

# DEMENTIA AND PALLIATIVE CARE - TOOLKIT FOR THE PRIMARY CARE PRACTITIONERS

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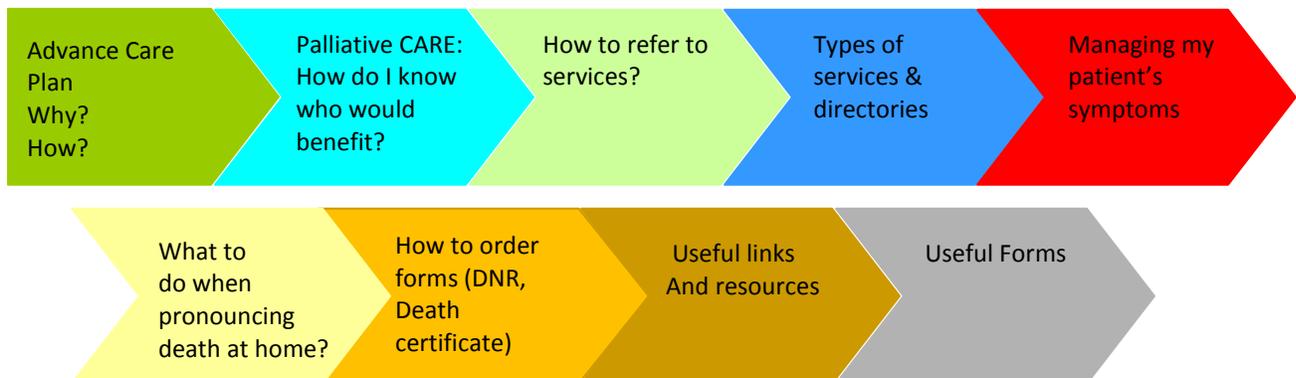
## INTRODUCTION

Dementia is a progressive and terminal condition that affects all aspects of the patient's life. Patients and their caregivers need communication and education to help them cope with changes as they arise. This includes preparation for end of life decisions and care needs. This education and communication is a **process** that occurs over time – begin it early and reassess as needed.

Key messages:

- The discussion is a process that matures over time and thus needs to start early.
- The conversation is not necessarily about particular decisions, but about your patient's values, goals and beliefs.
- Identifying a proxy or a substitute decision maker (SDM) is key.

To help you find your way – Here is an outline of the content by color coding:



## ADVANCE CARE PLAN (ACP) - WHAT IS IT? WHY IS IT IMPORTANT?

Participating in advance care planning (ACP) allows a person to express their wishes and values about the care they would like to receive if they become unable to express it themselves. Learning about a patient's values eases decision-making for the substitute decision-maker if they are called upon to direct care decisions.

ACP is a process of exploring a person's values, beliefs and goals. By asking certain questions, you and the SDM learn about what the person values. This will ease decision-making as the disease progression takes away a person's decision-making capacity. Here are a few examples: What gives your life meaning? What do you value? Are there circumstances, for example -- loss of physical functioning or loss of mental awareness, -- in which you would not want to prolong your life? In these situations, would you rather want nature to be allowed to take its course and be allowed to die naturally? What kinds of conditions would be unacceptable to you?

Remember, ACPs are flexible and can be changed.

The links below provide tools and resources to help you and your patients prepare an ACP.

[Video about ACP](#)

[Speak up hyperlink](#)

[Canadian Virtual hospice hyperlink](#)

## HOW DO I INTRODUCE ACP WITH MY PATIENT?

### If your patient is well:

1. Consider asking if he or she has ever heard of advanced care planning. Next, explain that it is a normal part of your work (as their primary care practitioner) to help people think about how they want to be cared for if something sudden happened and they weren't able to express it themselves. You might explain it as similar to needing a will to ensure the right decisions – the decisions they make -- are made after they have died.  
See this manual: [How to talk to patients about Advanced Care Planning](#)
2. Ask your patient to think about ACP and, if they want to, set up an appointment with you to discuss in more detail. Invite your patient to bring a family member or other support person if they wish.
3. Include this discussion on a regular basis – perhaps yearly.
4. If they are interested:
  - ✚ Refer to the Alzheimer Society of Toronto – [First Link program](#) – for consultation and support in creating an ACP.
  - ✚ Or, use another tools to assist such as: Speak Up – Advance Care Plan Workbook. View this [link](#)
  - ✚ Document the patient's/family's wishes in the chart so that all health-care professionals involved are aware.
  - ✚ Some topics to consider: In addition to the general discussion about values and goals, you might discuss organ donation, burial/cremation, funeral/memorial service/ financial and legal affairs, final gifts or bequests, cultural beliefs and rituals.

