



Waiting for God

Becoming a Caregiver to a Dependent Senior: What you need to know

June 1, 2024

Ottawa Public Library



Agenda

- Meet the hosts
- Must Knows for Caregiving
- What Happens at End of Life
- Breakout sessions
- Wrap up

What you will get from this session:

Peace of mind knowing what to expect as you care for your dependent senior

Free Caregiver Package:

- PDF file with information shared today
- Free access to SSC – CoP
- Discount of SeniorSynCare monthly subscription



Why we are here

Company Origins

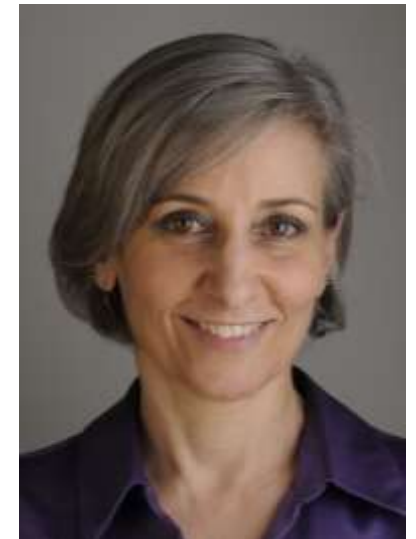
- Stella's legacy



- Change how we approach end of life
 - Re-discovery dying at home wherever possible
 - Help the community of care find peace and meaning rather than chaos and frustration

Moderators

- Marie-Chantal Ross
- Brenda Buckley





Some Caregiver Statistics Worth Noting

- Caregivers provide 75% of the care in our health system giving Canada \$24-31 billion in unpaid labour every year
- Research shows that many caregivers experience isolation, depression, and financial stress
 - Compared with their non-caregiving counterparts, caregivers are 16% more likely to live with 2 or more long-term health conditions
 - 26% of those caring for older adults and 45% of those caring for people with dementia experience a myriad of adverse outcomes, including deteriorations in mental and physical health, disruptions in social and family relationships, and increased risk of death
- The average informal caregiver spends 19 hours a week on caregiving duties
 - 1 in 10 provides more than 30 hours of care per week.
 - Without training, caretakers provide medical and nursing care in the home, navigate complicated health and long-term care systems, and serve as substitute decision makers.



Some Caregiver Statistics Worth Noting

- Caregivers provide 75% of the care in our health system giving Canada \$24-31 billion in unpaid labour every year
- Research shows that caregiving is associated with increased stress
 - Compared with those who do not care for someone, caregivers are more likely to experience depression and financial strain
 - 26% of those caring for someone with dementia experience mental and physical health problems, and an increased risk of falls
- The average informal caregiver provides more than 20 hours of care per week
 - Without training, caretakers provide medical and nursing care in the home, navigate complicated health and long-term care systems, and serve as substitute decision makers.

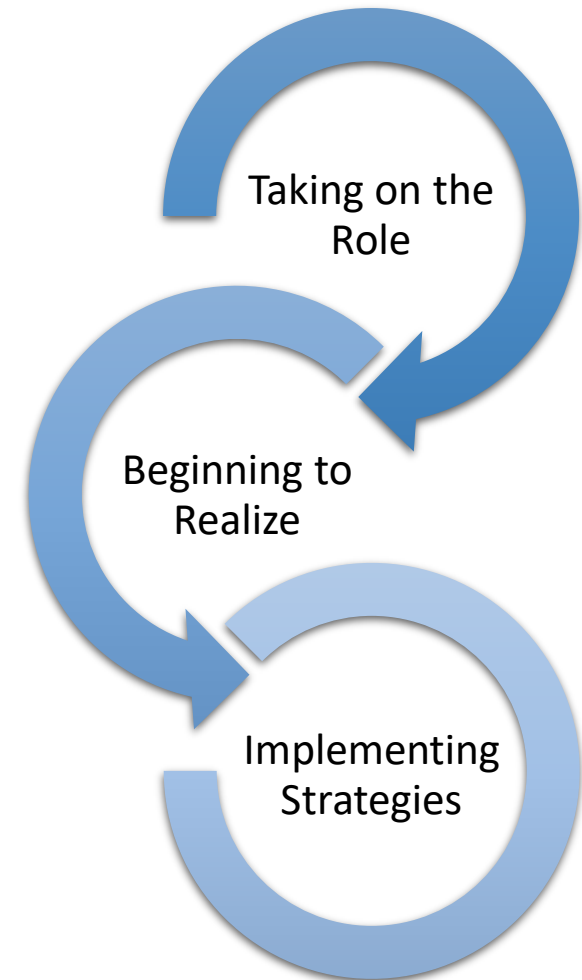
A growing body of research shows that Caregiving also provides benefits

