caregiver programs in order to feel that it is safe to participate...."

To help promote cultural change, focus on the benefits of the program, that it's been established to assist employees with adult caregiving issues, and that there will be no strings attached. Re-assure employees that all aspects of their use of the program will remain strictly confidential....It is important to keep the program visible, by mentioning it in employee newsletters, lunch room posters or company-wide email."¹⁴

“Creating a flexible workplace makes sense for employees and employers. Policies such as flexible hours, alternative work arrangements, job-sharing, access to training opportunities, and recognition of child and elder care responsibilities can make the difference between organizations that attract and keep their employees and those that don’t.”

The Hon. Linda Reid, Minister of State for Child Care, 2008

Creating a caregiver friendly workplace

Employed caregivers’ needs are diverse and unique to their situation. One type of benefit or policy may make sense for one caregiving employee and not another. Also, the employed caregiver’s needs will change as their family member’s health situation changes. Flexibility is key.

Below are some supportive workplace programs, benefits or policies that can help employed caregivers. *Which of the following already exist in your organization and which could be introduced?*



Potential Workplace Supports

1. Flexible work arrangements

- Informal or occasional flexibility
- Part-time work and job sharing
- Temporary reduction of hours
- Phased retirement
- Compressed work weeks
- Flex time
- Tele-commuting or flex-place
- Shift-exchanging
- Cross-trained employees

2. Paid Time Off

- Sick days
- Paid sick leave that can be used to care for family members
- Flex days

- Vacation days
- Sabbaticals
- Personal days
- Family leave
- Medical or emergency leave
- Personal leave
- Bereavement leave

3. Paid or Unpaid Time Off

- same as #2 above

4. Policies

- Eldercare policies
- Funeral or bereavement leave policies
- Gradual return-to-work policies

5. Insurance Coverage (for employee and dependents)

- Health insurance
- Dental insurance
- Life insurance
- Long-term care insurance
- Unemployment insurance
- Workers' compensation insurance

6. Financial Assistance

- Publicizing federal or provincial tax credits
- Travel discounts to help long-distance caregivers
- Dependent-care reimbursement plan

7. Access to Information

- Management/supervisor/human resource training and support on family caregiving issues
- Availability of information related to family caregiving - books, DVD's, websites, pamphlets, handouts
- Caregiver resource library, possibly online
- Education about local community services and information and referral services that reduce caregiver burnout
- Publicizing the Compassionate Leave benefits available through EI
- Workplace caregiver fairs

- Lunch and learn sessions
- Workplace caregiver support groups
- Elder-care counseling and referral through Human Resources
- Elder-care counseling through Employee Assistance Program

8. Direct Service Programs

- Geriatric case or care management
- On-site adult day program
- Near-site adult day program

Source: Partially adapted from www.worldatwork.org

"A better balance between work and life is an issue for everyone, not just those with caring responsibilities. Simple changes can make all the difference to all employees trying to balance their personal and working lives more successfully. Money is saved through reduced sickness absence, stress, recruitment and training costs and productivity is raised through better morale...it makes good business sense. It's a win-win situation for all concerned."

Margaret Hodge, U.K. Minister for Employment and Equal Opportunities

Additional Ways to Support Your Caregiving Employees

In 2003 the Family Caregivers' Network (FCNS) completed a 3-year project, *Supporting Family Caregivers*, which was funded with a grant from the J.W. McConnell Family Foundation. As part of this pilot project FCNS partnered with Camosun College and Thrifty Foods in Victoria, BC to develop strategies to best support employed family caregivers.

The primary audiences of these strategies were employed family caregivers and their employers, managers, supervisors and colleagues. The key findings from this project are listed below:¹⁵

- A need to **build awareness and understanding of family caregiving** amongst supervisors and managers and to build understanding and awareness amongst employees about the constraints managers and supervisors face in supporting their needs was identified.
- It is important to have someone in the right position in the workplace hierarchy who functions as a **'champion'** for the caregiving issue and can help move the activities or strategies forward.
- **Multiple strategies** are for engaging various staff in a discussion about caregiving is needed. These strategies may include profiling caregivers in the workplace newsletter, lunchtime discussions/brown bag lunch sessions, and incorporating family caregiving within a Wellness Committee agenda.
- **Workplace-related newsletter articles** can be powerful catalysts for change/action. The articles not only raise people's consciousness about the issue, but when the articles profile a person/employee dealing with the issue, they bring the issue to life and make it more 'real'. Workplace-related articles about family caregiving also bring the issue "out of the closet" and provide a strong signal to staff that their organization understands and appreciates issues related to work life balance.

- A **Listserv group or discussion forum** is an important vehicle for support in the workplace. It is effective because it is flexible: workers can access it anytime, at home or at work, and people can respond either to the whole group or to an individual. The Listserv also can be respectful of privacy, in that it provides a different communication option for people who aren't comfortable with face-to-face conversations or group support. Listservs provide a written record of discussions and of the practical suggestions that are posted.
- Employees who attended **Brown Bag (Lunch and Learn) Sessions** indicated that these sessions increased their awareness about resources for caregivers in the community. Some commented that, despite the evident complexities of the health, legal and residential care systems, the sessions made them aware that there "was someone out there to help". One participant noted that the sessions provided a vehicle for mutual support at the workplace.
- **Employers benefited from improved access to strategies and educational resources** to support their employees. From the perspective of members of Camosun College's Wellness Committee, a major impact of the project was that it led to family caregiving coming "out of the closet". As a result of project activities, staff who were family caregivers increasingly self-identified and came out to seek information, education and mutual support. This led to a ground-swell of community-building at a grass-roots level, which ultimately got the ear of managers and senior administrators.

Leave from Work in BC

When considering workplace policies for supporting your caregiving employee, keep in mind that under the Employee Standards Act (BC) employers are required to provide the following unpaid leave to their employees:

Pregnancy Leave: A pregnant employee can take up to 17 consecutive weeks of unpaid leave. This leave may be extended by up to six weeks if she is unable to return to work for reasons related to the birth or termination of the pregnancy.

Parental Leave: A birth mother who has taken pregnancy leave is entitled to up to 35 consecutive weeks of unpaid leave. A birth mother who has not taken pregnancy leave is entitled to take up to 37 weeks of unpaid leave. A birth father or an adopting parent is entitled to up to 37 consecutive weeks of unpaid leave. This leave may be extended by up to five weeks if the child requires an additional period of parental care. Birth parents must give their employers at least four weeks written notice of their intention to take parental leave.

Family Responsibility Leave: An employee can take up to five days of unpaid leave in each employment year to attend to the care, health or education of a child in the employee's care, or to the care or health of any other member of the employee's immediate family. Employees are expected to give their employers as much notice as possible and provide sufficient information for their employers to understand the reason for the leave.

Compassionate Care Leave: An employee can take up to 8 weeks of unpaid leave within a 26 week period to care for a gravely ill family member. The employee must obtain a medical certificate which states that the family member is gravely ill with a significant risk of death within 26 weeks.

Bereavement Leave: An employee is entitled to up to three days of unpaid leave on the death of a member of the employee's immediate family. This leave may be for purposes other than to attend a funeral.

Employees are expected to give their employers as much notice as possible and provide sufficient information for their employers to understand the reason for the leave. Employees are not required to give notice in writing or disclose personal or private information. An employer may not terminate an employee or change a condition of employment, without the employee's written consent because of a leave or pregnancy.

Reprinted from <http://www.labour.gov.bc.ca/esb/esaguide/#2>

What other businesses are doing to support their caregiving employees

In **Canada**, several organizations have been awarded praise for their elder-care initiatives. Below are some examples:



The **University of Toronto** has a life advisor who provides information to employees on family topics including eldercare.



Shell Canada makes eldercare information available to its employees and provides assistance in finding eldercare services.



Ernst & Young have a back-up caregiving program that provides emergency care to children, spouses or other relatives.



Pfizer provides a top up salary up to 100% for those on compassionate leave for a period of 8 weeks.¹⁶

WorkLife BC 2008 Award Recipients:¹⁷



Benefits by Design (small workplace, Port Coquitlam): With a staff of 42 people, they offer a range of flexible options including start and end times to the work day to suit employees' schedules, telework and a nine-day fortnight schedule in which employees can work an extra 45 minutes a day and take every tenth day off. They have a health and wellness committee that meets once a month to look at family balance issues. One employee was able to have a reduced work week, and work from home, so he could care for his wife who had breast cancer. He was also able to take a few months off with full pay.



Pacific Blue Cross (medium workplace, Burnaby): They offer teleworking, job sharing, a compressed work week, banked hours and support for child and elder care responsibilities. Writes one employee: "My mother had a very serious stage three cancer. My parents live on Vancouver Island, about 90 minute from Victoria. Her chemo/specialist appointments were in Victoria, so I was able to use my family responsibility leave/flex time to attend them with her each month or as needed. It was extremely important emotionally for me to be with her. My manager was very compassionate and knowing I didn't have to worry about taking so much time off helped me cope. My mother did not survive, however I am so grateful for my family responsibility leave, as I would have quit (any) job to be by my mother's side."



North Shore Community Resources (small workplace, North Vancouver): Eldercare is becoming an increasingly important issue as well, as another employee testifies: “This agency has bent over backwards to be supportive and understanding regarding my care responsibilities for my parents. Not only can time be flexed around appointments and needs, but management and staff are genuinely concerned about individual staff situations. It is made clear that family commitments are a priority and that the agency, as a family support agency, demonstrates this for its staff as well as providing related services to the community. In other words, it practices what it preaches.”

Organizations in the United Kingdom



British Telecommunications (BT) employs 160,000 employees in 61 countries; 81% work flexibly and 18,000 work exclusively from home. BT attributes its 20% increased production and annual savings of \$375 million (Cdn) to embracing flexible work accommodations for caregivers and others. According to Caroline Waters, Director of People and Policy for BT, “Supporting our carers isn’t difficult, disruptive or expensive; it’s plain business sense – a small change in working hours or flexible arrangements can make all the difference both to your carer and to your business.” BT now chairs Employers for Carers, a cooperation of UK employers and government devoted to helping other employers support caregivers in the workplace.¹⁸



Employers for Carers is a service for employers in the United Kingdom to help employers retain the employees in their workforce caring for a family member. They promote the business benefits of supporting carers and provide advice and support on carer-friendly policy and practice. Employers for Carers can help businesses remain competitive with a healthy and productive workforce. Employers for Carers has evolved from a group of employers committed to working carers, is chaired by British Telecom and supported by the specialist knowledge of Carers UK. For more information visit www.employersforcarers.org.

Organizations in the USA



McGraw-Hill lets employees enroll one other adult family member, which can be an elderly relative, on their health-insurance plan at regular family rates.



The **Verizon Wireless** division allows some employees to take advantage of their emergency in-home care for older adults.



Mellon Financial Corp. offers a free emergency eldercare service. Says one employee, "I was able to come to work and concentrate on my job and not have the stress of worrying about what was going on with my father."



Unilever offers its salaried U.S. employees emergency-care services, flexible working arrangements and other benefits to help care for elderly relatives. One employee used the company's free concierge service to arrange repair of an elderly parent's storm-damaged house in another state.



