



**Celebrating Family Caregiver  
Week in BC  
May 4 - 10, 2013**

### Celebrate Yourself!

1. You are special, in so many ways. You are giving of your time, your energy, and maybe a large part of your life to make someone else's life better.
2. You are traveling the path of a caregiver. Whether it is a spouse, parent, child, relative or friend you are caring for – you are traveling the caregiver path. Just the fact that you are continuing to do so says so much about how big your heart is! Yes, you are a kind, compassionate and loving person!
3. You are human. Let go of your mistakes. As caregivers, we are often stretched as far as we can go on many levels. In areas where you feel you are falling short, let it go. Remember, you are probably more than making up for weaknesses in areas where you are particularly strong. Letting go should be a daily task. Whether you choose to do so when your head hits the pillow at night, or you vow every morning to be the best caregiver possible. Just let go.
4. No one can do exactly what you do, the way that you do it. This can mean so much to the one you are caring for. While many folks can provide compassionate, loving care, you are the one who is a stabilizer (constant) in the patient's life. It is at the sight of you that their eyes light up and a smile crosses their lips. Revel in what you have to offer and the joy and comfort you bring on a regular basis. You are a person, a caregiver and someone else's reason for continuing on. Celebrate yourself – and all the wonderful things about YOU!

Source: <http://alzheimerscareresourcecenter.com/2013/02/monday-mojo-celebrate-yourself/>

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## Celebrating Family Caregiver Week in BC

### FREE Webinars and Tele-workshops for Family Caregivers

#### **Balancing Caregiving and Employment (*webinar*)**

With our aging population, the number of people juggling caregiving, work and other life responsibilities is increasing. One in four working Canadians are attempting to balance employment and caring for a family member or friend and many are experiencing stress, guilt and emotional and financial exhaustion as a result. 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 while balancing caregiving and work.

**Tuesday, May 7, 12:00 - 1:00 PM**

Barb Small, Family Caregivers' Network Society

#### **Respite: Getting the Break You Deserve (*webinar*)**

Are you getting tired, perhaps exhausted, from looking after your family member or friend? Does it seem like years since you've had a break? When you do manage to find time for yourself, do you feel guilty about it? What do you do when your family member refuses to go into a respite facility or to an adult day program to give you a break? This webinar explores the benefits of respite, how to overcome some of the barriers and challenges that prevent family caregivers from getting respite, provides information on community resources and explores some of the emotional issues that can arise around the use of respite such as guilt and letting go.

**Wednesday, May 8, 6:30 – 8:00 PM**

Maureen Grant, Community Social Worker,

#### **How to Caregive Well: No Matter What Your Situation (*tele-workshop*)**

Are you finding yourself caught up in the uniqueness of your own personal caregiving situation? Do you believe that no one else can, or will, understand what you are experiencing? Perhaps it's about the disease or the symptoms or your family dynamics or the medications or... Join Allison as she speaks to the qualities that apply to, and can enhance, any caregiving situation. Through recognizing the shared experiences of family caregivers, you can expand your network of available support for you on your caregiving journey.

**Thursday, May 9, 6:30 – 8:00 PM**

Allison Reeves, Registered Clinical Counsellor



**REGISTER** by calling the Care-ring Voice Network at 1-866-396-2433 or register on-line at [www.careringvoice.com](http://www.careringvoice.com). Webinars are offered through your computer and telephone. If you don't have a computer, you can simply listen over the telephone. Tele-workshops are simply offered over your telephone.

FCW Media Sponsor:



We gratefully acknowledge



and



for partial funding of all of these

educational sessions.

# Understanding and Navigating the System

By Danielle Billey, Cara Brighton, Erica Messing, Satnam Sidhu, and Winston Martin, South Island Home and Community Care Dietitians, Vancouver Island Health Authority

## The Dietitian's Role in Palliative Care

When we think of nutrition we usually think of health, wellness, disease prevention, and sometimes treating illness. Rarely does “end of life care” come to mind, which is odd, really, considering nutrition is a part of life from the day we’re born until the day we die.