**If your patient has advanced illness:**

Talking with patients/family/Substitute Decision Maker about end of life care takes patience and skill. Below is a summary of the important aspects and a sample dialogue of this communication.

**ENGAGING YOUR PATIENT IN A DIALOGUE ABOUT PALLIATIVE CARE**

**PREPARE** - for the conversation – know information about prognosis, treatment options, outcomes and available resources for your patient. Set aside some private time when you won't be interrupted.

**ASK** - your patient for permission to discuss these topics.

**CHECK** - for your patient's level of understanding of their disease and **identify** knowledge gaps.

**PROVIDE INFORMATION** - to fill in gaps in understanding. This may require breaking bad news if your patient (or their family) isn't aware of the diagnosis, expected outcomes or complications.

**VALIDATE EMOTIONS AND EXPLORE** - your patient's feelings, fears, hopes about their future and their illness.

**EXPLORE** your patient's values about their life – what gives their life meaning and **listen** closely to their answers.

**ASK** if your patient needs help discussing this with their family.

**DOCUMENT** your discussion.

**PROVIDE** tools for on-going discussion about ACP see link: [ACP workbook](#) and refer to Alzheimer Society for further consultation and support at: T: 416-322-6560 F: 416-322-6566 link to [referral form](#)

## BASIC COMMUNICATION SKILLS FOR THIS CONVERSATION

- ✚ Communicate in shorter sentences. Listen more than you talk.
- ✚ Pause often to assess your patient's understanding.
- ✚ Encourage him/her to ask questions.
- ✚ Monitor for, allow space for and validate emotional responses

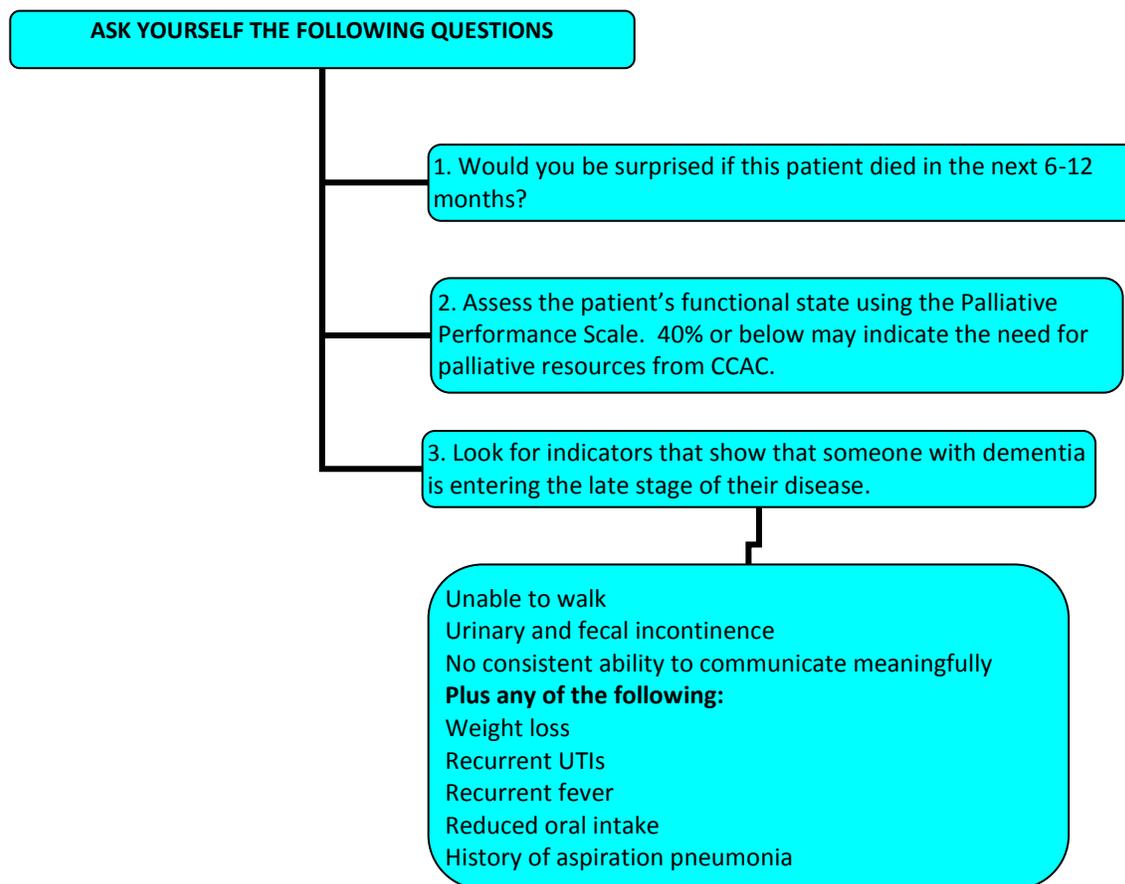
**\*\*For more detailed instruction about how to conduct a PC dialogue look in appendix "C" (Page 12).**

