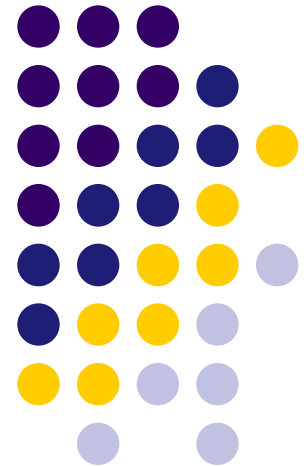


# Caregiving and Dementia at the end-of-life

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# Today's Discussion

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- Day to day care
- Advanced Care planning
- Grief and Bereavement
- Lessons learned and tips

# Day to Day

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- Maintaining:
  - Nutrition
  - Hygiene
  - Bowels/Bladder
  - Medications
  - Pain Management

# Nutrition

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- While still able to drink and eat. Small frequent meals are usually better than trying to get a person to eat one large meal.
- Liquid nutrition is easier to digest than regular food and clients seem to be able to take it easier than food.( i.e. boost, ensure, Carnation Instant Breakfast).
- The more we focus on getting the person to eat the more agitated and upset the person becomes and are more reluctant to eat.
- Finger foods are helpful as it gives the person the ability to feed themselves.
- Offer food then walk away, come back a short time later and offer again.

# Nutrition

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- Don't focus on the eating. It will only upset the patient.
- Offer liquids in adult Sippy cup.
- Towards end of life a person's ability to eat or drink becomes less of a priority.
- The body instinctively will only take in what it needs and can use.
- Proper mouth care will become more important than the eating.

# Hygiene

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- Maintain regular routine with bath time.
- If the patient has always taken a shower or a bath maintain that routine.
- Always provide privacy.
- Remove hearing aids or glasses once in the tub or shower to reduce any fears of not being able to see or hear while getting into the shower or tub.
- Allow the patient to do as much of their own care.
- Don't rush, take as much time as needed.

# Hygiene

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- If having a bath or shower is too difficult then a sponge bath is quite good and makes the care easier for everyone involved.
- As time progresses a bed bath will become the norm.
- Maintain good oral hygiene by doing mouth care as often as possible.
- Vaseline to lips will keep them moist and prevent cracking.
- Good skin care to prevent breakdown is vital.

# Maintaining Bladder/Bowels

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- We have become obsessed with bowel movements and bladder functions.
- We sometimes know more about a person's bowel habits than we do about them.
- Normal function is always good but we must keep an eye on what isn't the norm. If a person only went once every 4 days that will not change.
- Never let the bowels go more than 4 days without movement. Especially if on pain medications.
- Continue with bowel meds as needed to maintain bowel functions.



# Maintaining Bladder/Bowels

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- Decrease as needed but never stop them.
- Monitor urinary output, remembering that a person will only put out what they taken in. (If they have had limited fluid in then you can expect little out.)
- Additional agitation and confusion usually, in the elderly, and changes in behaviour can indicate a UTI.
- Towards the end of life bowel functions will be decreased greatly. Don't focus on this. It is normal.

# Medications

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- Allow the person to take their oral medications on their own as long as they can safely do so.
- Ensure that they are not pocketing the medications.
- Give medications slowly.
- Crush medications and put into apple sauce or jam to help with swallowing. Check with your pharmacy to insure that medications can be crushed.
- Remember to never crush any medication with “Contin” in the name. This will give all the medication at once instead of slowly (time release)
- Toward end of life medications maybe stopped or changed to injectable.



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# Monitoring Pain

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- Watching facial expressions – grimacing with movement, touching.
- Moaning with movement or touch.
- Pulls away when being touched.
- Agitation or aggression for no apparent reason.
- Did the person have pain issues before becoming ill, were they on anything for discomfort before now?
- Keep a record of when the pain occurred, if and when pain medication was given and if it helped control the pain.

# Monitoring Pain

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- Family or main caregiver are good resources as to reading a person's body language regarding discomfort or pain.
- Speak to your health team members regarding any concerns regarding pain management.

# Advanced Care Planning

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- What is Advance Care Planning?
- It is a process of reflection and communication, a time for the person to reflect on their values and wishes, and to let others know their future health and personal care preferences in the event that they become incapable of consenting to or refusing treatment or other care. (1)
- Advance care planning means having discussions with family and friends, especially the Substitute Decision Maker – the person who will speak for the person when they cannot. It could also include writing down their wishes, and may even involve talking with healthcare providers and financial and legal professionals. (1)



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# Advanced Care Planning

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- This discussion should be done long before the person ever needs advance care.
- Discussing personal values in relation to illness and death, finances and living arrangements.
- Complete legal paperwork to ensure that their wishes are recorded (living will) and a substitute decision-maker is named.
- Laws about advance directives and substitute decision-making vary between provinces and territories. Check your provincial standards.