It’s easy to forget that nutrition isn’t just the science of calories, nutrients and hydration. It’s also, and perhaps more importantly, a universal source of pleasure, socialization, friendship, nurturing, safety and love.

It is normal for a person with a terminal illness to gradually lose appetite, weight and strength. Anorexia is part of the process and may also be the body’s way of making sure that it takes in only as much food as it can handle.

This can be distressing to caregivers. After all, we equate food with life. To not eat is to remind us that life is

coming to an end. Perhaps that is why it is so common for us to want to believe that, “if they’d just eat they’d get better”.

In fact, neither wasting nor strength will be improved by food; and pushing food on someone who is dying can cause them distress.

To make nutrition goals clear, keep firmly in mind that “palliation” means “to relieve suffering”.

This means not only to do what gives comfort, but also to avoid causing suffering:

- Find ways to love, nurture, and provide pleasure that do not involve food (*see page 2*)
- Focus on ease and pleasure when eating and drinking
- Provide only the foods and drinks that the client wants, offering small amounts
- It’s OK if the client doesn’t want to eat
- The individual is not “starving to death” -

a diminished appetite is a symptom, not a cause of illness

- Remember: constant pressure to eat and drink is uncomfortable
- During the last days of life dehydration may make someone more comfortable

Palliation is helping our loved ones ease out of this life as comfortably as possible. Nutrition, and the cessation of it, are a natural part of this process.

## Foods That May Be Palatable at End-of-Life

Focus on the goal of pleasure and comfort at all times. Offer favourite items whenever possible. If your loved one is able to chew soft foods, make them easier to swallow by adding moisture with sauces, gravy, butter or syrup.

### Some food suggestions to offer:

- Cottage cheese and soft fruit (puree if needed)

(Continued on page 6)

## Celebrating Family Caregiver Week in BC May 4 - 10, 2013



### Lieutenant Governor a New Champion For Family Caregivers

We are thrilled to announce the personal patronage of The Honourable Judith Guichon. In her Celebratory Role, Her Honour will help increase awareness of the incredible role that family caregivers play in our society. This is truly an exceptional opportunity at a time when it's really needed - today there are over one million people caring for a family member or friend.

You may already know about the Provincial Proclamation – that for the past 10 years our Lieutenant Governors have been enacting an Order in Council to proclaim the second week in May “Family Caregiver Week”. This is undertaken as part of the Vice-Regal Role. The Proclamation highlights the following:

*Whereas Family Caregivers are a vital component of the health care team and support to individuals who are frail, elderly, chronically ill or living with a disability in facility, community and home settings, and*

*Whereas, the role of the Family Caregiver has become even more important with the growing complexity of care needs, an aging population and the shift to community-based care and,*

*Whereas, recognition is due to Family Caregivers for their dedication and commitment to improving the quality of life for their friends and family members, often under conditions which impede their own physical, emotional and financial health and wellness...*

In Victoria we are hosting a Caregiver Tea at Government House on May 6, where Her Honour will speak in recognition and celebration of family caregivers.

We hope you'll find a way to celebrate Family Caregiver Week! Ideas and the official Proclamation can be accessed at <http://www.fcns-caregiving.org/2013/04/family-caregiver-week-2013-promotion/>.



The Nellie McLung and Bruce Hutchison branches of the Victoria Public Library will be displaying a collection of family caregiving books during Family Caregiver Week. Other libraries may also have similar displays. The FCNS office also has a resource lending library of books, DVD's and handouts on many topics of interest to family caregivers.