You can learn more about the skills required to communicate compassionately, honestly and supportively in the following link:

[Heart to Heart Communication Skills Course](#) (Also, see this article on Breaking Bad News and Communication [How to Break Bad News](#))

## HOW DO I KNOW THAT MY PATIENT WITH DEMENTIA WOULD BENEFIT FROM PALLIATIVE CARE?

It is difficult to know your patient's prognosis with any certainty. Several organizations suggest the following steps to identify who might benefit from palliative care services. (For other conditions such as cancer, heart failure and renal dysfunction visit this link: [The GSF Prognostic Indicator Guidelines](#)).



(Thomas .K. et al, (2011) Prognosis Indicator Guidance (PIG) 4<sup>th</sup> Edition, The Gold Standards Framework Centre In End of Life Care CIC)

## HOW TO REFER TO PALLIATIVE CARE SERVICES

Use the Palliative Common Referral Form – you only need this one form to refer to all palliative services such as: CCAC, Temmy Latner Centre for Palliative Care, In-Patient Palliative Care Units, residential hospices and community hospice support (see form attached) or follow this link: [http://www.ccac-ont.ca/Upload/toronto/General/Palliative\\_CRF\\_Nov2010.pdf](http://www.ccac-ont.ca/Upload/toronto/General/Palliative_CRF_Nov2010.pdf)

Provide as much information as possible written or as a printed attachment to facilitate better and more appropriate care for your patient. You can always call the Temmy Latner Centre to consult with a physician regarding the referral at: 416-586-4800 ext. 7884

## WHAT PALLIATIVE CARE SERVICES ARE AVAILABLE FOR MY PATIENT WITH END-STAGE DEMENTIA?

### TYPES OF PALLIATIVE SERVICES

#### COMMUNITY IN HOME SERVICES

1. **Central CCAC Home Care Palliative Program** – Provides in-home services that include enhanced hours of Personal Support Workers, Nursing services, etc. There is no waiting list for this service. For the patient to be eligible for this program a Palliative Performance Scale needs to be completed (see this [link](#)) and sent together with the Palliative Common Referral form. The score should be 40% or less to be eligible. **T: 416-506 9888; F: 416-506 0374; Link to referral form: <http://www.ccac-ont.ca/Upload/toronto/General/MedicalReferralFormCS101.pdf>**
2. **PALLIATIVE CARE Home-based PROGRAMS** – Provides physician care at the home on a consultation or shared care basis with the family physician/team. See the directory attached for the different services. Waiting time is flexible according to urgency and may be up to 2 – 4 weeks. Patients are accepted into the program when their goals of care are appropriate for a home-visiting palliative care physician – that is, the goals of care are to provide management for pain and symptom management, in the home environment with avoidance of hospital visits.