Alston & Bird LLP, a law firm based in Atlanta, has added a catastrophic leave-sharing program that allows employees to donate vacation time to other employees who may have family members who are sick but have exhausted their own leave. "We recently had an employee whose husband had a stem-cell transplant and employees donated four months of time to her so she could stay home and take care of him when he came home from the hospital," says a spokeswoman.



Tim Gavin of Minneapolis says the emergency eldercare service offered by his employer, **KPMG**, helped him provide care for his parents, more than five hours away, after his 85-year-old mother underwent triple-bypass heart surgery last year. An aide came to the house to make meals and do housecleaning for his mother and 88-year-old father and provide transportation to medical appointments.¹⁹

How supportive is your business to your employed family caregivers?

“In the absence of a corporate culture supportive of caregiving, employees feel unable to share information about their caregiving responsibilities, and to seek support”.²⁰

Use the following checklist, adapted from an employee checklist created by VON Canada, to assess your business on a variety of key elements related to how supportive your current work environment is to your caregiving employees. How would your workplace rate?

Key Elements	Key Questions	Comments
Corporate Culture		
Culture	Does the workplace show corporate commitment and support for the balancing of work and caregiving, with the creation of an environment that lets staff know that the employer cares for them outside of work as well? How is this shown? (eg. through the initiation of work-family policies and programs, discussion of caregiving issues in newsletters, at staff meetings, wellness fairs.)	
Written Policies and Procedures	Are there written policies and procedures for managers and staff, outlining the process and conditions for granting flexible work arrangements, with the direction to give every consideration to such requests?	
Written Resources	Are written resources available that empower working caregivers to identify and use workplace caregiver benefits, and to communicate effectively with managers on caregiving issues?	
Management Training	Is there training for managers on the importance of helping employees to achieve a healthy work- family balance, with <ul style="list-style-type: none"> • clear articulation of the "business case" for work-family policies; • training on how to implement effective work- family practices; and • how to problem-solve unique situations? 	

Key Elements	Key Questions	Comments
Corporate Culture cont'd		
Overall Evaluation of Managers' Support to Caregiving Employees	Is there a linkage of the performance evaluation and compensation of managers to their flexibility in assisting employees to address family caregiving responsibilities? How is this assessed (e.g. through feedback surveys from employees)?	
Direct Supervisor	What is the specific attitude of supervisors to flexible work arrangements and working creatively together to help balance work and caregiving responsibilities?	
Designated Staff Member	Is there a designated staff member to help employees understand benefits to which they may be entitled and to help problem-solve the balancing of work and family caregiving responsibilities?	
Team Approach	Is there promotion of a team approach at the work site, so that workload can be shared or adjusted as required in the team, and to assist with the provision of emotional support for caregiving employees?	
Definition of Family/Care Receiver/ Caregiver	Is the definition of family broad and inclusive (i.e. includes care of in-laws, all relatives with whom the employee lives, recognition of nonfamily, blended family, and extended family, etc.)?	
Flexible Work Arrangements		
	<p>What alternative work arrangements are available to caregiving employees? Are these included in collective agreements?</p> <p>Options include:</p> <ul style="list-style-type: none"> • Flex-time • Telecommuting • Job sharing • Compressed work week • Reduced hours of work 	

Key Elements	Key Questions	Comments
<i>Flexible Work Arrangements cont'd</i>		
	<ul style="list-style-type: none"> • Flexible schedules • Protected part time employment • Variety of extended unpaid leave arrangements with job guarantees on return • Personal days off • Time in lieu of overtime • Family leave (specified number of paid days per year). 	
<i>Information and Referral, Employee Supports</i>		
	<p>Does your workplace offer programs and services to support caregivers, such as:</p> <ul style="list-style-type: none"> • Information and referral to community services, including home care, long-term care, community support programs, respite care, legal assistance etc? • EAP Programs: employers should ensure through evaluation, that EAP providers make adequate provision for following through with services for family caregivers. • Access to private consultants for specific topics/advice (such as legal)? • Assistance in negotiating the service system, and identifying and accessing the resources needed for their caregiving situation? • Eldercare/dependent care programs that provide assistance with case management, financial and estate planning, legal services, and insurance paperwork and processing; and end of life planning? • Support groups? • Family life seminars? • Telephone hotlines? • Caregiver fairs? • Resource banks? 	

Key Elements	Key Questions	Comments
<i>Practical Assistance/Direct Care Services</i>		
	<p>Does your workplace offer:</p> <ul style="list-style-type: none"> • Direct dependent care services (such as subsidizing costs of access to on-site or offsite day care)? • Insurance coverage/Extended health benefits for caregiving necessities, with a broad definition of home health care to cover rehabilitation, mental health services, home medical equipment, aids for daily living and services (nursing; home support; therapy)? • Emergency elder care? • Public/private partnerships of the employer and community caregiver services to develop caregiver support programs in which employers: (1) refer their employee caregivers to community services, and employee assistance programs that offer caregiver support and counselling; and (2) provide financial assistance to enable participation in programs (e.g. for day care)? • Flexible benefits plans, flexible spending accounts? 	
<i>Corporate leadership/advocacy in addressing the needs of family caregivers</i>		
	<p>Is the business involved in advocacy activities, through coalitions or working groups, to promote the development of legislation, supports, and benefits to assist caregivers, such as:</p> <ul style="list-style-type: none"> • Support of the Compassionate Care Benefits under EI? • At the provincial level, legislation to permit individuals to obtain an unlimited period of unpaid leave to care for a family member, with specific job guarantees on their return to work? 	

Key Elements	Key Questions	Comments
<i>Corporate leadership/advocacy in addressing the needs of family caregivers</i>		
	<ul style="list-style-type: none"> • Legislation (provincially) to provide full benefits to permanent part-time employees? • Amendments to provincial employment standards for Family Responsibility Leave, to grant employees specified paid leave to meet caregiving responsibilities? • Federal tax legislation that allows employers to make contributions towards the care of dependent family members, without such care being treated as a taxable benefit? • Promotion of new legislation that provides tax relief and subsidies to caregivers in recognition of home labour and lost opportunity costs? • Pension drop-out scheme similar to that which exists for child care in the CPP/QPP? • Increase in the level of benefits provided by income tax credits, to give meaningful relief to caregivers? • Promotion of direct subsidization of equipment? • Encouragement of corporate policy makers and benefits managers to use their market power to influence insurers to cover visiting nurse services, adult day care, respite care, other community caregiver programs etc., and to offer group long-term care insurance as an employee benefit? 	

How did your workplace/business rate? What do you need to implement to make your workplace more caregiver friendly?

Creating a Work Environment that Supports Family Caregivers

Companies that want to retain valued workers who are responsible for caring for adult family members can use these steps to create a workplace culture that supports them.

1. Evaluate your work culture, human resources and work life flexibility. Review existing policies, programs and benefits to see if they can be modified to better address family caregiving needs. For example, if you have child care benefits, can they be expanded to older or disabled adults? Can a wellness fair be expanded to include community resources for caregivers of adults?
2. Check the costs of lost productivity in your organization by using the online eldercare calculator created by Met Life's Mature Market Institute available at www.eldercarecalculator.org (see page 5).
3. Analyze organizational and employee needs by doing surveys or conducting focus groups. Use this information to build a business case for implementing caregiving supports tailored to your company.
4. Based on your evaluation revise existing policies, programs and benefits to reflect these changes and identify any gaps.
5. Research community resources and government benefits available for family caregivers such as [Compassionate Care Benefits](#) (see page 45) through Employment Insurance.
6. Enhance current offerings to include new programs, policies and benefits that are cost-neutral or money-saving solutions. Make sure that a list of benefits that serve caregivers is included in employee orientation packets and communicated or distributed to all employees.
7. Add care management programs to the employee benefit plan. These provide the employee with access to an expert case manager who can provide guidance to resources and services to assist with the demands of caregiving.

8. Inform managers and human resource staff about issues related to caregiving and employee-sponsored caregiving initiatives, and train them in the resources, skills and solutions they might need to mitigate caregiver-related work-life conflicts.

9. Offer training workshops to help employees better assess their home and work situations, learn about company and community resources, learn how to effectively and comfortably talk to their direct supervisor about their issues as caregivers and jointly develop a plan that balances their work and caregiving responsibilities.

10. Talk with your current employee assistance program. Many employee assistance programs will expand their offerings to include access to resources to help employees with caregiving challenges.

Adapted from: Workforce Management Online, April 2007, www.workforce.com and *Caregiver's Impact on the Workplace*, Jamie Marcellus, October 2012, www.benefitscanada.com.

Create an action plan to support your caregiving employees

Here are some ideas that range from simple to more complex for creating a plan of action to support your caregiving employees. Some can be implemented right away, while others will require more planning to put into place. Even small changes can make a big difference to a family caregiver who is struggling.

Quick, low-cost ideas

- Create a workplace culture that recognizes family caregiving
- Display caregiver information and resources in common areas and make available in the Human Resource department
- Include information in company newsletters
- Make caregiving handouts and information about community resources readily accessible
- Host lunch and learn information sessions for caregiving employees on caregiving issues
- Provide training for management/human resources personnel on the impact of caregiving, work-life balance and resources/supports available
- Incorporate caregiver support into corporate wellness program

Flexible workplace options

- Review existing workplace flexibility policies or create one
- Offer flexible work schedules, such as flex-time, shortened work week or flexible daily schedule
- Provide options for employee leave time, such as paid family leave or using sick time to provide care for a sick family member
- Offer job-sharing or telecommuting
- Create open-door policy so that employees feel comfortable approaching managers/supervisors/HR to discuss their workplace needs relating to caregiving

Policies and Benefits

- Provide Employee Assistance Programs
- Extend benefits package to include additional insurance such as long-term care insurance and dependent life insurance that covers spouse and parents
- Partner with other businesses in your area to share ideas and resources

Section 2:

Resources to Support Your Caregiving Employees

Family Caregivers' Network Society

Our Mission: To inform, support and educate on issues of concern to family caregivers.



Programs and services offered include:

- Family caregiver support groups, offered on a drop-in basis and facilitated by trained volunteer facilitators.
- Telephone, in-person and on-line support.
- Information and referral to community resources and help navigating the healthcare system.
- Educational workshops, tele-workshops and webinars on topics of interest to family caregivers.
- Resource lending library of DVDs, videos and books, as well as informational handouts on topics of value to family caregivers. Handouts can be picked up at our office, mailed or emailed.
- Bi-monthly newsletter, *The Network News*, which contains information about events, support groups, a legal column, a healthcare system column and other articles and information of importance to family caregivers. It is available by mail or by email.
- Comprehensive website with resources for family caregivers.
- Resource Guide for Family Caregivers, 2nd edition for purchase.
- Volunteer Ambassador Program: knowledgeable volunteers with family caregiving experience available to present to community groups and organizations on the services and role of FCNS.
- “Lunch and Learns” sessions for employees, human resource staff and management teams of organizations and businesses.
- Educational seminars for healthcare provider training programs, disease-specific organizations, volunteer organizations and other organizations focused on increasing awareness and knowledge of the role and responsibilities of family caregivers.