## FREE Spring Tele-workshops for Family Caregivers

### The Loneliness of Being a Spousal Caregiver

Many unique, and often profound, challenges arise when caregiving a spouse or partner. Whether it is a chronic health problem, issues with mobility or decreased cognitive function, as your spouse's condition progresses and you become their caregiver, it can feel more and more like you are losing your relationship. When you caregive the person you love, you no longer experience the level of day-to-day intimacy that you did before - whether it's the casual chats over morning coffee or the shared moments of levity. Join other spousal caregivers to share and explore the loneliness that ensues. What to do? Come and learn that it might be much simpler than you realize.



**Tuesday, May 28, 2013**

**6:30 – 8:00 PM**

### How Do You Choose What To Do Next When Everything Needs Doing?

Many family caregivers take on the demands of caregiving without letting go of anything else in their already busy lives. One of the biggest challenges of being a family caregiver is time management and prioritizing. How do you juggle all that you think needs to be done? In this tele-workshop you will learn concrete strategies that will help you develop a framework for your caregiving responsibilities. When you are exhausted or frustrated or overwhelmed you will find this tool helpful. It's printable, so please have a pen and paper handy.



**Thursday, June 13, 2013**

**6:30 – 8:00 PM**



**Facilitator:** Allison Reeves, M.A. Registered Clinical Counsellor.

**Register** by calling 1-866-396-2433 or on-line at [www.careringvoice.com](http://www.careringvoice.com).

Tele-workshops are simply offered over your telephone.

We gratefully acknowledge  and  for partial funding of all of these educational sessions.

**"I see possibilities in everything. For everything that's taken away, something of greater value has been given." Michael J. Fox**

**"Never give from the depths of your well, but from your overflow. "**

(Dietician, continued from page 3)

- Yogurt and soft fruit (puree if needed)
- ¼ sandwich with moist, minced filling
- Scrambled egg
- Sometimes adding citrus fruits or juices to a food can help improve taste
- Avoid highly seasoned or salty foods

**If a person cannot chew, offer pureed foods and liquids:**

- Custard, pudding, popsicles, or ice cream
- Oatmeal
- Cream soup/ blended soup
- Milkshakes or smoothies
- Meal replacement drinks
- Juice or chocolate milk

Offer small pieces or

spoonfuls so less energy is required to eat. Offer food or fluids every couple of hours. Allow the person to rest after eating or drinking. Keep the head of the bed elevated to help with digestion.

### Ways to Nurture a Loved One Without Food

When a loved one refuses to eat it is a natural part of their body preparing for death. **It is okay not to eat.** A different kind of energy is needed now. A spiritual energy, not a physical one, will sustain from here on.

### Ways you can nurture without food:

- Give loved ones your time, just be present
- Read together
- Listen to favourite music
- Enjoy a movie

- Share photos, stories and laugh about old times
- Journal your loved one's stories
- Light candles or an indoor fire
- Visit with a calm, cuddly pet
- Take cues from your loved one
- Make sure clothing and positioning are comfortable
- Gentle touch and massage
- Sponge bath
- Hair brushing
- Provide good mouth care for comfort:
  - oral cleaning with swabs
  - lubrication with artificial saliva
  - ice chips

## 5th Annual Charity Golf Tournament

**New date:** Friday, September 13, 2013

**New Location:** Cordova Bay Golf Course

Best Ball, Shotgun Start, Skill Prizes Awarded

Silent Auction and Deluxe Buffet Dinner

\$160 per golfer (\$25 charitable receipt)      \$50 dinner only



**Join the fun by gathering a foursome, donating an item to the silent auction or becoming a sponsor. Sign up early!**

## Things That Family and Friends Can Do For the Family Caregiver:

- Say thank you. Be creative. There are many ways of saying thank you.
- Ask what you can do to help, don't just jump in.
- Offer specific help, for

- example shopping, yard work, banking.
- Send flowers as a supplement to your involvement, not as a substitute for it.
- Share the visiting, work out a schedule so that the caregiver can have a break.

- Invite the caregiver to dinner out after a difficult day.
- Don't give advice unless it is asked for.
- Be supportive of decisions regarding your relative.