Organization	Address	CONTACT	CATCHMENT AREA
<b>Temmy Latner Centre</b> Mount Sinai Hospital Joseph and Wolf Lebovic Health Complex provide link	60 Murray Street, 4th Floor, Box 13, L4-000 Toronto, Ontario M5T 3L9	T: 416-586-4800 ext.7884 F:416-586-4804 <a href="mailto:info@tlcpc.org">info@tlcpc.org</a>	North: to Steeles Ave. South: to Lakeshore Blvd West: to Jane St. East: to Warden Ave

3. **COMMUNITY HOSPICES** – Volunteer-based program that provides in-home volunteer support free of charge. The volunteers go through a 40-hour training program and can provide: counseling for the patient and the family, emotional support, respite, some home help like cooking and light cleaning. Some volunteers can provide other therapies like massage therapy to relief pain according to their expertise. The hospices can also help in locating volunteers that specialized in providing ethno-cultural sensitive support. (See attached directory for the list of hospices).

### List of Community Hospices:

NAME	PHONE NUMBER	Address	Area served
Hospice Toronto	416-364-1666	2221 Yonge St #400, Toronto, ON M4S 2B4	Central Toronto (north to St. Clair Ave., south to Toronto Islands, east to Victoria Park Ave., and west to the Humber River.
Alliance Hospice	416-385-8885	220 Sherway Dr, Toronto, ON M9C 0A7	Toronto
Dorothy Lay	416-626-0116	29 Gervais Dr Suite 100, North York, ON M3C 1Y9	Etobicoke
Hazel Burns Hospice	416-782-5915	2562 Eglinton W, York, ON M6M 1T4	City of York
Jewish Hospice	416-638-7800 ext. 201	4600 Bathurst Street, 6th Floor Toronto, ON, M2R 3V3	Toronto
Les Centers De'Accueil Heritage	416-365-3350	33 Hahn Pl, Toronto, ON M5A 4G2	Toronto
Philip Aziz Centre	416-363-9196	558 Gerrard E, Toronto, ON M4M 1X8	GTA
Scarborough Hospice	416-498-8126	2660 Eginton Ave. East, Scarborough M1K2S3	Scarborough
Wellness Centre (Chinese population)	416-847-4086	90 Scottfield Dr. Toronto ON, M1S 5W4	Scarborough

**Hospice Association of Ontario** - 40 Wynford Drive, Suite 313, Don Mills, Ontario, M3C 1J5; Telephone: 416-510-3880; Fax: 416-510-3882; Link.

## WHAT IF MY PATIENT CANNOT OR DOESN'T WANT TO STAY AT HOME?

### IN-PATIENT PALLIATIVE SERVICES

In-patient units and residential hospices provide multidisciplinary care to patients whose goals of care are to avoid acute care hospitalization and to focus on comfort and quality of life rather than life-prolonging treatments. They have specialized ability to manage difficult symptoms at the end of life. Patients and families must have a DNR in place.

- ✚ Short-term inpatient units – up to 3 months stay
- ✚ Long-term inpatient units – up to 1 year stay – Long Term Care charges apply
- ✚ Residential hospices – up to 3 months stay

LONG  
and  
SHORT  
TERM  
STAY

**Hospital-based Palliative Care Units**

<i>Toronto Central</i>		
Baycrest	3560 Bathurst St (south of Hwy 401)	416-785-2500
	14 St. Matthews Rd	416-461-8251
Bridgepoint Health	(Broadview/Gerrard)	
St. Michael's	30 Bond St (Yonge/Queen)	416-864-5226
Sunnybrook	2075 Bayview Ave (Bayview/Lawrence)	416-480-6182
Toronto Grace	650 Church St (Church/Bloor)	416-925-2251
Toronto East		
Providence	3276 St.Clair Ave East (Warden/St.Clair)	416-285-3666
Scarborough General	3050 Lawrence Ave East (McCowan/Lawrence)	416-438-2911
Toronto East General	825 Coxwell Ave (Coxwell/Danforth)	416-469-6580
Toronto West		
TRI – EW Bickle	130 Dunn Ave (King St West/Jameson)	416-597-3422
William Osler – Etobicoke	101 Humber College Blvd (Finch/Hwy 27)	416-747-3400
<i>Greater Toronto Area</i>		
Lakeridge Health	1 Hospital Court, Oshawa	905-576-8711
Markham-Stouffville	381 Church St, Markham	905-472-7000
William Osler – Brampton	2100 Bovaird Dr, Brampton	905-494-6442
York Central	10 Trench St, Richmond Hill	905-883-1212