- Personally rewarding
- Feeling more useful and needed
- Learning new skills
- Satisfaction and gratification
- Enjoyment of companionship



What to Expect as a Caregiver

- Taking on the Role
 - Usually sudden
 - Life turned upside down
 - Own life gets set aside
- Beginning to Realize
 - Stress and anxiety, lack of sleep, fatigue/exhaustion, loss of privacy, and conflicts with loved ones
 - Realization that they are not sufficient prepared
 - Finding actionable information is difficult
- Implementing Strategies
 - Reordering of family and social relationships
 - Sharing of roles and responsibilities
 - Letting go
 - Intentional humour
 - Finding meaning in the bigger picture



Modified from Source: Moral-Fernandez, et al. The start of caring for an elderly dependent family member: a qualitative metasynthesis, BMC Geriatrics, 2018

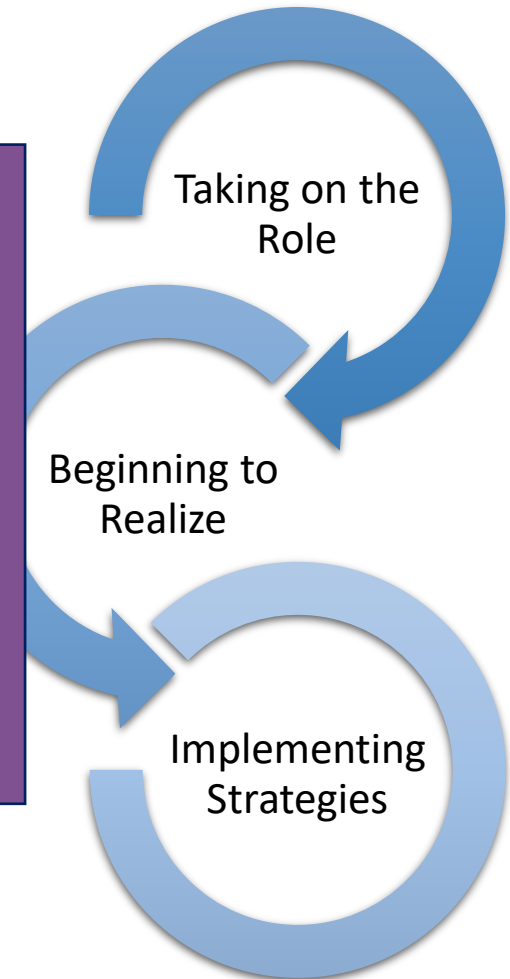


What to Expect as a Caregiver

- Taking on the Role
 - Usually sudden
 - Life turned upside down
 - Own life gets set aside
- Beginning to Realize
 - Stress and anxiety, loss of self, conflicts with loved ones
 - Realization that they are not alone
 - Finding actionable information
- Implementing Strategies
 - Reordering of family
 - Sharing of roles and responsibilities
 - Letting go
 - Intentional humour
 - Finding meaning in the bigger picture

To avoid burnout it is necessary to

- Take breaks
- Seek support
- Practice self-care
- Set boundaries
- Seek professional help