*Adapted from: Wendy Johnson, Aging is a Family Affair, 1990*

## How to De-Stress and Refresh with Mini-Retreats

Frazzled and rushed? Struggling with the pressures of daily life?

Many of us are! Yet you may not have the luxury of a weekend at the spa or a trip to the mountains to decompress. Fortunately, you can relax yourself deeply - several times a day if you like - without taking any extra time out of your life.

Join certified life coach Julia James for an interactive workshop on Mini-Retreats. Learn how to:

- Improve your health, happiness and performance in just minutes a day
- Completely relax and refresh in minutes, no matter where you are
- Create a supportive environment for a more relaxed way of life

*Julia James is a certified life coach and author of the award-winning book and audio CD series, The Mini-Retreat Solution.*



## FCNS Annual General Meeting

**Tuesday, June 25, 2013**

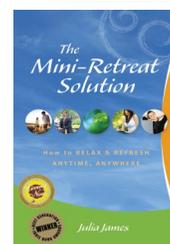
**5:00 - 6:45 PM**

Salvation Army Citadel, Multipurpose Room  
4030 Douglas Street (McKenzie & Pat Bay Highway)

Light refreshments will be served.

FCNS members Free Non-members \$10.00

Please RSVP to 250-384-0408 or [caregiversupport@fcns.ca](mailto:caregiversupport@fcns.ca) by June 19th to reserve your seat.



We have a volunteer opening for a **Family Caregiver Support Group Facilitator** to co-facilitate our Victoria Caregiver Support Group which runs the first Monday of each month from 7:00 – 9:00 PM.

For more details visit [www.fcns-caregiving.org/2013/04/volunteer-support-group-facilitator-position-available/](http://www.fcns-caregiving.org/2013/04/volunteer-support-group-facilitator-position-available/) or call 250-384-0408.

# Legal Considerations in Caregiving

By John Jordan, Lawyer, Dinning, Hunter, Lambert and Jackson

## The Law as it Affects Employed Family Caregivers

This article is a brief overview as to what extent the existing laws in British Columbia assists caregivers to balance paid employment and unpaid caregiving. It is evident that current public policy fails to recognize the social and economic value of family caregiving to families, communities, the economy, employers and the health care system.

It would appear that the law, which has been revised in a piecemeal fashion, has not changed sufficiently to respond to the challenges facing family caregivers because of the many changes that have occurred in social and labour demographics over the last 100 years. Caregiving relationships vary greatly, caregiving needs fluctuate within a single relationship and caregivers also maintain different types of employment situations including full, part-time, casual and self-employment.

There is no single law in BC or Canada that deals with the circumstances of working

caregivers. The situation of working caregivers are primarily governed by legal provisions found in employment and labour law, human rights, pension, tax policy and health law. Presently, legal recognition of the circumstances of the family caregiver seems to falls into different categories: a. employment leave provisions; b. family responsibility accommodation; c. measures that offset income loss.

**Under the BC Employment Standards Act**, eligible employees are entitled to five days unpaid family responsibility leave to meet the care needs of children and immediate family members (Section 52), and eight weeks unpaid compassionate care leave to provide end of life care to family members (Section 52.1), the latter of which may also trigger the entitlement of six weeks of insurance employment benefits under the federal employment insurance system. It appears that BC and Canada provide benefits with respect to income replacement for end of life caregiving, but little recognition of other forms of family caregiving.

**Family responsibility accommodation** and the workplace is a somewhat uncertain area of law in Canada. Besides the prohibition against discrimination against employees in the terms and conditions of employment contained in the BC Human Rights Code, there is no employee right to work flexibly in relation to family caregiving obligations. Accommodation of caregiving responsibilities is generally at the discretion of employers, unless the employee makes a successful human rights claim. There are very few cases that deal with caregiving of adult family members. Most cases pertain to child care. Human rights legislation has proven itself to be a poor vehicle for providing more flexibility in accommodation of family responsibilities.