**Residential Hospices**

Carpenter House	2250 Parkway Dr, Burlington	905-631-9994
Casey House (HIV/AIDS)	9 Huntley St (Jarvis/Bloor)	416-962-7600
Dorothy Ley Hospice	220 Sherway Dr (Queensway/West Mall)	416-626-0116
Hill House Hospice	36 Wright St, Richmond Hill	905-737-9308
Ian Anderson House	430 Winston Churchill Blvd, Oakville	905-337-8004
Kensington Gardens	38 Major St (Spadina/College)	416-963-9640 extension 1426



## HOW DO I MANAGE MY PATIENT'S SYMPTOMS?

*Like all patients at the end of life, symptom management in patients with end-stage dementia requires diligence to ensure comfort.*

Here are a few suggestions:

- ✚ **Pain** - it can be difficult to assess pain in these patients. It may help to use non-verbal pain scores and rely on the observations of caregivers. Start with acetaminophen and proceed with small doses of opioids such as 0.2 mg of hydromorphone as needed. At home, medication can be delivered subcutaneously either by intermittent injection or via a continuous infusion.
- ✚ **Agitation and delirium** - are more likely a concern. First choice for these symptoms is anti-psychotic medication such as haloperidol or risperidone. The management of delirium and agitation are similar for other patients at the end of life.
- ✚ **Dehydration:** at the end of life, dehydration is not painful or uncomfortable. Pay particular attention to dry mouth and teach families to provide good mouth care with moist swabs (not lemon-glycerine swabs as these are drying).
- ✚ **Other symptoms** - such as **dyspnea** and **respiratory secretions**, the management is the same for all patients at the end of life. See the resources provided to learn more about symptom management at the end of life.

✚  
**\* If you are unsure about managing symptoms at home, please consult a physician from the Temmy Latner Centre for Palliative Care at: 416-586-4800 ext. 7884.**

### **Additional information:**

There are many palliative care courses to learn about palliative care. There are also online resources and textbooks. Listed below are some useful links to resources for practitioners caring for patients with advanced illness and at the end of life.

- [Fraser Health Symptom Guidelines](#)
- [Canadian Virtual Hospice Clinical Guidelines](#)
- [NICE Guidelines on Care of Patients with Dementia](#)
- [Cancer Care Ontario Symptom Management Tools](#)
- [Cancer Care Ontario Collaborative Care Tools](#)

## WHAT DO I DO WHEN I PRONOUNCE DEATH AT HOME?

If the patient you are caring for dies an expected death at home, you should go to the home to: 1) pronounce death and 2) complete the death certificate. Once this is done, the patient's family can call the funeral home of their choice. The funeral home will take the body from the home. They also take the death certificate and will assist the family with next steps. Make sure you advise the family to return all unused medications to the pharmacy. You can not remove them from the patient's home.

### Forms you will need:

- **Death certificate Form** – can be photocopied (as long as it is blank) and does not require ordering (see attached) or follow this [link](#)

**\*\*When you are in doubt regarding the cause of death, or when death is not by an expected natural cause, consult with the Coroner's office at [416-314-4100](tel:416-314-4100).**

## HOW DO I ORDER FORMS

**DNR – DO NOT RESUSCITATE FORM** – The DNR form has serial numbers therefore it cannot be copied. You will need to order it through Service Canada.

Attached is an order form you will need to fill out and fax to the Ministry at: **[416-679-8192](tel:416-679-8192)**  
Find more information in this [link](#).

Here are the specific details of the DNR form you will need for your order:

Form number: 014-4519-45      Edition date: 2008/1

Title: Do No Resuscitate Confirmation Form

### **Ordering information:**

Submit completed order request from using the order form number (attached to this guide):

014-0350-93 (attached to this toolkit) to [OSSDistribution@ontario.ca](mailto:OSSDistribution@ontario.ca) or by fax to 416-679-8192

**MEDICAL DEATH CERTIFICATE – FORM 16** – can be photocopied (as long as it is blank) and does not require ordering (see attached) or follow this [link](#)