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Ethical Implications

- You are there to ensure your dependent senior's needs and desires are met, not your own
- Informed Consent
- We never know how we will feel about a situation until we have experienced it, be patient
- General guidelines:
 - There is a need to respect their dignity (worthy of honour and respect).
 - Fostering trust is important. Your dependent senior must trust you. Always act honestly and with integrity (having strong moral principles).
 - Promote justice – tied to trust, your senior must feel they are being treated fairly and equitably.
- Compassion and care are key



About Dependent Seniors

- Nobody wants to lose their independence
 - Dependent seniors can:
 - Be rather ungrateful
 - Confuse the situation particularly if lucidity is lacking
 - Refuse to acknowledge they need help when it is obvious they do
 - Be frustrating because they cannot learn new tasks easily
- Caring for dependent seniors requires a community of care
 - Need somebody to take the lead
 - Dependent senior or substitute decision maker
 - Each member has a role or roles
 - Clear communication and organization are necessary
 - Best if full community understands the end-of-life plan



SeniorSynCare



- Need a way to stay organized and connected with a dependent senior's community of care
- Private communications with those who interact with dependent senior
- Need to schedule the life of an adult with high needs



Helping You Care For Your Dependent Senior

Waiting for God brings you optimal tools to care for aging parents, grandparents, friends, and your loved one as they transition from independence to dependence.

Our technologies keep your community of care connected and organized as we help coordinate end-of-life care.

We also provide services to help you plan for their end-of-life.

SeniorSynCare

Only \$49.99 per month

Sign up now and get the first

End-Of-Life

Consultation

Only \$45 for an hour video





Death Denial is Real and Unhelpful

The personal struggle with mortality has become an important instrument in the public problem of managing the dying process

- Western culture does not like to speak about death
 - Very few cultures globally are comfortable with a candid discussion relating to death
- Discussions are necessary, but difficult
 - Person approaching end of life wants to discuss it, but loved ones cannot engage
 - Family wants to discuss it, but senior is anxious about death
 - Those with faith and atheists are usually least anxious
- Death denial is an obstruction to palliative care and is an impediment to open discussions of dying, dying at home, stopping 'futile' treatments, advance care planning and control of symptoms



Being Prepared

We don't know when the end will come, but we can be prepared

- Will/Last Testament
- Advanced Care Planning
- Do Not Resuscitate
- Organ Donation
- Body Disposition
 - In Ontario body or cremated remains must be buried in a licensed cemetery
 - The best gift you can give is a prepaid burial/internment
- Funeral/Celebration of life
- Keep good communication with your dependent senior's family physician



Services at your Disposal

- There is no lack of services to support you and your dependent senior
 - Provincial services – request a case worker from your senior’s family doctor
 - Private services
 - Volunteer services
- End-of-life doula
 - [Death Doula Ottawa](#)
- Shared housing
 - [SpacesShared - Homeshare Evolved](#)
 - [Canada HomeShare](#)



Services at your Disposal

SeniorSyncCare Community of Practice

- Free of charge
- Provides discussion platform for caregivers to share information and provide support
 - Private, secure server
- SeniorSynCare discount (\$24.99/month) if registering from SSC-CoP

<https://cop-ottawa.seniorsyncare.com>

End-of-life Consultations

- \$45/hour
- \$25/half hour
- Video or home discussion specifically addressing your needs

<https://www.waitingforgod.ca/consultation/>



What to Expect as End-of-Life Approaches

Who is an End-of-Life Doula?

- A trained professional who provides emotional and spiritual support to the dying person and their loved ones
- Not a medical professional, but can work alongside hospice and palliative care teams
- Offers companionship and facilitates communication between loved ones and advocate with the care teams
- Respects individual wishes and beliefs
- Educator in death and death planning
- May assist with practical tasks like preparing a vigil or creating a memory box





What to Expect as End-of-Life Approaches

What is Death Planning?