#6 - 3318 Oak Street, Victoria, BC V8X 1R1
Tel: (250) 384-0408, 1-877-520-FCNS (3267)

Fax: (250) 361-2660

Email: caregiversupport@fcns.ca
www.familycaregiversnetwork.org



FCNS Support Groups for Family Caregivers

Victoria Support Group

1st Monday of each month
 7:00 - 9:00 pm
 Family Caregivers' Network office
 #6 - 3318 Oak Street, Victoria

Sidney Support Group

3rd Tuesday of each month
 10:00 AM - Noon
 The Lounge,
 Beacon Community Services, Shoal Centre
 10030 Resthaven Drive

Salt Spring Island Support Group

Every Wednesday
 11:00 AM - Noon
 Seniors for Seniors Centre, Ganges
In partnership with the Alzheimer's Resource Centre, however the group is open to all family caregivers.

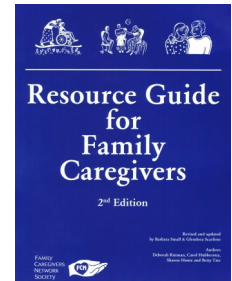
Attendance at all our support groups is on a drop-in basis. The groups are facilitated by trained volunteer facilitators. For more information, contact the Family Caregivers' Network at 250-384-0408 or email caregiversupport@fcns.ca.

Disease and Condition Specific Support Groups

For a list of disease/condition specific support groups, please look under Support on our website at www.fcns-caregiving.org/support/disease-specific-caregiver-support/ or on the back page of each edition of our bi-monthly Network News Newsletter. These will include caregiver support groups at community organizations such as the Alzheimer Resource Centre, BC Cancer Agency and the MS Society.

Resource Guide for Family Caregivers, 2nd edition

If you provide care and support for an adult family member, partner, friend or neighbour, who either lives at home or in a facility, this comprehensive guide will be indispensable to you.



Prepared by the Family Caregivers' Network Society, this 160-page guide is presented in an easy-to-read format and contains practical information to help caregivers make informed decisions.

This valuable resource will assist family caregivers to identify:

- What it means to be a caregiver
- Self-care tips for family caregivers
- How to balance family caregiving and employment
- How to communicate with health care providers
- What community-based supports are available
- How to choose the most appropriate home-based care services
- What kind of professional assessments are available
- Tips for moving from home into a care facility
- What is normal aging
- What is palliative care
- What financial and legal arrangements need to be made

The cost for a paperback copy is \$15.00 for FCNS members and \$20.00 for non-members (plus \$12.00 postage and handling for mail orders). We accept cash, cheque, credit cards or purchase orders. You can also order through our website and pay on-line using Pay Pal.

For further information or to purchase a paperback copy:

Email: caregiversupport@fcns.ca

www.familycaregiversnetwork.org

Tel: (250) 384-0408

A digital copy of the Resource Guide is available to download for FREE from our website at www.fcns-caregiving.org/education/products-for-family-caregivers/resource-guide-for-family-caregivers/

Network News Newsletter

This newsletter is published bi-monthly by FCNS. The purpose of the *Network News* is to provide support, information and education on issues of concern to family caregivers.

Each issue includes information regarding:

- Upcoming events
- Educational workshops and tele-workshops
- FCNS support groups and other caregiver support groups in the community
- Articles and information of importance to family caregivers.
- A column on legal issues related to caregiving
- A column on navigating the healthcare system (VIHA)

The *Network News* is available by mail or by email.

Please contact our office at (250) 384-0408 or email caregiversupport@fcns.ca to put your name on our mailing list to receive your own copy.

You can also sign up to receive the Network News through our website at www.familycaregiversnetwork.org.

Digital copies of past issues of the Network News are also available on our website.

Lunch and Learn Sessions for Your Caregiving Employees

To help support your employees the Family Caregivers' Network Society is available to come to your workplace and facilitate a 45 minutes to one-hour "lunch and learn" session. Topics include:

Balancing Life, Work and Caregiving

With our aging population, the number of people juggling care, work and other life responsibilities is increasing. One in four working Canadians are attempting to balance employment and caregiving and many are experiencing stress, guilt and emotional and financial exhaustion. Caregivers are turning down promotions, taking early retirement and quitting their jobs in order to care. This session will provide concrete strategies and resources to help you to avoid caregiver burnout and stay strong.

Family Caregiving 101

Are you providing care and support for an elderly, chronically ill or disabled adult family member or friend and want to learn more about the ins and outs of what is available in your community to assist you? Join us and learn where to go for help, how to take care of yourself and about respite.

First Care for Yourself: Self-care Strategies for Family Caregivers

When you provide care and support for a family member or friend, you will find that you can only provide good support over the long-term if you care for yourself as well. Self-care is one of the most important and most often forgotten challenges of being a caregiver. In this session we will explore the key concerns experienced by family caregivers and identify strategies for supporting yourself, while supporting another.

Caregiving After Facility Placement

This session will focus on how caregiving changes after your family member or friend is admitted to a facility, including ways to foster a positive adjustment for both of you. Tips on changing roles, the challenges of letting go, effective visiting, advocacy, and self-care are highlighted.

Tips for Long-distance Caregivers

Caring for someone long-distance can be just as stressful, or sometimes even more stressful, than being there. There are a number of ways for a long-distance caregiver to become involved in the caregiving process. This session will be beneficial to you whether you are providing care from a distance or are the primary caregiver and communicating with other family members who live out of town.

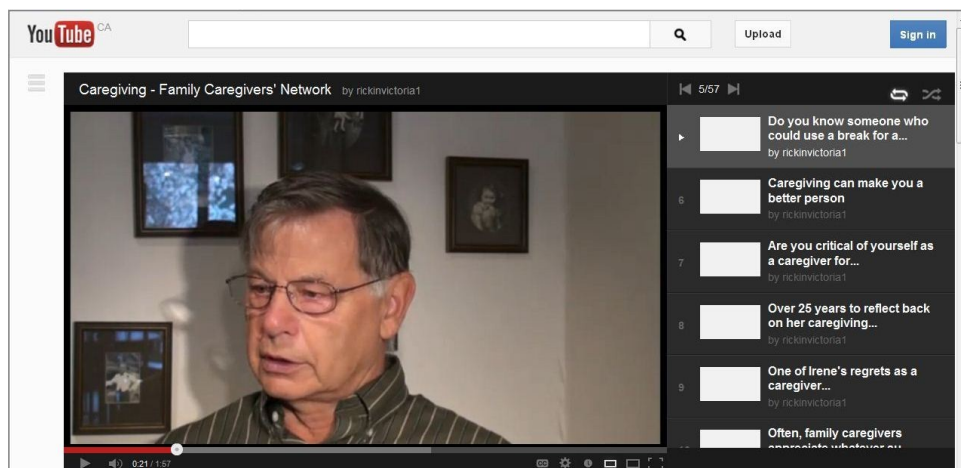
Family Caregivers' Network You Tube Video Series



This series of 60+ videos available on You Tube have been designed for the busy and stressed or overwhelmed family caregiver. Each video is only 1-3 minutes in length, making it easier for caregivers to view them when they have only a small amount of time available. These videos are both educational and inspiring, and they'll also act as a catalyst for family caregivers to seek additional support when they need it.

Visit www.youtube.com/view_play_list?p=7DA8749733558E94 to view these videos.

Thank you to Rick Hoogendoorn, FCNS Board President, for putting together these videos and to all the family caregivers who participated in them and were willing to share their stories in order to help other family caregivers.



Developing a Care Plan

According to the American Association of Retired Persons (AARP), a care plan “assesses an individual’s medical and social service needs, and then coordinates assistance from paid service providers and unpaid help from family and friends to enable persons with disabilities to live with as much independence as possible.”

A care plan ensures that the care recipient, family caregiver and other family members, as well as healthcare providers are all on the same page regarding health care and living arrangements, and that each knows his or her role in managing the needs of the person needing care.

Tips to consider when creating a care plan:

- engage in the conversation early so that you can be prepared in advance and not simply be reacting to a crisis.
- create a flexible plan so that it can be adjusted for unexpected changes.
- consider options and resources in your community and then ensure resources are in place.

Resources for Care Plans (including sample care plans):

VON Canada, Caregiver Connect

On-line caregiving tools including developing a daily care plan. Copy attached.

www.von.ca/en/caregiver-connect/caregiving_tools/default.aspx

American Association of Retired Persons

Prepare to Care: A Planning Guide for Families. Copy attached.

www.aarp.org/relationships/caregiving/info-04-2010/prepare-to-care.html

RBC Your Caregiving Planner

Whether you are giving or receiving care, this on-line planner will help you assess your current informal caregiving needs.

www.rbcroyalbank.com/retirementresearchcentre/calculators/index.html

Vancouver Island Health Authority, Home and Community Care (H&CC)

South Island: 250-388-2273, 1-888-533-2273

Central Island: 250-739-5749, 1-877-734-4101

North Island: 250-331-8570, 1-866-928-4988

www.viha.ca/hcc/



Home and Community Care through VIHA provides a range of health care and support services to eligible clients living in the community. Their in-home and community-based services support clients to improve their health and quality of life, and remain independent and in their own home for as long as possible. H & CC also offers clients other options based on their needs, such as residential care and assisted living.

VIHA, Home and Community Care Handbook for Clients

This handbook outlines the services offered through VIHA, Home and Community Care, as well as what can be expected as a client of Vancouver Island Health Authority (VIHA) Home and Community Care.

VIHA, Patient Care Quality Office - Compliments and Complaints

Registers and resolves public enquiries and complaint about patient care services provided by VIHA. [Making a Complaint](#) - steps to follow.

Health Authorities Throughout BC

The other provincial health authorities also offer similar services.

[Click here](#) for a map of the regions covered by each health authority.

Below is the link to the Home and Community Care departments in each health authority. Telephone numbers are not listed as they tend to have individual numbers for each community which can be found on the websites.

Fraser Health Authority, H &CC

Fraser North, Fraser South and Fraser East

Interior Health Authority, H & CC

Thompson/Caribou, Okanagan, Kootenay/Boundary, and East Kootenay.

Northern Health Authority, H & CC

Northwest, Northeast and Northern Interior

Vancouver Coastal Health Authority, H & CC

North Shore/Coast Garibaldi, Vancouver and Richmond

Home and Community Care Services:

- support clients to remain independent and in their own homes for as long as possible;
- provide services at home to clients who would otherwise require admission to hospital or would stay longer in hospital;
- provide assisted living and residential care services to clients who can no longer be supported in their homes; and
- provide services that support people who are nearing the end of their life, and their families, at home or in a hospice.²¹

Home and Community Care - Who does what?

Nursing: Home Care Nurses provide assessment, teaching, treatment, counselling and monitoring. The service is provided in clients' homes, if they are home-bound, and in nursing clinics for those able to attend.

Case Management: Case Managers carry out assessments to determine eligibility and need for home support, attendance at adult day centres or placement in assisted living and residential facility care. Case managers also provide ongoing co-ordination of services, referrals and monitoring.

Hospital Case Management: Liaison Case Managers in the hospital organize community supports necessary to discharge clients safely home or assess for residential facility care placement from a hospital stay.

Home Support: Community Health Workers provide personal care and respite care to individuals in their homes.

