Caregivers: Supporting loved ones at the end-of-life

Presented by
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Speak Up: Start the conversation about end-of-life care

- Includes Advance Care Planning Day – April 16, 2012
- Provides a website with resources

www.advancecareplanning.ca
What is Advance Care Planning?

- A process of reflection and communication.
- A time for you to reflect on your values and wishes.
- A time to let others know your future health and personal care preferences in the event that you become incapable of consenting to or refusing treatment or other care.
Why is advance care planning important?

Research has shown that:

- If you have an advance care plan you are much more likely to have your end-of-life wishes known and followed.
- Your family members will have less stress and anxiety –because they know your wishes.
- You will be more satisfied with your care as will your family and substitute decision maker
- You will have a better quality of life and death
What is Advance Care Planning?

Advance care planning means having discussions with family and friends, especially your substitute decision maker - the person who will speak for you when you cannot.
How do I choose a substitute decision maker?

- Choose someone who you trust and feel will be comfortable carrying out and communicating your wishes.
- Don’t forget to have the conversation – it’s important that your substitute decision maker knows about their role and your wishes.
- This person will make medical decisions on your behalf if you are incapable of communicating your wishes because of illness or injury.
How to begin

1. Think about what’s right for you.

2. Learn about end-of-life care options and medical procedures.

3. Decide who will make decisions for you if you cannot.
How to begin

4. Have the conversation.

5. Write down or record your wishes if you like.

6. Review your plan regularly.
Use a Workbook

- To think about and write about your values and beliefs.
- To learn about end-of-life care and medical procedures.
- To write about your preferences for care.
- To name your substitute decision maker
ACP Workbook
Hospice Palliative Care

Hospice palliative care is a broad term used to identify a standard of care that encompasses both Loved One’s and their Caregivers. It refers to a holistic, multi-disciplinary approach that aims to improve the client’s quality of life.
Grief...

• Is a healthy, natural human reaction to loss
• Is unique to everyone
• Does not have a specified time frame
• Can take as long or short of time as needed
• Is determined by an individual's personality, cultural beliefs, spiritual beliefs, coping abilities, and available support network.
Why do we grieve?

• We anticipate the loss of a Loved One
• The changes in our roles and responsibilities within the family
• Over changed to our future plans
• To prepare ourselves for things to come
Symptoms of Grief

**PHYSICAL**
- Fatigue
- Weight Loss
- Weight Gain
- Nausea
- Diminished Immunity
- Body Aches & Pains
- Trouble sleeping

**EMOTIONAL**
- Shock
- Disbelief
- Resentment
- Sadness
- Guilt
- Anger
- Fear
5 Stages of Grief

As defined by Elizabeth Kubler-Ross

Denial
Anger
Bargaining
Depression
Acceptance

An individual can experience stages is any order, even skipping some.
Individuals experience each stage in their own, unique way
How can we cope with grief?

- Plan ahead, deal with estate planning and unfinished business
- Build a support network
- Discuss feelings, changes in roles and responsibilities, share concerns, discuss individual needs
- Identify your Loved One’s wishes and include them in planning their care
- Allow yourself time to grieve, understand that for everyone it is different, let it happen naturally
How can we cope with grief?

- Remember that grief never really goes away, it lessens over time as we incorporate it into our everyday lives.
- Focus on short term plans rather than long term plans.
- Draw on spirituality and cultural beliefs to guide you.
It is okay to ask for help

Instead of looking at yourself as weak, view asking for help as a positive step.

You are taking control of your grief by recognizing there is a problem.
“I have seen death too often, to believe in death. It is not an ending, but a withdrawal. As one who finishes a long journey, stills the motor, turns off the lights, steps from his car. And walks up the path to the home that awaits him.”

An American Poet
The best thing to do for a grieving person is . . .

- Accept them for the individuals that they are
- Listen, recognize feelings, don’t minimize them
- Understand you cannot take a person’s grief away

BE COMPASSIONATE, SUPPORTIVE, & CARING
Caregiver Stress

What creates caregiver stress?

- Increasing caregiver responsibilities
- Finances, education, jobs, legal matters
- Availability of medical support, home care needs
- Medications (type, too many)
Symptoms of Stress

**PHYSICAL**
- Increased Heart Rate
- Muscle Tension
- Headaches
- Upset Stomach
- Shortness of Breath
- Sweaty Palms
- Dizziness

**EMOTIONAL**
- Guilt
- Sadness
- Helplessness
- Frustration
- Nervousness
- Anxiety

**Additional Emotions**
- Worry
- Anger
- Hopelessness
- Lost
- Panic

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Thursday, 5 April, 12
Caregiver Burnout

Am I suffering from Caregiver burnout?