# Advanced Care Planning

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- Open discussion regarding DNR.
- Is there a back up plan in case of emergency.
- Ensure that your health care team is aware of all Advanced Care Plans.
- In Ontario we have the Expected Death In The Home (EDITH) Protocol which helps you through the process of ensuring that the discussion is started.

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

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Includes Advance Care Planning Day –  
April 16, 2013

Provides a website with resources

[www.advancecareplanning.ca](http://www.advancecareplanning.ca)



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# Grief and Bereavement

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- “Grief is the price we pay for love.” - Queen Elizabeth II) (2)
- Grief has been identified as the “constant yet hidden companion” of dementia (Kenneth J. Doka). (3)
- Caregivers often experience a continuous and profound sense of loss and subsequent grief as they live through the changes associated with the progression of the disease. You may be grieving the losses that are occurring in your own life as well as in the life of the person with dementia. (3)

# Grief and Bereavement

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- Feel the pain: Allow yourself to really feel what you are feeling, no matter what that is.
- Cry: Crying is very therapeutic.
- Talk: It is important to talk about your feelings even at the most difficult times. It can be helpful to talk to a person outside the family, such as a counsellor or trusted friend.
- Keep a journal. A journal is a private place where anything can be written.

# Grief and Bereavement

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- Consider your own needs: Just relaxing with a cup of tea or having a good chat on the phone.
- Hold off making decisions: Thoroughly explore all options before making major decisions. You may be unable to make important decisions at times.
- Be kind to yourself: Be patient with your feelings. Have patience with yourself.
- Learn to laugh again. Rediscover your sense of humour.
- Grief counselling for caregiver should be considered when appropriate.

# Lessons Learned

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- Mr. P – wife had dementia and esophageal CA. Every evening the wife would say she wasn't home and wanted to go home. He would put their coats on and go drive around the block and come back to their street, once she saw the house she would say that was their home. Mr. P did this every evening until his wife could no longer walk.
- Mr. & Mrs. J – both had dementia. His wasn't as bad but he did have lung CA. It was difficult to get them both to understand the situation as he was now end stage. He would have great conversations about his time in the Navy. Speaking about the navy was the only way to examine him as he had war injuries.

# Lessons Learned

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- Mrs. T – lung CA with dementia. Played all the old time music and would become very upset once the music stopped. This was the only way of knowing that she was present in the moment.
- Ms. D – known to have Korsakoff's dementia. They could not get this lady to drink anything, always requiring IV hydration. She was well known in the community and they inquired as to what her favorite drink was. They would give her orange juice with ice in it and tell her it was a screw driver. After that client never require IV hydration again.

# Lessons Learned/Tips

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- Always speak to the person and not at them.
- Learn from your patients, they have wonderful stories to tell.
- Suggest to families that they use an adult Sippy cup to promote drinking.
- Ice chips and popsicle's is a great way of giving someone fluids.
- Always offer family additional services available in your area.
- Remember the 3 R's: Respect, Realism and Respite.
- Be yourself.

# User Contributed Questions

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- How do you bridge physical care for conditions of aging (pain, lack of mobility, hearing/visual impairments, weight loss/diet limitations) with mental/emotional care (e.g. dementia, depression, etc.)? How do you not focus on one and leave out the other? How to really enhance the holistic continuum of care?

# User Contributed Questions

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- Do you have any suggestions on dealing with a patient's anger?



# User Contributed Questions

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- Do you have any tips around self-care for caregivers?

# Quote

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**Yesterday is history,  
Tomorrow is a mystery,  
But today is a gift.**

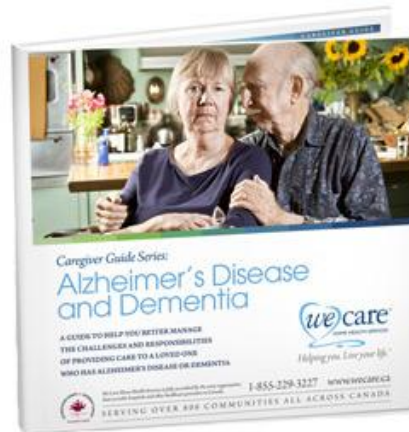
**That is why it is called the present.**

Master Oogway from Kung Fu Panda (4)

# Additional Resources

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- We Care's Being a Family Caregiver Guide and Alzheimer's Disease and Dementia Guide
- Caregiver Relief Services: [www.wecare.ca](http://www.wecare.ca)



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# References

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- 1: Speak Up- Advance Care Planning Fact Sheet)
- 2: A MESSAGE from the Queen, read by the British ambassador to Washington, Sir Christopher Meyer,
- 3: Grieving – Alzheimer's Society of Canada
- 4: Kung Fu Panda- Dream Works Movie

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# Questions?