Social Work: Social Workers provide assessment and counselling for issues such as adjustment to illness, client/family anxiety, caregiver issues, palliative care, behavior management and suspected abuse/neglect.

Rehabilitation: Physiotherapists and occupational therapists provide assessment, treatment, consultation and education in order to promote and maintain optimal functional independence in a safe home environment.

Nutritionists: Clinical nutritionists provide assessment, consultation and education to nutritionally compromised individuals who are home-bound.

Quick Response Team: This is an interdisciplinary team, who provide rehabilitation, nursing, social work and home support. Their goal is to provide short-term service to prevent hospital admission and to facilitate early hospital discharge. They are involved in more urgent home assessment and treatment until the Home and Community Care team is able to take over care.²²

Home and Community Care: A Guide to Your Care, Ministry of Health



This downloadable guide is for people who have difficulty coping with activities of daily living because of health-related problems or have palliative care needs. The guide includes general information about services available to help British Columbians live as independently as possible and information about end-of-life care. It also provides useful information for family and friends. It can be found at [www.health.gov.bc.ca/library/publications/year/2007/Guide to Your Care Booklet2007 Final.pdf](http://www.health.gov.bc.ca/library/publications/year/2007/Guide%20to%20Your%20Care%20Booklet2007%20Final.pdf).

Veterans Independence Program (VIP)



Veterans Affairs
Canada

Anciens Combattants
Canada

The Veterans Independence Program is a national home care program provided by Veterans Affairs Canada. The program was established in 1981 to help clients remain healthy and independent in their own homes or communities. It is open to veterans and limited services are available to primary caregivers. VIP does not replace other federal, provincial or municipal programs. Instead it complements these other programs where necessary in order to best meet the needs of clients.

If you are a Veteran and qualify for VIP, the services you receive will depend on your circumstances and health needs. These services may include:

- grounds maintenance, including grass cutting and snow removal;
- housekeeping, including help with routine tasks such as doing the laundry, cleaning your home, or preparing meals;
- personal care services to assist you with personal needs, such as bathing, dressing, and eating;
- access to nutrition services, like Meals-on-Wheels and Wheels-to-Meals; and
- health and support services provided by health professionals.

Guide to Access Health Care Benefits and Veterans Independence Program

www.veterans.gc.ca/public/pages/services/vip/vipbroch_e.pdf

Residential Care



At some point in the caregiving journey many families are faced with the decision of facility placement. This decision is often precipitated by a crisis or a change in health and becomes necessary either because the care recipient is no longer able to safely remain at home or because family members can no longer provide the level or type of care that is now needed. There comes a time when a move to a care facility may be the way to provide the best care needed and to relieve the overwhelming demands on the family.

It is natural for family members to feel guilt, grief, or anxiety in facing this decision and there will often be differing perspectives from the various people concerned. The transition can bring with it new challenges and stresses for everyone involved. When this time comes it is important to acknowledge the reality of the current situation, rather than holding on to the way things used to be. It is not a failure on the part of the family that they are no longer able to provide the level of care that is needed. As the care recipient's health declines the amount of care required can become overwhelming. In addition, the equipment needed to provide the necessary care may only be available in a facility.

If the time is approaching for residential care to be considered, plan in advance and do your research. Knowing what your options are and the steps in the process can help lessen the stress that this transition can bring.

Residential care is available in facilities that are **subsidized** by the local health authority and also through **private** care facilities where the resident pays the cost.

To access care facilities that are subsidized by the health authorities, contact the Home and Community Care department of your local health authority ([see page 35](#)). An assessment by a Case Manager must be completed to determine eligibility and urgency of need. See next page for further details on subsidized facilities.

Private care facilities are businesses and you do not need an assessment by the health authority for admission but staff at the facility will help determine if the facility is suitable to meet the person's needs. The resident pays all costs and prices and services will vary depending on the facility. If interested in a particular facility you can ask for a tour and to see references. There may be a waitlist if there is no bed available at that time.

Residential care subsidized by the Health Authorities



Residential Care facilities provide 24-hour professional care and supervision to adults in a supportive, secure environment. Publicly subsidized Residential Care Services are available to adults with complex medical and cognitive care needs and an assessed and urgent need for 24-hour care. Services are aimed at meeting the complex health needs of those admitted to a facility and include:

- Accommodation
- 24-hour nursing care
- Other professional services such as nursing, physical therapy, social work and nutritional support
- Hospitality services (meals, housekeeping, recreational activity programs, emergency response)
- Personal care assistance
- End-of-life care²³

Information on eligibility, costs and residences can be found at www.viha.ca/hcc/residential/ or contact the Home and Community Care department of your local health authority and speak to a Case Manager.

Needs-Based Access to Residential Care



BC Ministry of Health does not maintain wait lists for access to subsidized residential care facilities throughout the province. Instead, access is prioritized according to need. The goal of needs-based access is to ensure clients obtain the care they need, when they need it. Clients with the highest need and urgency, whose care needs cannot be met with home support or other supportive care, have priority access for the first available, appropriate bed.²⁴

First Available, Appropriate Bed

If you are eligible, and have been assessed as needing publicly subsidized residential care, a "first appropriate bed" policy is in place. This means that you are required to accept the first appropriate bed that becomes available within your local health services area. Clients can still ask for their choice of facility, but must accept the first appropriate bed while they wait for their chosen facility to become available and must be prepared to move within 48 hours of being offered a bed.²⁵

Additional Information on subsidized residential care can be found in the following brochures distributed by VIHA and the BC Ministry of Health:

VIHA Residential Care Guide

www.viha.ca/NR/rdonlyres/4CFF2480-72D7-4B1A-B489-D0A68B4BBC4F/0/viha_residential_care_guide.pdf

VIHA, Preparing for Residential Care Fact Sheet

[www.viha.ca/NR/rdonlyres/CBEBD094-2296-42BD-A577-CE74E12B6CFE/0/Patient Information Sheet SWI RC.pdf](http://www.viha.ca/NR/rdonlyres/CBEBD094-2296-42BD-A577-CE74E12B6CFE/0/Patient_Information_Sheet_SWI_RC.pdf)

More detailed information about the calculation of client rates for residential care services can be found in **Questions and Answers on Client Rates for Publicly Subsidized Residential Care Services**, at www.health.gov.bc.ca/hcc/pdf/residential-care-client-rates.pdf

Client Rates for Publicly Subsidized Residential Care Services - Effective February 1, 2012

www.health.gov.bc.ca/hcc/rcr.html

Ministry of Health, Resident's Bill of Rights

www.health.gov.bc.ca/ccf/residents_bill_of_rights.html

VIHA Licensing Office, Residential Facilities

www.viha.ca/mho/licensing/residential_facilities.htm



Assisted Living Services

Assisted Living is a private living unit in a setting that includes additional supports and services so that residents can maintain independence while ensuring they are safe and supported. Publicly subsidized Assisted Living is for seniors and people with physical disabilities who need a safe environment to live and help with daily tasks. In addition to accommodation, Assisted Living includes daily personal care as well as light housekeeping, meals and activities.²⁶

Information on eligibility, costs and residences can be found at www.viha.ca/hcc/assisted/ or contact the Home and Community Care department of your local health authority and speak to a Case Manager.

Additional Information can be found in the following brochures distributed by VIHA:

VIHA Assisted Living Guide

http://www.viha.ca/NR/rdonlyres/DAD5E7CF-9699-47F3-B35E-D8629081E1B9/0/viha_assisted_living_guide.pdf

Assisted Living Residences - VIHA

<http://www.viha.ca/NR/rdonlyres/46B09EAC-6E68-4C41-978F-77FBED567CEE/0/ALResidencesMarch2009.pdf>

Senior Living Housing Directory

Senior Living Housing Directory is a valuable online resource for seniors and family members looking for alternative housing to match their desired lifestyle, or medical/mobility needs.

Senior residences and housing communities throughout BC are listed in this comprehensive directory. Each listing includes information about housing type, capacity, costs, services, fees, subsidies, type of care, amenities, staffing, security and restrictions.

www.seniorlivingmag.com/housingdirectory

Senior Living
MAGAZINE



End-of-Life Care

Palliative care focuses on care and comfort at end-of-life and consists of medical care and personal care along with social, emotional and spiritual support. Family Caregivers play a significant role in ensuring both physical and emotional quality of life for their family member who is ill. Regardless of whether they choose to die at home, in hospice or in hospital, this can be a very stressful and emotional time for everyone involved. There are many resources available to help support families during this time.

Victoria Hospice



A key resource in our community that provides palliative care is [Victoria Hospice](http://www.victoriahospice.org). Hospice provides an integrated program which includes expert physical care and social, emotional and spiritual support to patients and their families facing death and bereavement. Care is provided in patients' homes, on Hospice's in-patient unit, and in other hospital settings throughout our community. Hospice offers a Palliative Response Team (PRT) that is on call 24 hours a day for short-term crisis consultation and treatment in patients' homes. PRT is also available to support death at home.

For more information contact Victoria Hospice at (250) 370-8715 or visit www.victoriahospice.org.

To find hospice services in other communities visit the Directory of Hospice Palliative Care Services website at www.chpca.net/canadian_directory_of_hospice_palliative_care_services.htm.

The **Canadian Virtual Hospice** provides support and personalized information about palliative and end-of-life care to patients, family members, health care providers, researchers and educators.

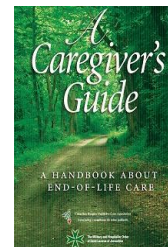


This website, www.virtualhospice.ca, includes discussion forums, videos, resources, an "Ask the Professional" section and FAQ's. There is a section specifically designated to caregivers and caregiving. Virtual Hospice has been ranked as one of the best health websites in Canada by the Canadian Association of Health.

Several informational videos are available on You Tube at www.youtube.com/user/cvhcvpsc

A Caregiver's Guide: A Handbook About End-of-Life Care

A Caregiver's Guide presents family and informal caregivers the medical and nursing information they will need in clear, easily understood language. Free copies are available at the Family Caregivers Network office at #6 - 3318 Oak Street, Victoria, BC. This informative and practical book is produced by the Canadian Hospice and Palliative Care Association. A digital version is also available to download at www.stlazarus.ca/english/news_pages/caregiversguide.html.



This guide will help family and informal caregivers to understand the journey upon which their loved ones have embarked, to become effective, informed members of the palliative care team and to provide essential physical, spiritual and emotional support.

BC Palliative Care Benefits Program



The [B.C. Palliative Care Benefits Program](#) covers the costs for equipment, medical supplies and drug costs. This program supports individuals of any age who have reached the end stage of a life-threatening disease or illness and who wish to receive palliative care at home. Benefits under the program continue for as long as the person is diagnosed as requiring palliative care.

All BC residents who are enrolled in the Medical Services Plan and who wish to receive palliative care at home can request their physician to assess their medical eligibility for the program and submit an application on their behalf.