Are you…

- Feeling emotionally and physically drained?
- Experiencing more emotions than usual?
- Feeling so helpless that you can’t make decisions?
- Having days when you just can’t get out of bed?
# Manifestations of Burnout

<table>
<thead>
<tr>
<th>PHYSICAL</th>
<th>EMOTIONAL</th>
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</thead>
<tbody>
<tr>
<td>Exhaustion</td>
<td>Apathy</td>
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<tr>
<td>Disorientation</td>
<td>Irritability</td>
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<tr>
<td>Startling easily</td>
<td>Loneliness</td>
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<tr>
<td>Poor sleep patterns</td>
<td>Nightmares</td>
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<tr>
<td>Poor appetite</td>
<td>Intolerant</td>
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<tr>
<td>Weight loss/gain</td>
<td>Withdrawal from activities and people</td>
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<td>Spending all your time in the house</td>
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Causes of Burnout

- Working while also caring for your Loved One
- Caring for your own family as well
- Not receiving adequate support from other family members or the community
- Financial stress, hardships, worrying about being able to pay for everything
- Family quarrelling
- Being unprepared, not fully informed of what being a caregiver really means
Let’s Prevent Burnout

1. Focus on one day at a time
2. Learn what being a caregiver really means
3. Join a support group
4. Find the positive in the here and now
5. Take time for yourself. Take care of yourself.
6. Take on smaller and simpler tasks
7. Know your limits. Don’t over exert yourself
And most importantly . . .
And most importantly . . .

CELEBRATE
And most importantly . . .

CELEBRATE EACH AND EVERY DAY!
Put 2 P’s in Coping

PRACTICAL
Be practical in what you can actually do.

PROACTIVE
Be prepared and ready for the challenges ahead.
Caregiver Challenges

- Feelings of resentment, anger, grief, anxiety and helplessness leading to more guilt
- Feeling uncertain over the future, knowing what to expect and be prepared for, fear of the unknown
- Taking on a new role within the family, along with new responsibilities
- Feeling responsible for your Loved One’s illness
Expect the Unexpected

There is no definitive answer to the question: “*What should we expect?*”

- Death is experienced in various ways, and is unique to every individual
- No one can truly say for sure when someone is about to die.
Common Changes

Your Loved One . . .

- Will grow weaker as the body begins to shut down
- Will eventually be unable to get out of bed, eat or drink
- Will sleep more and more, eventually becoming unable to communicate
- Will gradually require more care
- Have non-essential medications stopped, having only those that provide comfort continued
- May experience confusion, delirium, hallucinations
When Death is Near

- Breathing will change, becoming fast and shallow, with pauses in between breaths
- These pauses will become longer
- Hands and feet will become cool to touch and the skin will take on a purple colour
- Heart rate will increase, but its strength will decrease
Caregiver Resources
Financial Supports

- There are various financial resources available to both your Loved One and Caregiver’s
- For your Loved One:
  - CPP Disability Benefits
  - Quebec Pension Plan
  - Provincial Palliative Care Benefit Programs – these will cover the cost of medications and basic medical supplies to palliative patients
Financial Supports

- Provincial/Territorial Social Assistance – will aid people with a chronic, long term disability. Eligibility needs to be met in order to qualify
- Employment Insurance Sickness Benefits – temporary sickness benefits to your Loved One
- Employers Insurance Plans – covers prescription drugs, medical/dental/vision. Extended benefits may cover some home health care costs such as nursing and personal support. Survivor benefits are available with some insurance plans in the even of disability or death. Check with the insurance company to obtain a list of all the benefits available to you and your Loved One
Financial Supports

- Life Insurance/Living Benefits – some insurance companies may pay a portion of a life insurance policy to a palliative patient long before death
- Tax Credits
  - Costs related to health goods and services
  - Disability Tax Credit
  - Additional Living Costs related to disability
Provincial Palliative Care Benefit Program

BC Palliative Care Benefits Program
Alberta Palliative Care Drug Coverage
Saskatchewan Palliative Care Drug Plan Program
Manitoba Palliative Care Drug Access Program
New Brunswick Extra-Mural Program (home health care and palliative services)
Prince Edward Island Palliative Home Care Drug Program
General Programs

- Other provinces will have a prescription drug program or health benefit program.
- These provinces are:
  - Ontario
  - Quebec
  - Nova Scotia
  - New Brunswick
  - Newfoundland & Labrador
  - PEI
  - Northwest Territories
  - Nunavut
Caregiver Financial Supports

- Compassionate Care Benefits
- Caregiver Tax Credit
- Information about these supports is available at: www.servicecanada.ca
For Research on Caregiving

• For more research on caregiving and what to expect please visit:

  www.wecare.ca
  www.thecareguide.com
  www.thefamilycaregiver.com
Community Resources

- Community resources are available in all provinces.
- To locate a listing of the community resources available in your province go to: www.seniors.gc.ca
- Here you will find a listing of community resources by province.
- This website also contains info on End of Life care, hospices and Caregiver information.
Community Resources

- For other information on community resources you can go to:
  
  www.seniorsinfo.ca

- Here you will find another listing of community resources listed by province as well as caregiver information, end of life care, legal/financial information
References

- [www.virtualhospice.ca](http://www.virtualhospice.ca); Canadian Virtual Hospice
- [www.chpca.net](http://www.chpca.net); Canadian Hospice Palliative Care Association
- [www.servicecanada.ca](http://www.servicecanada.ca); Service Canada
- [www.seniors.gc.ca](http://www.seniors.gc.ca); Information for seniors
- [www.seniorsinfo.ca](http://www.seniorsinfo.ca); Information for seniors
- [www.thefamilycaregiver.com](http://www.thefamilycaregiver.com); Canada’s Home Care and Family Caregiving Resource
- [www.thecareguide.com](http://www.thecareguide.com); The Careguide Source for Seniors
- The Fundamentals of Palliative Care;