

# “I don’t know what to say”...Beginning difficult conversations

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# Plan for today

- What constitutes a difficult conversation
- Setting the Stage: Tips for getting started
- Conversational Strategies for hard topics
  - Sharing the Diagnosis
  - Communicating Changes in Function with HC Team
  - Accepting Help
  - Driving ability
  - Intimacy
  - Advanced Care Planning
- Resources
- Question and Answers



# “We need to talk”...

## What constitutes a difficult conversation?

- A hard to broach topic. A situation where you need to talk to someone about an emotionally charged issue, usually change related and/or a need not being met.
- The anticipation of talking about the topic fills you with a sense of dread, apprehension, fear.
- Something we don't want to talk about with another but need to. It can't be avoided.
- We have strong feelings about the topic and an investment in the outcome of the conversation.

# Consider this....

- Shows you care
- What matters to you vs. what is the matter with you
- Anticipation is often worse than reality
- How would you like to be approached
- Be proactive
- Tap into other supports

# Try this.....

- Set the stage
- Remember the basics of communication
- One topic at a time
- Focus on a positive or use humor
- Set a time limit

# Try this...

- Get your facts first
- Prepare yourself
- Be ready with options/solutions
- Prepare for a negative response
- May need to re-approach
- Provide an opportunity to raise a concern
- Finish with something enjoyable

# Common challenging topics

- Sharing the diagnosis
- Recognizing and sharing changes with HCP
- Accepting help
- Concerns about driving
- Intimacy
- Advance Care Planning



# #1 Sharing the diagnosis

- At work
  - Consider the nature of the work relationship
  - Access human resources
- With family and friends
  - Consider the relationship and personality style
- With the children in your life
  - Calm, hopeful approach
  - Age appropriate information

## #2 Recognizing changes and sharing changes with the care team

- Be prepared with details and examples
- Use “I” statements
- Manage the possible reactions (anger, denial)
- Share their own opinion at the appointment
- Jointly make a list for the appointment

# #3 If there is anything I can do...Accepting Help

- Normalize. It is not possible to go it alone, these diseases require help to manage.
- Reframe accepting help as a way to maintain independence, not take away. Focus on positives, what is gained, not lost.
- Listen to concerns and don't try to change mind, plant seed, start low, go slow, small steps.
- Doctor can suggest as part of health care plan - write a prescription.
- Offer. I'd like to spend more time with mom vs you need a break.

# Strength in Numbers: Asking for help

- Asking for help is not a sign of weakness. Takes strength!
- Allows you to take control. Build a care team.
- We all need to learn to ask for and receive help



## #4 Conversations about driving ability

- Get the facts – learn about warning signs. Observe driver.
- Discuss concerns with a doctor.
- Safety first. Quit while ahead. If possible, make an action plan after diagnosis.
- Driving test – Do not argue, get tested.
- Understand what loss of driving represents, have a plan of action. Be a supportive presence.
- Prepare for several conversations on the topic. Is a process.
- Focus on positives, no parking, money saved on insurance. Have alternatives ready.

# #5 Intimacy

- Communicate
  - Share feelings and worries
  - Show appreciation for each other
  - Share requests for what intimacy can look like
  - Find ways to re-kindle and fuel the relationship
  - Reframe your definition of intimacy



# #6 Advance Care Planning

- Advance care planning
  - Process of reflection and communication
  - Reflect on values and wishes
  - Share your choices for future health and personal choices
- An ongoing conversation
- Keep the number of participants small



# Advance Care Planning

- Any particular concerns ie financial, health
- Some opening statements
  - “I heard from a friend about ACP and I think I am going to do one”
  - “I was answering some questions about end of life and I want to share my answers with you and I am wondering what your answers might be”
- Respect choices



# Underlying emotions of loss and grief: impact on conversations

- **Loss** *is the experience of parting with an object or person OR a change in a relationship that one values*
- **Grief** *is the normal package of emotions including sadness, anger, fear, guilt that accompany a loss*

# One model to deal with loss and grief

- Acceptance of the reality of the loss
- Embrace the pain of the loss, acknowledge it
- Adjust to the newness and the changes that have resulted
- Slowly begin to withdraw from the loss and reinvest in life in a different way

# How do you deal with loss and grief

- Keep a journal
- Establish goals for yourself
- Take action to stay healthy
- Work together
- Create something new
- Honor your memories

# HOPE

*Foundations of HOPE*

**H***elp*

**O***ptimism*

**P***hysician*

**E***xercise*



# Take home messages

- “Quality of life is not what those outside the life looking in think it is, but rather it is what the person living the life says it is”.
  - Rosemary Parse
- Very individualized and unique



# Caregiving is a journey



# Be kind to yourself



# Resources

- Driving Fitness and Testing rules vary by Province. Check your Provincial Ministry of Transportation website for guidelines and tips.
- We Need to talk: Family conversations with older drivers
  - [https://www.thehartford.com/sites/the\\_hartford/files/we-need-to-talk-2012.pdf](https://www.thehartford.com/sites/the_hartford/files/we-need-to-talk-2012.pdf)
- Accepting Help
  - <http://www.alzheimer.ca/bc/~media/Files/bc/Newsletters/Insight/Insight-fall-2017.pdf>



# Resources

- Advance Care Planning
  - [www.gowish.org](http://www.gowish.org)
  - [www.conversationproject.org](http://www.conversationproject.org)
  - [www.agingwithdignity.org](http://www.agingwithdignity.org) (Five Wishes document)
- Books
  - “How to talk to children through a parent’s serious illness” by Kathleen McCue
  - “Difficult conversations: How to discuss what matters most” by Douglas Stone, Bruce Patton, Sheila Heen
  - “Glad No Matter What: Transforming Loss and Change into Gift and Opportunity” by Susan Ariel Rainbow Kennedy
  - “Sex, love and chronic illness” by Lucille Carlton

# Resources

- Conversation starters
  - [http://www.caregiverstress.com/wp-content/uploads/2011/08/HomelInstead\\_40-70Booklet\\_Web.pdf](http://www.caregiverstress.com/wp-content/uploads/2011/08/HomelInstead_40-70Booklet_Web.pdf))
  - [www.sagefinder.com](http://www.sagefinder.com)
- National Organizations/Provincial Societies
  - [www.parkinson.ca](http://www.parkinson.ca)
  - [www.mssociety.ca](http://www.mssociety.ca)
  - [www.alzheimer.ca](http://www.alzheimer.ca)



# Questions & Answers

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