For more information call the Ministry of Health Services Info Line at 250-952-1742 or 1-800-465-4911 or visit www.health.gov.bc.ca/pharmacare/outgoing/palliative.html

Compassionate Care Benefit Program (EI)

The [Compassionate Care Benefits Program](#) is available through Employment Insurance for employed family members caring for a gravely ill relative at risk of dying within 26 weeks. These benefits consist of six weeks total compensation per terminally ill family member plus two weeks of unpaid waiting period. For more information visit the Human Resources and Social Development Canada website at:

Compassionate Care Benefits website: www.servicecanada.gc.ca/eng/ei/types/compassionate_care.shtml

Compassionate Care benefits information brochure:
www.servicecanada.gc.ca/eng/ei/publications/compassionate.pdf

EI Benefits for Parents of Gravely Ill Children (Effective June 2013)

This new benefit will provide income support for up to 35 weeks within a year for parents or legal guardians of minor children (under 18 years of age) with a life-threatening illness or injury. A medical certificate signed by a Canadian-certified pediatrician or medical specialist would be required to be eligible for the benefit. Details are still under development.

Community Resources for Family Caregivers

Provincial family caregiver support organizations

In addition to the Family Caregiver's Network Society there are various other family caregiver support organizations throughout BC that provide similar services. A comprehensive list is available under "Provincial Resources" on the FCNS website www.familycaregiversnetwork.org.

Senior Services Directory - Victoria



Also, **Seniors Serving Seniors** publishes a Seniors' Services Directory available in hardcopy or online at www.seniorsservingseniors.bc.ca/directory.asp. This directory lists over 500 community resources in the Victoria Capital Regional District. Although it is originally focused on services for seniors the resources listed are useful and applicable to others as well. Many other communities have similar directories for resources in that particular community.

HealthLink BC

The **HealthLink BC Directory** (www.healthlinkbc.ca) is a resource available to British Columbians which provides detailed information about how, and where, to find health services in B.C. It contains directory information about health, mental health, and addictions treatment services in B.C., including the organizations that offer the services and the locations where they are offered.

The **8-1-1** service in British Columbia is a health information phone line operated by HealthLink BC, which is a part of the Ministry of Health. By calling **8-1-1** you can speak to a health services representative, who can connect you with a registered nurse, registered dietitian, or a pharmacist. They will help you get the information you need to manage your health concerns or those of your family.



Seniors Health Care Support Line



The new Seniors Health Care Support Line is now available to provide seniors and their families with support for health-care-related issues that they may have had trouble resolving. Seniors who have issues accessing health-care services or with the health care they received can now call this line to receive timely resolution of problems. This toll-free phone line is available Monday-Friday from 8:30 AM to 4:30 PM by calling 1-877-952-3181 or 250-952-3181 in Victoria.

Safe Medicine for Seniors, VON Canada



Safe Medicine for Seniors: A Guide for Caregivers

This guide is for anyone helping or taking care of a senior in any way. The checklist questions help identify any problems you or the person you're helping may have with medicine. The tips offer suggestions on ways you can help.

Medicine Chart

There is some basic information you need to know about the medicine the person you're helping is taking, especially if you have to act on the person's behalf with doctors, pharmacists, specialists or hospitals. For instance, what the name is, what it is for, when and how to take it. You can use tools such as a medicine chart to help you keep track.

Checklist: What else to know about the person taking medicine

If you help someone fill prescriptions, take medicine or go to appointments, you may need information such as: How many kinds of medicine does the person take? When was the person's last doctor appointment? When was the last time the person (or you) talked to a pharmacist?

All of these tools are available on the VON Canada website at www.von.ca/safemedicinesproject/english/cg_seniors/tools.cfm

Knowledge is the Best Medicine, Canadian Pharmacist Association

Knowledge is
the *best* medicine

"Knowledge is the best medicine" is a program that helps you take control of your health and work with your prescriber and the rest of your healthcare team to manage your medicines safely and appropriately. This program is supported by leading health organizations in Canada who believe that an educated patient is a healthier patient. Website includes a "Create Your Own Medication Record" and "My MedRec" iPhone app. Visit www.knowledgeisthebestmedicine.org/index.php/en/.

Disease/Condition Specific Organizations

The Family Caregivers' Network Society provides programs and services for all family caregivers of adults regardless of the health situation of the care recipient. In addition, there are various disease/condition specific organizations that in addition to providing programs and services for the person living with the disease/condition, also provide some programs and services for the family caregivers and other family members and friends. Below is a partial list of these organizations. Additional information can be found in the telephone directory, on-line or through the resources listed above.

A.L.S. Society

1-800-708-3228, www.alsbc.ca

Alzheimer Resource Centre - Alzheimer Society of BC

250-382-2052, www.alzheimerbc.org

(Alzheimer's disease or a related dementia)

Arthritis Society

250-519-4000, www.arthritis.ca/bc

BC Cancer Agency

250-519-5500, 1-800-670-3322, www.bccancer.bc.ca

BC Schizophrenia Society, Victoria Branch

250-384-4225, www.bcssvictoria.ca

Victoria Brain Injury Society

250-598-9339, www.vbis.ca

Victoria Epilepsy and Parkinson's Centre

250-475-6677, www.vepc.bc.ca

Multiple Sclerosis Society

250-388-6496, www.mssociety.ca/chapters/svic

The Prostate Centre

250-388-0214, www.theprostatecentre.org

Stroke Recovery

Peninsula Stroke Recovery Branch, 250-652-3016

Victoria Stroke Recovery Association, 250-383-2623

Help at Home: Resources to Assist Family Caregivers

As they age many individuals are trying to stay in their own homes for as long as possible. This can put added stress on family caregivers as the health and independence of their aging family member declines. There are many products and services in the community that can help support someone to stay in their home longer and can aid in reducing the impact on the family caregivers.

The types of services will vary dependent on the community that the care recipient lives in and the costs will range from free to a fee-for-service. Below is a list of some of these services:



Medical Equipment and Aids

A variety of aids and equipment are available for purchase or loan to help individuals with communication, mobility or specific personal care needs. These include medical equipment,

incontinence supplies, specialized clothing, mobility aids, vision aids and hospital beds. Community loan cupboards may exist from which you can borrow medical equipment.

Visit the FCNS website for a list of these resources in the CRD, www.fcns-caregiving.org/resources/equipment-loans/. Several private businesses also focus solely on selling medical aids and equipment.



Occupational and Physiotherapists

Rehabilitation professionals are available through the Home and Community Care department of your local health authority. These individuals can do a home safety assessment to ensure that the home environment is safe and supports optimal functional independence. See page 60 for more details.

Home Adaptation

Another step toward ensuring safe independence at home is to have the house adapted to be more accessible as mobility and health changes. The [Home Adaptations for Seniors' Independence](#) (HASI) program

through CMHC “offers financial assistance for minor home adaptations that will help low-income seniors to perform daily activities in their home independently and safely”. See page 60 for more details on resources.



Help at Home cont'd



Emergency Response and Medical Alert Systems

These systems provide 24-hour-a-day monitoring services which connect to a live person in the case of a fall or other emergency. The equipment can be in the form of a personal help button on a wrist band or pendant and may also include auto alert when a fall is detected. Some systems also provide automatic medication reminders in the form of an audio alert. Having one of these systems installed can help your family member live independently longer and help relief some of the worry from the family caregiver.



Volunteer organizations may provide home visitors, walking companions, and volunteers to assist with odd jobs, reading, letter writing, and driving to appointments or shopping. Some agencies also provide reassurance calls to check-in with your family member each day to ensure they are okay. Check for the volunteer organization in the area where the care recipient lives.

House cleaning services are a very useful resource for family caregivers and some will provide additional services, including laundry, moving furniture, taking out garbage and doing garden work. The private home support agencies often offer housekeeping services.



Other support services may be available in your community to provide help in the home and improve the quality of life for both the family caregiver and the care recipient.

For resources in your local community, check your yellow pages, contact the Home and Community Care division of your health authority, visit a senior's center or look under "Resources" on the Family Caregivers' Network's website at www.familycaregiversnetwork.org.

Home Safety Assessments



Through VIHA's Home and Community Care, Community Rehabilitation department a continuum of occupational therapy and physical therapy services are available to promote and maintain optimal functional independence in a safe home environment. For example, one area Occupational Therapists and Physiotherapists are involved with within HCC is Home Safety Assessments. When an individual is at risk for falls or is having increased difficulty with mobility they are available for a home safety assessment. If you are interested in a home safety assessment or Occupational Therapist, please contact the VIHA Home and Community Care, General Enquires Line at 250-388-2273 or 1-888-533-2273. For the contact information for other health authorities within BC [see page 35](#).

Home Adaptations for Independence Program



The Province recently announced the new Home Adaptations for Independence (HAFI) program to help low-income B.C. seniors and people with disabilities finance home modifications for accessible, safe and independent living. Eligible homeowners, renters and landlords can receive up to \$20,000 per home in the form of a grant or forgivable loan.

Eligible adaptations include items that directly address the household's disability or diminished abilities, such as handrails in hallways, ramps for ease of access, easy to reach work areas in the kitchen or walk-in showers with grab bars.

For more information, visit BC Housing's website (www.bchousing.org/HAFI) or call 604-646-7055 or toll-free at 1-800-407-7757 (ext. 7055).

Canada Mortgage and Housing Corporation Publications (CMHC)



CMHC also provides several free books on adaptable housing including:

[Maintaining Seniors' Independence: A Guide to Home Adaptations](#)

[Maintaining Seniors' Independence through Home Adaptations: A Self-Assessment Guide](#)

These can be found on the CMHC website at www.cmhc.ca. Click on Renovating a Home, Publications, Building and Design, then Adaptable Housing. Each publication is available in digital and hardcopy formats.

Care-ring Voice Network



Provides tele-workshops and webinars for family caregivers on a wide-range of topics. Sessions are hosted by various community agencies across Canada, including the Family Caregivers' Network Society.

Visit www.careringvoice.com for more information or to register for a tele-workshop or webinar.

Caring for a loved one who is sick?

Maybe you're feeling overwhelmed,
looking for home care support,
or having difficulty accessing services. Whatever it is...

We can help.

Care-ring Voice is a free and confidential program that connects caregivers and families to information and support through tele-learning. We host workshops and seminars by telephone and the web on a range of life-changing topics.

Visit us online at

www.careringvoice.com



CARE-RING VOICE NETWORK



Tyze On-line Networks



With a Tyze on-line network you can organize medical appointments, schedule outings, share information and private documents. Post pictures and stories to celebrate important events and stay connected with family and healthcare professionals.

With your own Tyze on-line network you can share the caregiving responsibilities and easily keep everyone up-to-date with health changes, challenges and celebrations.

Tyze on-line tools include: message and calendar systems, a virtual “to-do” list, the ability to assign tasks to individuals, a way to share pictures and stories and a safe place to store and access documents. Visit www.tyze.com for a free demo.

See the [next page](#) for an example of how a Tyze On-line Network helped one family balance caregiving and employment.

Then sign up for your Tyze On-line Network through the Family Caregivers’ Network to get your first year free (a value of \$129).

Limited quantities available. Call 250-384-0408 or email caregiversupport@fcns.ca for more information.



How a Daughter Coordinates Care Online

Christabel's mom was diagnosed with cancer in 2008 and it metastasized to her bones shortly after. The family is small so there was no one but Christabel and her brother around to provide support. Both work full time.



One month before my university graduation in October 2008, a doctor explained to us that my mother had cancer spreading throughout her bones. The room turned inside out. I had always thought that my mother's bones were made of steel. These bones had held our family together.