- Creating a roadmap for your end-of-life wishes
- Includes medical care preferences, funeral arrangements, and legacy planning
- Empowers you to make informed decisions
- Provides peace of mind for you and loved ones





What to Expect as Senior's End-of-Life Approaches

Indicators that the death process has started – physical death can be years away

- As our body ages, we reminisce more
 - Conversations tend to focus more on their youth – it is almost as if the first memories and the last they remember – parents, grandparents, homes and towns, etc.
- New information does not stick as easily
 - Can get agitated at things they once enjoyed
- Less interest in things they enjoyed before
 - Favourite TV shows no longer important, etc.
- Start to wonder about the meaning of life
 - Often want to talk about their deaths, but either culturally unacceptable, or people will not engage (death denial)
- Loss of energy and slower recovery time
 - Social engagement can become a source of fatigue
 - Trips and travel can take days to recover from



What to Expect as Senior's End-of-Life Approaches

Indicators

- As our bodies age
 - Conversion of energy to heat
 - Remembering things
- New information processing
 - Can get confused
- Less interest in things
 - Favorable to negative
- Start to withdraw
 - Often denial
- Loss of energy
 - Social engagement can become a source of fatigue
 - Trips and travel can take days to recover from

Remember that end of life is natural

- It is only in the last 200 years or so that humans stopped embracing death
- Signs are there to help us come to terms with what is happening
- This is when we can start to be less rushed
- Often people become the best versions of themselves – they drop societal messages and life for now and those they love
- End of life draws on community

last they

gave (death



What to Expect as End-of-Life Approaches

Changes to look for as body begins to prepare for death (usually a couple months before)

- The digestive system is the first to begin to shut down
 - Often eat only if love of food (such as chocolate)
 - Many people try to force seniors to eat, might be good to remember death plan
- Begin to sleep much more
 - Major changes in sleep can be an indication
 - Some people can sleep for up to 20 hours
- Even less interest in social engagement
 - Too much social engagement can lead to negative health outcomes



What to Expect as Senior's End-of-Life Approaches

As death approaches the body continues to shut down (could be days)

- When you thought they were sleeping a lot before, it is going to increase yet.
- Confusion
- Restlessness
- Vision like experiences
- Less Responsive
- Physical changes in temperature, respiration, pulse and blood pressure
- Congestion
- Refusing food and drink
- Extremities becoming cold



What to Expect as Senior's End-of-Life Approaches

As death

- When sleeping increases
- Confusion
- Restlessness
- Vision
- Less R

Maybe list a few things that are helpful to both the dying person and those caring for them

- Sitting by bedside – reading, singing
- Warm air blankets as touch can become painful
- Not a good idea to tell them they are hallucinating, go with the visions
- Be open to talk about what happens after physical death (only if person takes you there)

ulse



What to Expect as Senior's End-of-Life Approaches

The last days or hours

- Terminal Lucidity – The last Hurrah!
- Drop in Blood Pressure
- Glassy teary eyes
- Half open eyes
- Irregular breathing
- Cold hands and feet (may be purple)
- Weak pulse
- Decreasing urine output
- Minimal responsiveness
- Increased restlessness



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Hearing is last sense to shut down – they can hear you

There is evidence that they continue to hear after heart stops

ulse



What Caregivers can Expect

Grief creates a full range of emotional and physical

- Caregivers can have a range of experiences
 - Some people have shared death experiences, most do not
 - Some feel joy, most feel immense loss – particularly true for caregivers whose lives have revolved around these people in deep and intimate ways
- A sense that nothing is right
- Forgetfulness
- Tight and heavy chest and throat, numbness, gastrointestinal upset



Breakout Session

- Arrange yourselves in groups of 4
 - Introduce yourselves and choose a reporter
- Icebreaker – 10 minutes
 - Each group will receive a card, take turns answering
- Discussion on Fears – 10 minutes
 - Take turns sharing what scares you most about being a caregiver
- Discussion on Stressors – 10 minutes
 - Take turns sharing what stressors are causing the most discomfort
- Plenary
 - Reporter will share with larger group what the fears and stressors are



Thank you

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End of Life Doula

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Link to Caregiver Package:

- SeniorSynCare – Community of Practice
- Presentation slides
- Feedback form



<https://www.waitingforgod.ca/caregiver-workshop-package/>