**Initiatives to counteract income loss include tax incentives**, as well as pensions and payments or wages paid to the caregiver in recognition of caregiving labour. This however is an area in Canada that does not provide

*(Continued on page 9)*

*(Employed cont'd from page 8)*

extensive protection. Programs that exist to support family caregivers, notwithstanding the many studies over the last few years that deal with the financial strain associated with family caregiving have not been pursued. There is little to address the long term income security of caregivers.

The income tax system currently includes a number of tax credits that are available to taxpayers who reside with family members who have a physical or mental disability and are dependent on the taxpayer for financial support. A significant problem however, relates to the non refundability of existing tax measures, including the Caregiver Tax Credit. Most are accessible only to high income earners. One of the other problematic features involved in this program from a caregiver policy point of view, is that eligibility is linked to financial dependency rather than caregiving labour. There is no BC or federal tax credit that compensates or recognizes caregiving labour.

In BC, payments to caregivers are only possible indirectly and by way of exceptions to health policy. The Choice In Support of Independent Living Program

provides eligible people with disabilities with access to funds that they may spend at their discretion on their own care; however payments to caregivers who are also family members are permitted only in very limited circumstances. No BC program provides direct payments to family caregivers in recognition of their labour.

**Public pension measures** that take into account the impact of earnings and pension security presently only address the care of young children. The Child-Rearing Provision permits a parent to exclude years during which he or she was not engaged in paid employment in the determination of Canada Pension Plan entitlement. This measure allows an individual to discount his or her earnings during the first seven years of the child's life. There is no parallel with respect to caregiving of adults. In BC there is also no specific caregiver pension. Caregivers who reduce their earnings in order to provide caregiving do not have available any pension security protection.

**Reform-** Possible options for reform include the following: extension of current compassionate care leave benefits, amendment to the BC Employment Standards Act to create a right to request

changes in employment in order to manage family caregiving obligations; creation of a tax credit that is accessible to low income people and targets the individual providing caregiving; provision by the government for income replacement for low income family caregivers and provisions in the Canada Pension Plan for a drop out provision applicable to all years of fulltime family caregiving.

Family caregivers need flexibility and support to manage their individual caregiving responsibilities. Family caregiving responsibilities accommodation has been, in the past, considered a private family issue. This approach may no longer be viable, as combined with an increasing life expectancy and a declining birth rate, the changing characteristics of Canadian families over the last century will likely require some rethinking of the value of family caregiving and the role of legislation in supporting caregiving labour.

**Editor's Note:**

*The purpose of this column is NOT to advise people on their legal affairs or concerns, but to provide basic information for discussion with their own legal counsel.*

## Volunteer Appreciation

This month we would like to recognize and celebrate Bonnie Davoren who has been volunteering with the Family Caregivers' Network (FCNS) for 20 years!

Bonnie is, and has always been a very busy lady. She has been a family caregiver in the past and is a retired registered nurse, certified in Geriatric Nursing, and a post graduate in gerontology. In addition to volunteering with FCNS, Bonnie has also been involved with the South Vancouver Island Family Planning Clinic, Therapeutic Touch Group, the Gerontological Nurses Group and the Return to Health program through Seniors Serving Seniors.

Bonnie has put in many, many hours as a volunteer with FCNS in many capacities over the past twenty years. To highlight *just a few*:

She was an active member of the Board of Directors for five years. Currently, she is facilitating the Victoria Support Group - which she has done for the past 12 years! She is the creator and ardent promoter of the Medical Information Package and the Wellness Booklet, distributed by FCNS. Bonnie continues to help out at events, workshops and fundraisers and is always willing and happy to promote FCNS wherever she goes.