I was travelling and working long hours. I couldn't take her to appointments. I couldn't take time off. I wanted an online space to convene everyone and when I found Tyze, I immediately thought, wow, this is amazing. Here's this private space that I trust and that's totally uncluttered.

I invited a small group in and started by saying we could use help with things like groceries or appointments but that even a phone call or a visit would be really awesome. Some of the smallest things make the biggest difference. Engaging a community is so much better than overloading one person who you eventually burn out.

Right away after we got set up on Tyze people were visiting, calling, taking her to appointments. Even people who lived far away started to keep in touch way more. My mom isn't cured, but I've noticed a big difference in her outlook. I have no doubt that social support is as important as medical support.



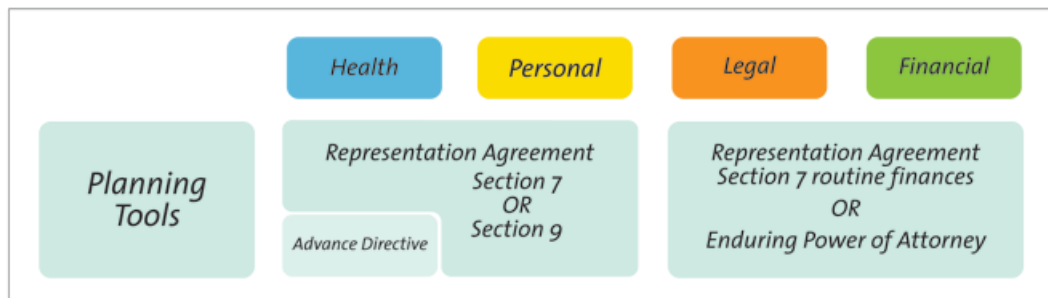
When it comes right down to it our family doesn't have to hire a nurse because of Tyze. My brother and I can keep our jobs. It's just so huge. I think bringing out the strength of a group is really fascinating.

I just see so many uses for Tyze. It's helped our family so much. It's so powerful to give people the opportunity to show how much they care.

Personal Planning and Legal Considerations

Personal planning involves making arrangements in advance in case you need assistance with managing your legal, financial and health related affairs due to illness, injury or disability. It is important to ensure that the person you are caring for has taken the time to complete the appropriate documents. These documents help ease future decision-making, such as withdrawing money from the bank, selling a house or providing informed consent for a medical procedure.

The Nidus Personal Planning Resource Centre (www.nidus.ca, Tel: 604-408-7414) provides detailed information on all of these topics and more in easy-to-read format. As outlined on the Nidus website, each document is different. They cover different aspects of the four life areas. The capability requirements as well as the signing and witnessing procedures for each document are also different. The diagram (from Nidus website) below outlines the different types of planning tools that need to be considered²⁷:



An **Enduring Power of Attorney** appoints another person, called an “attorney,” to make financial and legal decisions for someone. When appointing an “attorney” it is important that someone is designated who is trustworthy and who is capable of dealing with financial matters. If no Enduring Power of Attorney has been completed and a person is incapable of managing their own financial affairs the Public Guardian and Trustee’s Office (PGT) or a court appointed committee may be required.

A **Representation Agreement** authorizes someone to act on someone’s behalf to manage their medical affairs when they are no longer able to do so. It is important that the person making the Representation Agreement communicates how they want to be cared for to their appointed representative.

Most people consult a lawyer or notary to prepare these documents and for advice on how to best meet the needs of their specific situation.

Advance Care Directive

Advance care planning allows you to have a say in the healthcare you will receive if you are too sick to speak for yourself. By documenting your wishes and discussing them with your family and healthcare professionals, they will be better able to act on your behalf.

An Advance Care Plan, sometimes called a living will or advance directive, is a set of instructions written by you. If you are not able to make your own health decisions, the advance care plan tells the person providing care what kind of care you want. The instructions and tools you need are provided in My Voice: Advance Care Planning Guide provided by the Ministry of Health. It is available to download off their website at:

www.health.gov.bc.ca/library/publications/year/2012/MyVoice-AdvanceCarePlanningGuide.pdf

Other Personal Planning Resources

Some of the excellent documents and tools available through the Nidus website include:

[Stay in Charge of Your Life: The Nidus Guide to Personal Planning](#)

[Health Care Consent: How Decisions are Made if You are Not Capable](#)

[Personal Information Record](#)

The Personal Information Record is a place to record information about people and documents your representative might need to locate. For example, the name of your family doctor and pharmacist, who to contact if you are seriously ill, bills to keep track of and personal identification that may require safekeeping.

[Values and Beliefs Discussion Guide](#)

The Values and Beliefs Discussion Guide is a booklet you can use to give guidance to your legally authorized supporters.

[Planning Circle Exercise: Identifying Your Personal Supporters](#)

Identifying your personal supporters is one of the first steps in personal planning. This planning circle exercise is designed to help you with this step.

[Nidus Personal Planning Registry](#)

The Nidus Personal Planning Registry™ is a service that lets you keep track of and store your personal planning information and copy of your documents. It makes sure your wishes are available when needed.

Financial Resources

Family caregiving can impact individuals in different ways. Costs may include loss of income due to either illness or caregiving, home care and other medical care not subsidized by the health authority, the purchase of equipment for the care recipient's use, adaptations to the home to make it more accessible and the possible cost of facility placement if not subsidized.

It is hard to predict all the costs that you might incur as a family caregiver. Preparation in advance by both the care recipient and caregiver is essential to help mediate this financial burden. An effective financial plan needs to consider the many scenarios that might arise and the costs that might be incurred. Some options to consider include critical illness or long-term care insurance, use of RRSP's, reverse mortgages or home equity loans. Speak to a financial advisor or your bank for more information. Tax credits are also available to offset some of these expenses.

Income Tax Information for Family Caregivers



Canada Revenue
Agency

Agence du rever
du Canada

Here are some income tax credits that you might want to explore when completing your personal income tax return. Each have several conditions that must be met in order to qualify to claim the deduction. Also, there are specific criteria regarding claiming more than one of these deductions at the same time.

Tax credits may vary with tax year. Further information about these can be found on the Canada Revenue Agency website at www.cra-arc.gc.ca by using the Search function or from your accountant or tax preparer. Below is information from the CRA website:

Caregiver Amount (Line 315): You may be able to claim the caregiver amount if, you (either alone or with another person) maintained a dwelling where you and one or more of your or your spouse's or common-law partner's dependants lived. Each dependant must be 18 years of age or older and be dependent on you due to an impairment in physical or mental functions and in the case of parent or grandparent, born in 1945 or earlier. Additional conditions must also be met.

Amount for an Eligible Dependant (Line 305): You may be able to claim this amount if, at any time in the year, you met all of the following conditions at once:

- you did not have a spouse or common-law partner or, if you did, you were not living with, supporting, or being supported by that person;
- you supported a dependant in 2011; and
- you lived with the dependant (in most cases in Canada) in a home that you maintained. You cannot claim this amount for a person who was only visiting you.

The dependant must also meet certain criteria.

Amount for Infirm Dependants Aged 18 or Over (line 306): If you are eligible for this amount, you can claim an amount for each of your or your spouse's or common-law partner's dependants who has a severe and prolonged impairment in physical or mental functions and is 18 years of age or older. **Check criteria for eligibility.**

Disability Amount Transferred from a Dependant (Line 318): You may have a dependant who is able to claim the disability amount, and that person may not need to claim all or part of that amount on his or her Income Tax and Benefit Return. Under certain conditions, your dependant may be able to transfer some or all of this amount to you. If your dependant is eligible for the disability tax credit (DTC), you may be able to claim the disability amount on your tax return.

Eligible Medical Expenses (Lines 330 & 331): Ensure you also check out the long list of eligible medical expenses that can be claimed.

Compassionate Care Benefit Program (EI)



The **Compassionate Care Benefits Program** is available through Employment Insurance for employed family members caring for a gravely ill relative at risk of dying within 26 weeks. These benefits consist of six weeks total compensation per terminally ill family member plus two weeks of unpaid waiting period. For more information visit the Human Resources and Social Development Canada website at:

Compassionate Care Benefits website: **www.servicecanada.gc.ca/eng/ei/types/compassionate_care.shtml**

EI Benefits for Parents of Gravelly Ill Children (Effective June 2013)



This new benefit will provide income support for up to 35 weeks within a year for parents or legal guardians of minor children (under 18 years of age) with a life-threatening illness or injury. A medical certificate signed by a Canadian-certified pediatrician or medical specialist would be required to be eligible for the benefit. Details are still under development.

Choice in Supports for Independent Living (CSIL)



Choice in Supports for Independent Living (CSIL) is an alternative for eligible home support clients. CSIL was developed to give British Columbians with physical disabilities and high-intensity care needs more flexibility in managing their home support services.

CSIL is a "self-managed model of care." Eligible clients receive funds directly for the purchase of home support services. They assume full responsibility for the management, co-ordination and financial accountability of their services, including recruiting, hiring, training, scheduling and supervising home support workers.

Who is Eligible for CSIL?

Eligible clients must be:

- Be 19 years of age or older
- Be approved for Home Support services
- Require daily personal assistance
- Be medically and functionally stable
- Be able to direct all aspects of your care, or have an alternate decision maker to do this for you
- Be able to direct and manage the CSIL contract obligations, or have an alternate decision maker to do this for you.

For more information contact your local health authority or visit www.health.gov.bc.ca/hcc/csil.html or [www.viha.ca/hcc/services/choice+in supports for independent living csil.htm](http://www.viha.ca/hcc/services/choice+in+supports+for+independent+living+csil.htm)

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Additional handouts and articles for family caregivers can be found on the Family Caregivers’ Network Website at: www.fcns-caregiving.org/education/resource-lending-library/. Hardcopies are also available from our office at #6 - 3318 Oak Street or email caregiversupport@fcns.ca and we can email digital copies to you.

A Caregiver's Bill of Rights

I have the right...

- To take care of myself. This is not an act of selfishness. It will give me the capacity of taking better care of my relatives.
- To seek help from others even though my relative may object. I recognize the limits of my own endurance and strength.
- To maintain areas of my own life that does 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 do for this person, and I have the right to do some things for myself.
- To get angry, be depressed, and express other difficult feelings occasionally.
- To reject any attempt by my relative (either conscious or unconscious) to manipulate me through guilt, anger or depression.
- To receive consideration, affection, forgiveness, and acceptance for what I do 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 has sometimes taken me to meet the needs of my relative.
- To protect my individuality and my right to make a life for myself that will sustain me in the time when my relative 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 older persons in our country, similar strides will be made toward aiding and supporting caregivers.