## USEFUL LINKS AND RESOURCES

- + What to Expect in the Last Days of Life: A Guide for the Caregiver - Temmy Latner Centre. Download the guide in this [link](#).
- + Speak Up – A workbook to guide patients and their families regarding an ACP - [Link](#)
- + The GSF Prognostic Indicator Guidance - [link](#)
- + Toronto Central Palliative Care Network - <http://www.tcpcn.ca/>
- + Canadian Virtual Hospice - [www.virtualhospice.ca](http://www.virtualhospice.ca)
- + Hospice Life-Line and Hospice Association of Ontario - [www.hospicelifeline.com](http://www.hospicelifeline.com)



## FORMS AND APPENDIXES ADDED TO THIS KIT:

1. Appendix A – Feeding tubes (Page 10)
2. Appendix B – Summary of resources by need (Page 11)
3. Appendix C - Example of ACP and PC dialogue with a patient (Pages 12-16)
4. Common Palliative Referral form
5. DNR- sample only (put in patient’s home if they do not want resuscitation attempts by EMR or other medical professionals)
6. Death Certificate Form
7. Form Order (to order DNRs)

## APPENDIX A

### Feeding tubes

“Studies have found that feeding tubes do not result in improved survival, prevention of aspiration pneumonia, or improved healing of pressure ulcers. Feeding tube use in such patients has actually been associated with pressure ulcer development, use of physical and pharmacologic restraints, and patient distress about the tube itself. Assistance with oral feeding is an evidence-based approach to provide nutrition for patients with advanced dementia and feeding problems; in the final phase of this disease, assisted feeding may focus on comfort and human interaction more than the nutritional goals...” from “Five Things Physicians and Patients Should Question in Hospice and Palliative Medicine” (see ref # 1 below)

1. Five Things Physicians and Patients Should Question in Hospice and Palliative Medicine. *Journal of Pain and Symptom Management* Vol 45 No. 3, March 2013 Daniel Fischberg, MD, PhD, Janet Bull, MD, David Casarett, MD, MA, MMM, Laura C. Hanson, MD, MPH, Scott M. Klein, MD, MHSA, Joseph Rotella, MD, MBA, Thomas Smith, MD, C. Porter Storey Jr., MD, Joan M. Teno, MD, MS, and Eric Widera, MD, for the AAHPM Choosing Wisely Task Force
2. Palecek EJ, Teno JM, Casarett DJ, et al. Comfort feeding only: a proposal to bring clarity to decision-making regarding difficulty with eating for persons with advanced dementia. *J Am Geriatr Soc* 2010; 58:580e584.
3. Sampson EL, Candy B, Jones L. Enteral tube feeding for older people with advanced dementia. *Cochrane Database Syst Rev* 2009;2:CD007209.
4. Teno JM, Gozalo P, Mitchell SL, et al. Feeding tubes and the prevention or healing of pressure ulcers. *Arch Intern Med* 2012;172:697e701.
5. Teno JM, Mitchell SL, Gozalo PL, et al. Hospital characteristics associated with feeding tube placement in nursing home residents with advanced cognitive impairment. *JAMA* 2010;303:544e550.

## APPENDIX B

### Summary of resources by need

What am I looking for?	Resource	Contacts/links
Advance Care Planning (ACP)	Alzheimer Society of Toronto- Information, counseling and ACP guidance	T:416-322-6560; F: 416-322-6566 Referral form ( <a href="#">Link</a> )
	Speak Up – Resources and information about preparing an ACP	<a href="#">Link</a>
	Canadian Virtual Hospice - Resources and information about preparing an ACP	<a href="#">Link</a>
Communication skills regarding discussing Palliative care/ACP	Heart to Heart Communication Skills Course	<a href="#">Link</a>
	Article – How to break bad news	<a href="#">Link</a>
Assessment of need for palliative care	The GSF Prognostic Indicator Guideline	<a href="#">Link</a>
	Palliative Performance Scale	<a href="#">Link</a>
Consultation regarding palliative care issues	Temmy Latner Centre – Physician consult	416-586-4800 ext. 7884
	Psychogeriatric Resource Consultant – Mount Sinai Hospital	T: 416-586-4800 ext. 5251 Edanieli@mtsinai.on.ca
Referral to palliative care services	Use the common referral form	<a href="#">Link</a>
Managing symptoms	Fraser Health Symptoms Guidelines	<a href="#">Link</a>
	Canadian Virtual Hospice Clinical Guidelines	<a href="#">Link</a>
	Nice Guidelines for Support of People with Dementia and their families	<a href="#">Link</a>
	Cancer Care Ontario Symptom Management Tool	<a href="#">Link</a>
	Cancer care Ontario Collaborative Care Tools	<a href="#">Link</a>
Ordering DNR form	Service Canada	F: 416-679- 8192 <a href="#">Link</a>