Bonnie brings compassion, expertise and knowledge to her role as volunteer – such valuable qualities when supporting family caregivers. Her laughter, enthusiasm and zest for life are contagious – if Bonnie is at an event, you can be sure that those around her are feeling uplifted and encouraged!

Thank you Bonnie, for your many years of passionate support of the Family Caregivers' Network Society.

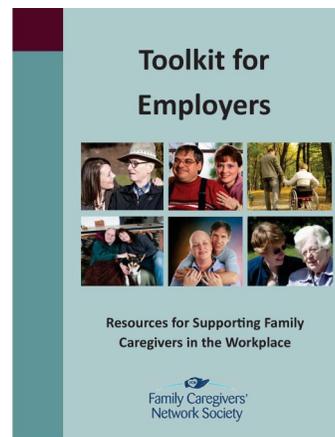


## New and Now Available!

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

FCNS has developed a **Toolkit for Employers** 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. The Toolkit is divided into two sections: Section 1: Information for Employers and Section 2: Resources for Your Employees Who are Family Caregivers.

For more information call 250-384-0408 or email [caregiversupport@fcns.ca](mailto:caregiversupport@fcns.ca).





## Family Caregiver Support Groups



### Victoria Support Group

1st Monday of each month, 7:00 - 9:00 PM  
FCNS office, 526 Michigan Street  
*(July, Aug. & Sept. groups moved to 2nd Monday due to statutory holidays)*

### Sidney Support Group

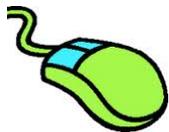
3rd Tuesday of each month, 10:00 AM - Noon  
Lounge, Shoal Centre, 10030 Resthaven Dr.

### Salt Spring Island Support Group

Every Wednesday, 11:00 AM - Noon  
Seniors for Seniors Centre, Ganges  
*(The SSI group is offered in partnership with the Alzheimer Resource Centre, however this group is open to all caregivers.)*

Attendance at all our support groups is on a drop-in basis and they are facilitated by trained volunteers. For further information call the FCNS office at 250-384-0408.

## Online Support for Caregivers



Cancer Chat Canada

<https://cancerchatcanada.ca/register.php>.

VON Canada Caregiver Connect

<http://www.caregiver-connect.ca>

## Community Support for Caregivers

**A.L.S. Society:** 250-721-0633, [www.alsbc.ca](http://www.alsbc.ca)

**Alzheimer Resource Centre:** 250-382-2052, [www.alzheimerbc.org](http://www.alzheimerbc.org)

**BC Cancer Agency:** 250-519-5525, [www.bccancer.bc.ca/RS/VancouverIslandCentre/default.htm](http://www.bccancer.bc.ca/RS/VancouverIslandCentre/default.htm)

**BC Schizophrenia Society,** Strengthening Families Together Program: 250-384-4225, <http://bcssvictoria.ca/>

**Huntington Society:** (250) 386-9891, [www.huntingtonsociety.ca](http://www.huntingtonsociety.ca)

**Multiple Sclerosis Society of Canada:** 250-388-6496, [www.mssociety.ca](http://www.mssociety.ca)

**Vancouver Island Crisis Line**  
1-888-494-3888, [www.vicrisis.ca](http://www.vicrisis.ca)

**Victoria Epilepsy and Parkinson's Centre:** 250-475-6677, [www.vepc.bc.ca](http://www.vepc.bc.ca)

**Peninsula Stroke Recovery:** 250-652-3016

**Victoria Stroke Recovery Assoc.:** 250-383-2623

**Victoria Brain Injury Society:** 250-598-9339, <http://vbis.ca/>

**We Rage, We Weep Alzheimer Foundation,** Project Lifesaver, Arts and Alzheimer's: 250-920-9573, [www.weragewewEEP.com](http://www.weragewewEEP.com)

Additional resources for family caregivers throughout BC can be found at [www.familycaregiversnetwork.org](http://www.familycaregiversnetwork.org) under Resources/Provincial Resources.

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