By Jo Horne, Author of Caregiving: Helping an Aging Loved One (AARP Books, 1985)

Ten Timely Tips for Caregivers

1. **Get help with tasks and chores early on in the illness** - your loved one will get used to having other people around the home.
2. **Involve other members of your family from the beginning** of the illness - even if you are the only one who sees the changes which are taking place - pass these on as information only - not as a debating issue.
3. **Access all the information you can about the illness and educate yourself as much as possible about its progression** - disease-specific organizations, your doctor, and the public library, for example, are sources of information.
4. **Recognize and learn to accept that anger, anxiety and guilt are normal feelings** given the situation you are experiencing - they come not only from being tired but also from the losses you are experiencing.
5. Join a support group as soon as you can - **You do not need to be alone on this journey.**
6. Every change in your loved one means more adaptation and change for you - **acknowledge that this gives you the right to feel off-balance some days.**
7. **Forgive yourself for not being perfect.** Caring for someone with a chronic or terminal illness turns your life inside out.
8. **Make friends with your family physician** and ask for time to speak with her/him alone - if you need to do so.
9. **Get regular physical check-ups, eat a balanced diet and try to take time out to express sadness, anger and helplessness.** Accept yourself for being human and try to do at least one thing that you enjoy every day.
10. **Take one day at a time while planning for the future.** Good planning means getting to know and implementing any legal and financial considerations, facility placement issues, or palliative care, and **BE KIND TO YOURSELF.**

By Dorothy Orr - Caregiver Support Counsellor (re: dementia) and adapted for all family caregivers by the Family Caregivers' Network Society.

Family Caregiver Stress Test

The following test will help you become aware of your feelings and the pressures and stress you currently feel. Responses are:

Seldom Sometimes Often Usually Always

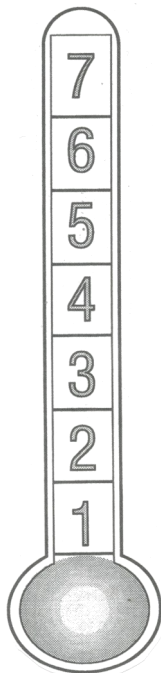
- | | |
|-------|--|
| _____ | I find I can't get enough rest. |
| _____ | I don't have enough time for myself |
| _____ | I don't have time to be with other family members besides the person I care for. |
| _____ | I feel guilty about my situation. |
| _____ | I don't get out much anymore. |
| _____ | I have conflict with the person I care for. |
| _____ | I have conflicts with other family members. |
| _____ | I cry everyday. |
| _____ | I worry about having enough money to make ends meet. |
| _____ | I don't feel I have enough knowledge or experience to give care as well as I'd like. |
| _____ | My own health is not good. |

If your response to two or more of these areas is "Usually" or "Often" it may be time to begin looking for help with caring for your family member or friend as well as help in taking care of yourself.

Source: Robert S. Stall, M.D. (2002) Caregiver's Handbook Buffalo, New York.

Emotional Manifestations of Burnout

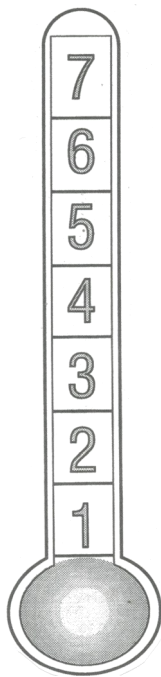
Where would you position yourself on this thermometer?



7. I'm so unhappy I want to die. I have no patience. I can't be bothered with anything. All I want to do is cry and sleep.
6. I'm so unhappy and irritable that I don't even recognize myself; I've changed so much.
5. I'm rather tired and irritable and not really interested in taking care of myself. Things are just beyond me.
4. Sometimes I'm happy, other times sad, often irritable. I don't really know where I'm going. It's becoming more and more difficult to pick myself up.
3. I brood about so many things. I don't laugh very often. I feel frustrated.
2. I'm becoming sullen. I seem to have lost some of my sense of humour.
1. I'm generally in good humour. I look at life optimistically and I don't let things get me down.

Physical Manifestations of Burnout

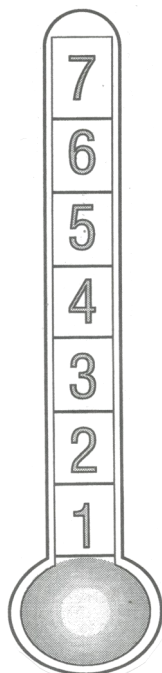
Where would you position yourself on this thermometer?



7. I feel empty, overextended. I have no energy left for anything. I am at the end of my rope. I am completely burned out.
6. I am unable to function normally; my only desire is to do nothing and to just let myself go. I feel washed out, dried up.
5. I feel more and more tired. I don't even know where I am going to get the energy to continue. Everything requires energy even when I want to do something for myself.
4. I feel an immense tiredness. I would really like my sleep, to rejuvenate myself but nothing works. I'm just as tired when I get up as when I went to bed.
3. I'm not in great shape and I have less and less energy. I often have the urge to sleep. Everything I do requires a lot of energy.
2. I have energy, I'm still in shape but I'm obliged to give up a number of activities and projects.
1. I feel in great shape and have the drive to do lots of things.

Self-Denial Aspects of Burnout

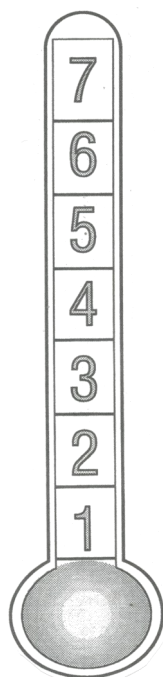
Where would you position yourself on this thermometer?



7. I don't have a minute to myself. Even with all the help I need, I'm completely overloaded and overwhelmed. I can't take it anymore.
6. My entire time is spent taking care of him or her. Even with help, all my time revolves around his or her care. I feel that my responsibilities are eating me alive.
5. I can't seem to find time to rest, even when I have help. In any event, I don't have any time, there is always something waiting for my attention.
4. There is no time for myself. The housework isn't done and I don't know how I can get a handle on the situation even if I get some help.
3. I'm unable to do everything I want. I have less and less time to go to the hairdresser, to the doctor's or to visit friends.
2. I'm still able to do just about everything and I'll continue as long as I must. I'm not too worried.
1. I'm able to do all the housework, take care of him or her and to think of myself. I'm well organized.

Social Aspects of Burnout

Where would you position yourself on this thermometer?



7. I have no desire to see anyone. I have nothing to say. I feel empty and alone.
6. It's been awhile since I've contacted anyone, friend or family. I've become quite isolated. I'm losing contact with everyone, even with myself.
5. I've no desire to have fun. At times I forget about my friends and family. My only "distraction" is him or her..
4. I can't seem to amuse myself. I am preoccupied. I don't find myself interesting. I must be a bore. I hardly ever call anyone.
3. I miss my friends and family. I hardly ever see them or even go out. I still find some time to call them. I find it a burden
2. I've less and less contact with family and friends. I'm not going out as often, but I call them regularly.
1. I maintain regular contact with family and friends. I find the time to confide in them, to go out, to change my headspace

Balancing Family Caregiving and Work

Approximately 70% of the one million family caregivers in BC are balancing the demands of caregiving and working full or part-time. This can result in caregivers quitting their jobs, retiring early, cutting back on hours, turning down promotions and loss of pension contributions. Employers experience higher absenteeism rates, more lateness and lower productivity.

If you are juggling the demands of work and caregiving, here are some ideas that might help:

- Talk to your employer, manager or human resource person about what is happening and your needs around caring for your family member.
- Flexibility is essential for a lot of caregivers to permit them to respond to emergencies or during periods of intense caregiving demands. Explore the options that are available in your workplace, such as flextime, a compressed work week, reduced hours of work, job sharing, leave of absence, gradual retirement or working from home. Even if these have not been used by anyone else before, your employer may still be open to considering them now.
- On the other hand, you may prefer to have a set work schedule so that you can plan for appointments and arrange for home support or respite.
- There are likely other family caregivers in your workplace who are also facing challenges. Consider developing your own support group at work. Meet during the lunch hour to share your challenges and successes. Or you might want to set-up something on-line where you can share resources, tips and questions with each other.
- Compassionate Care Benefits are available through Employment Insurance for employed family members caring for a gravely ill relative at risk of dying within 26 weeks. These benefits consist of six weeks total compensation per terminally ill family member plus two weeks of unpaid waiting period. For more information visit the Human Resources and Social Development Canada website at www.hrsdc.gc.ca.

Balancing Family Caregiving and Work cont'd

- Some employee benefits, such as extended health benefits and employee and family assistance programs, may extend to dependents and can help with family caregiving responsibilities. The workplace benefits available to you as a family caregiver may not be obvious or well-known even to your manager. You may need to do some research, along with your manager or human resource department about what benefits and options are available and how they apply to your situation.
- Make a list of what you need help with and when you need it. Decide what other family members can do and what outside services need to be brought in.
- Familiarize yourself with community resources that are available to help you. Contact the Family Caregivers' Network at 250-384-0408 or visit www.familycaregiversnetwork.org for resources in your area.
- There is also a section on the FCNS website, under the Education tab, dedicated to "Supporting Family Caregivers in the Workplace". This section includes valuable information and resources for both employees and employers,

By Barbara Small, Program Development Coordinator, Family Caregivers' Network Society, Senior Living Magazine, March 2011, Victoria, BC

Caregivers frequently give up their jobs and lose their professions. Caregiving becomes, in effect, their career.

Silver Donald Cameron, 2004

Accepting Help is Essential for Family Caregivers

The responsibilities of caregiving can often feel overwhelming and seem more than you can handle by yourself. More and more of your time and energy is used up navigating the healthcare system, finding resources or figuring out how to meet someone else's personal and medical needs. It is natural to feel overwhelmed and stressed. You don't have to do everything alone. In fact it is essential that you ask for help and support from the very beginning so that you don't burnout.

Asking for help is essential to the well-being of both the family caregiver and the person receiving care. When you share the responsibility, you will have more time and energy for a normal relationship with your family member and to take care of yourself as well. You are less likely to be angry and resentful. The care recipient's experience will also be enriched by having the opportunity to interact with more people.

Despite the fact that family caregivers may be overwhelmed with responsibility, they often do not ask for help or reject help when it is offered. Asking for help can be difficult when we don't know what we need, we don't want to be a bother, or we feel guilty that we can't do it all ourselves. Beliefs such as "no one can do this as well as I can" can also be an obstacle to asking for help. It's true. No one will do it exactly the same as you, but that does not mean that they cannot be helpful in their own way.

Recognize that asking for help is a sign of strength, not weakness. It means you are acknowledging the challenges of the situation and are being proactive in resolving problems and preventing stress. It is a sign of strength because it requires putting your pride aside and acting in the best interest of your family member and yourself.

You first need to admit that having some help will make a real difference to the care recipient's quality of life, and therefore yours as well. You need to identify what help you need. Which tasks would be the easiest to ask others to do? Which do you really want to do yourself? And which, if any, can you afford to pay others to do?

Discuss your needs with family members and friends who might be willing to help. They may want to contribute but don't know how. Create a list of tasks you need help with. Then focus on each individual's strength. Some people may be better at personal care while others may be better able to help around the house or run errands.

Accepting Help cont'd

Contact your local health authority to see what services are available to assist you, such as home support and respite. There are many businesses, community and volunteer agencies that offer services to reduce your load. People may not realize you need help if you don't ask for it. Remember, you have the right to ask for help. Everyone will benefit from sharing in the caregiving.