## APPENDIX C

### **A case example for how to conduct a dialogue about palliative care with your patient**

*Mrs. Smith is your patient. She is 89 yrs old and has advanced dementia. Her daughter Sheila called you because her mother returned from hospital after an admission for aspiration pneumonia. At the hospital, the speech and language therapist advised a change in diet to pureed and thickened foods. She said that Mrs. Smith's swallowing is now compromised from her dementia and she is aspirating thin fluids.*

*You have decided to visit Mrs. Smith in her home and discuss this with her daughter.*

**MD: Sheila, I understand you learned some new information at the hospital during the admission...would it be okay to talk a bit about what happened and what we might start to think about for the future?**

S: Sure, I was so shocked to learn all this – I mean, Mom has always eaten so well – she loves her food...

**MD: Yes, I remember you telling me this before – what were some of your mom's favorite foods?**

S: Chocolate! Anything with chocolate...and salty foods too.

**MD: I can understand that! So, let's start by you telling me...what did you learn during your mom's hospitalization?**

S: Well, she got pneumonia, and the doctors said that it was because she doesn't swallow properly – and the food went into her lungs and caused infection.

**MD: Okay... anything else?**

S: Uhm...well, they said it was from the dementia – I don't remember the details...but then they said we could put in a tube to feed her if this kept happening...is that true?

**MD: Well, let's go back to the reasons for the swallowing difficulty – I'd like to explain why the illness of dementia causes these problems...(MD explains the work of swallowing, the coordination...how it is like coordinating other actions, that it takes the coordination of many muscles and that that function is being lost due to the dementia).**

**MD: As your Mother's disease continues, it affects all these abilities. Remember when her walking slowed and then stopped? Now, she can't raise herself out of bed for the same**

**reason – the brain has lost that ability to do these activities...like speech, feeding herself, and now we are seeing with swallowing...**

*MD Pauses here, to let information sink in – and to wait for response from daughter...*

S: I see...

**MD: Pauses still...**

S: I guess I know all this... I just don't want to ...

**MD: Just don't want to....**

S: I Just don't want to face it – (she starts to cry)

**MD: Pauses...What is the hardest thing about all this?**

S: ....it is that I promised her I'd take care of her...and now this...I need to do what I said...I said I'd take care of her and I don't know what that means now...am I not taking care of her if she ends up getting pneumonia just from eating? I just want what is best for her...

**MD: She trusted you to take care of her... (empathic repeating of Sheila's statement)**

S: Yes, and I want to...we were always so close – she had such a hard life, she doesn't deserve this...she came to Canada...she worked hard all her life...she always did everything for everyone...she never gave her herself anything special.

**MD: She sounds like a strong woman –**

S: Oh yes, very strong. She never wanted help from people – she always wanted to help...

**MD: And you are now here to help her – that must feel like a huge responsibility...**

S: Yes, and what if I don't know what to do?

**MD: I understand – that must feel frightening. I'm going to help you with that responsibility. But first, I'd like to ask a little more about your knowledge about your mom's illness – is that okay?**

S: Sure.

**MD: I'm wondering what you understand about your mom's illness overall – have you read about what to expect when people suffer from dementia? – what kinds of things do you expect as she gets worse?**

*Depending on Sheila's answer, you may have to provide education about: (remember, short chunks of information)*

- *The terminal nature of dementing illnesses*
- *Aspiration risk*
- *Infection risk*
- *Role of feeding tubes (studies now show no clear value in prolonging life)*
  - *Pro: Will provide nutrition and may prolong life*
  - *Con: Still risk of aspiration, might pull out – might need restraints if agitated, doesn't necessarily prolong life. Studies now show that careful hand feeding is a good option for patients with advanced dementia*

**\*\*See article about the role of feeding tubes in dementia in Appendix A.**

**MD: I've given you a lot of information today – how are you feeling about what we've talked about...**

**MD: This is a lot of information to take in Sheila – can I suggest that we stop here? I will leave you with some information about all this – I think we should plan to talk again next week. We can go back over this to see if you have questions and then we can talk about how to think about planning for the future...does that make sense?**

S: Yes, thanks. I'm glad you are going to help me...I'll read this over...