By Barbara Small, Program Development Coordinator, Family Caregivers' Network, Senior Living Magazine, Sept. 2011, Victoria, BC

Stress Management Strategies for Family Caregivers

The demands of caregiving can be overwhelming. The daily tasks of caregiving – providing personal care, running errands, keeping up with housekeeping, navigating the healthcare system and dealing with family members can have both an emotional and physical toll. Add to that the various emotions experienced and trying to balance the rest of your life and it is not surprising that many family caregivers experience burnout.

Our responses to stress can be classified into three categories – physical, psychological or behavioural.

Physical responses - our body responds to the internal alarm created by stress with a fight-or-flight response, such as rapid breathing, headaches, indigestion or tense muscles.

Psychological responses - we can respond to stress with a change in emotions, concentration, and our ability to complete tasks or interact with others.

Stress can also reveal itself in changes in **behaviour**, such as eating, being accident prone, insomnia or restlessness.

When you are aware of how you respond to stress, you can use these changes as signals that you are feeling stressed. Then rather than simply addressing the symptom, you can take a look at your situation, explore what might be causing the stress and work at resolving that. For example, instead of taking a sleeping pill, explore what is preventing you from sleeping and problem-solve that situation.

There are two routes you can take to manage your stress. You can learn strategies to help reduce stress once it develops - such as deep breathing, relaxation or exercise. Or you can be proactive and change your lifestyle so that stress is less likely to develop in the first place. Proactive techniques include learning to be assertive, asking for help and expressing your feelings.

Below are some strategies to help manage the stress of caregiving:

Ensure you take time for self-care, such as exercising, healthy eating, getting enough sleep, connecting with others and asking for help. You are not being selfish when you take care of yourself. If you get sick, who is going to take care of both of you?

cont'd

Stress Management Strategies cont'd

Have realistic expectations about what you can or cannot do. You can provide a certain amount of care, but likely cannot do everything by yourself. Know when to ask for help and be willing to share the care.

Reach out and accept support: Ask family members or friends to help with some of the day-to-day tasks. Contact community organizations that provide respite care and services for family caregivers. Attend a support group where you can share your concerns and receive support.

Gather information about your family member's health problems and how their needs are likely to change over time. This will help you prepare in advance for these changes.

Making adaptations around the home or using available assistive devices can allow the person you are caring for to do more things for him or herself.

Have a sense of humour: Laughter helps puts things into a positive perspective and relieves stress. Look for the humour in situations and make time to go out and simply have some fun.

By Barbara Small, Program Development Coordinator, Family Caregivers' Network Society. Senior Living Magazine, April 2010

The Emotional Impact of Caregiving

Family caregivers experience a wide range of emotions in response to the responsibilities of providing care, including anger, grief, guilt, and resentment. And yes, there is some joy and satisfaction as well.

All these feelings are normal and will fluctuate continuously dependent on the current situation. It is important to find a way to express and manage these emotions, especially those that drain your energy. Left unexpressed these emotions can lead to caregiver burnout.

All your emotions are valid and real. Trust them as they come up. Take a deep breath and examine what is motivating the emotion and what small change you could make to shift that feeling. Difficult emotions can be a signal to you that the current situation is not working for you or that something needs to change. Then at those times when you feel happy and energized, notice what has caused this response so you can draw on it in the future when you need to.

Below are some suggestions to help you manage tough emotions:

- Attend a caregiver support group at the Family Caregivers' Network (FCNS) or through one of the many disease-specific organizations, such as the Alzheimer's Resource Centre or MS Society.
- Talk to a friend, a fellow caregiver, a co-worker or professional counsellor. Many community organizations, including FCNS, provide telephone support.
- Find time for activities that energize you and that you enjoy. Taking time to recharge will make you a better caregiver overall and help toward reducing any anger and resentment. Everyone will benefit.
- Look at the expectations you have for yourself, the person you are caring for and the current situation. Are your expectations realistic or are you setting yourself up for further frustration and guilt? Are you trying to maintain life as it was before any changes in health?
- When you feel angry or resentful, take a break and leave the situation if possible. A quick walk or some deep breathing can quickly help defuse your feelings.
- You may feel guilty when you are experiencing "negative" emotions such as anger and resentment, or when you take time for yourself. It is important to remember that you are doing the best you can, at the time, with what you know.

By Barbara Small, Program Development Coordinator, Family Caregivers' Network Society, Senior Living Magazine, June 2012, Victoria, BC

Respite Options for Family Caregivers

Respite is when a family caregiver allows someone else to temporarily take over their caregiving duties for an hour, a day, a week or longer. Respite can help prevent caregiver burnout and permits caregivers to continue caring for as long as possible. It gives caregivers a chance to rest, recharge, get errands done or take a much needed vacation.

There are several formal types of respite provided through local health authorities Home and Community Care departments, such as:

Adult Day Services:

These services include day respite, health monitoring, therapeutic and recreational activities and community bathing programs. They provide an opportunity for the care recipient to socialize and stay connected to their community and gives the family caregiver a break. For more information visit: www.viha.ca/hcc/services/adult_day_services.htm.

Home support:

Home Support is provided in the care recipient's home by Community Health Workers who are directed by a nurse. Community Health Workers help with things like medications, bathing and dressing for eligible clients. For more information visit www.viha.ca/hcc/services/home_support.htm.

Short-term admission to a residential care facility:

Scheduling a short-term admission or respite stay for your family member in a residential care facility or other facility that provides respite care. This type of respite can range from overnight to a week or more.

Piercy Respite Hotel:

The Piercy Respite Hotel in Victoria offers a safe, secure and supportive environment to guests who are 55+ years, enabling their family caregivers to have a period of rest and renewal. Guests of the hotel vary in their mental and physical abilities, but all must be medically stable, and must have a family caregiver who lives in Greater Victoria. The hotel operates 24 hours a day, seven days a week. Contact the Piercy Respite Hotel at (250) 370-5641 during business hours, seven days per week. For more information visit www.viha.ca/hshc/piercy_respite_hotel.htm.

Respite Options cont'd

You can access most of these types of respite services by calling the care recipient's Case Manager or the Home and Community Care department of your local health authority.

Private respite:

Similar services are also available through private home support agencies and private care facilities. These can be found in your telephone book, on-line or in a community resource directory, such as the Senior Living Housing Directory available at www.seniorlivingmag.com/housingdirectory.

Informal options for respite:

In addition to the above more formal forms of respite there are many other creative ways for caregivers to take a break. Respite is any activity or event which allows a caregiver to feel more rested and to feel as though they have had time off from their caregiving duties. It could include:

- A neighbour or volunteer coming over for a couple of hours to play cards with the care recipient while the caregiver goes out
- Spending time in the garden, at the beach or going for a walk
- Having a family member come and stay overnight so that the caregiver can sleep through the night
- Going out for coffee with friends
- Reading a book or watching a movie
- Trading homes for a weekend with a family member or friend that lives nearby. They can take over the caregiving responsibilities and the caregiver can relax.

Respite does not always mean separation from the person receiving care. It can mean sharing non-caregiving focused time together, such as going to see a play or to the spa. These activities help to reduce the sense of isolation and re-establish a balanced relationship between the caregiver and care recipient.

Family Caregiving from a Distance

Many family caregivers are presented with the added challenge of caring for a family member long-distance. Though more and more families are dispersed across the country or even around the world, the demands of caring for ill or aging family members are still present. Long-distance caregiving often involves specific concerns that are different from those families who live near each other.

Although your initial reaction may be to move your family member closer to you, consider first whether this might be more disruptive and stressful for everyone involved. Are you prepared to have them live with you? Or are you prepared to be their only social contact once they have moved away from what is familiar to them? If they are coming from out-of-province, when will they qualify for medical services in this province?

Below are some suggestions for bridging the miles and making caring for a distance easier:

- Since you can't simply drop in to see how things are going, call home often. Listen closely to their comments or complaints and ask questions that can alert you to changes in their health or routines.
- Establish a support network in your family member's hometown with contact people who can provide you with a clear picture of the situation. These people might include a close friend, a minister, a doctor or others who regularly visit them. Ask them to alert you if they notice changes in your family member's behavior, appearance, memory, mobility or food habits.
- Ask someone to check in with your family member on a regular basis. Keep the contact information of this person with you at all times and ensure that they have your contact information. If you are worried, you can't call that "nice young couple next door" to check in, if you don't know their name or telephone number. This happened to a friend of mine who couldn't reach her elderly parents living in Alberta.
- Gather information about services, resources and other options for care available in their community. Do this in advance even if you don't need these services right now. Have them on hand before a crisis happens. You can find these resources on the internet or pick up a copy of the local telephone directory next time you visit.

Family Caregiving from a Distance cont'd

- Schedule regular visits. You need to make the most of your limited time there, so plan in advance for what you need to accomplish during the visit, in addition to visiting with your relative. Be observant while you are there. Are they eating regularly? Are their bills getting paid?
- Some communities offer telephone assurance programs usually staffed by volunteers, who check in on frail and disabled persons living alone. Many volunteer organizations also have friendly visitor programs that provide regular visits to people who aren't able to get out.
- In a non-emergency situation, try to step back and evaluate whether you need to travel or if you can send someone else. Can someone locally handle the situation? This will free up your time and money for emergency situations or times when it is essential for you to be there.

By Barbara Small, Program Development Coordinator, Family Caregivers' Network Society, Senior Living Magazine, June 2011

Home Adaptations Can Ease the Demands of Caregiving

As people age or their health declines, caregiving at home can be extended and made easier by making modifications to the home where the care recipient lives. These modifications can make the home more safe and accessible for the care recipient, family caregiver and other family members.

Adaptations to a home can make it easier and safer to carry out activities such as bathing, cooking or moving around the home, as well as changes to the physical structure of the home to improve its overall safety and condition. Modifications might include handrails, stair lifts or making the bathroom safe and accessible by installing grab bars.

Home modifications can help relieve the emotional, physical and time burdens placed on family caregivers. These burdens can be eased through knowing that their family member is safe when the caregiver is not there, by making it easier for the care recipient to be more independent and also to help the caregiver carry out personal care activities.

The costs of home modifications can vary greatly. Low cost changes may include installing lever handle door knobs or grab bars. More expensive changes might include installing an exterior ramp.

Recently the Province of BC launched the new Home Adaptations for Independence (HAFI) program to help low-income seniors and people with disabilities finance home modifications for accessible, safe and independent living. The HAFI program is funded by the Government of Canada and the Province of British Columbia. Financial assistance up to \$20,000 per home is available to both homeowners and tenants. The amount is based on the cost of materials and labour necessary for the required adaptations and is in the form of a grant or forgivable loan. Eligible adaptations include items that directly address the household's disability or diminished abilities, such as handrails in hallways, ramps for ease of access, easy to reach work areas in the kitchen or walk-in showers with grab bars. For more information on the HAFI program, visit www.bchousing.org/HAFI or call BC Housing at 1-800-407-7757 (ext. 7055).

Canada Mortgage and Housing Corporation has also published several free books on adaptable housing including, "Maintaining Seniors' Independence: A Guide to Home Adaptations" and "Maintaining Seniors' Independence through Home Adaptations: A Self-Assessment Guide. These can be found on the CMHC website at www.cmhc.ca and are available in digital and hardcopy formats.

By Barbara Small, Program Development Coordinator, Family Caregivers' Network Society, Senior Living Magazine, August 2012.

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