**MD: Write down any questions and we'll continue next week...**

*At the next visit:*

S: I read through the information and I understand now what you mean about Mom getting sicker – I hadn't realized that things would continue to get worse – I thought she'd stay like this for a long time...

**MD: Yes, it is usually a surprise to families – you are not alone... and it is impossible to know to the timing...sometimes people are stable for quite awhile, then there are sudden changes. Sometimes we see a steady change overtime...I'll let you know what I see as we go forward...**

S; Okay, that would be helpful...

**MD: Do you have any questions to start: either about what you read or what we discussed last week?**

S: I understand that I'm going to need to make decisions about some different treatments – maybe about putting in a feeding tube, about life support, about where to care for her...she always wanted to be at home. That much I know for sure.

**MD: Well, I think I understand a bit better how to help you Sheila...let's talk a bit about how people make decisions for their loved ones at times like this...many people face these questions as their loved ones get sicker...I think I can help you think through this. Would that be okay?**

S: No, I'm okay to talk now...

**MD: Okay. So you've just mentioned that your mom always wanted to be cared for at home... while your mom was well, did she and you ever talk about other things she would have wanted if she got sick in the future? Sometimes people say to their children things like: "If I'm ever so sick that I can't care for myself – if I'm dependent on others, for example, or if I can't communicate, then please don't prolong things for me... please don't do a lot of tests and procedures to keep me going...just let nature take its course..." For these people, what is important to them is that they can communicate, can dress themselves, feed themselves, etc...and when they can't anymore, then they don't want their life prolonged by medical treatments... Other people say things like "as long as I can participate even a little – by nodding yes or no – then that would be good enough quality of life for me..." And still others would want all medical treatments available to prolong their life...when there are such treatments possible.**

S: No, Mom never said anything about this – we did have a neighbor though, who had a stroke and was on life support before she died...and Mom did say that she wouldn't want to be on life support...that really scared her. But that was the only time I heard her talk about the future...

**MD: Okay...that is important. So, when we don't know much from what they have told us, we think about what we know about them that will help us figure out what they would want if they COULD tell us now. In other words, you, as her decision-maker, your job is to think about what your mom would want in the future as her disease gets worse – not what you would want for her. Does that make sense?**

S: Yes...I see –

**MD: You know your mom well – you've told me a bit more about her life – it seems like she was very active and valued her ability to help others...is that right? What else was important to her....**

*(You spend time exploring this topic)...*

*At this point, you might not feel the family or patient is ready to move to discussion of specific goals and treatment decisions. You might continue to explore Sheila's feelings about her Mother, what it feels like to have her mother so ill. Usually, as you explore this, it becomes more obvious what decisions to make – it is often the emotions – the fear, the grief, the guilt – that make decision-making harder.*

If so, then you summarize what you've heard and carry on next time. At that visit, you might start to discuss different goals for the future – levels of treatment that respect the goals for the

patient – full medical treatments, medical treatments to reverse illnesses but no attempt at resuscitation, or, measures aimed at comfort without hospital level medical interventions.

OR,

*You might feel Sheila is ready to discuss decisions in more detail. If so, sometimes it is helpful to summarize what you've heard and make an initial recommendation... MD might feel ready to say something like:*

**MD: So, let me try something Sheila...tell me if this seems right to you...it isn't a decision you are making today, so don't feel that you have to know for sure, but...**

**From what you've described, your mother was a very independent, active woman who valued family, being helpful to others, always being the person people went to for help...She also wanted to stay at home – she didn't want to go back and forth to hospital. We also know she didn't want her life prolonged artificially on life support if she was dying... So we know quite a lot about how to make some decisions...**

**Given what you've told me, I would recommend that we continue caring for her in the way we have – that is, we keep her at home, we continue to have people help with bathing and feeding as we have. That we watch for infections that might make her uncomfortable. And, we continue to feed her carefully, with the foods suggested by the therapist.**

**At some point though, your mother may refuse the food – she may not swallow it, she may spit it out or she may lose the ability to swallow much safely. At that time, I would suggest we focus on keeping her comfortable, keeping her supported and cared for either here or somewhere with more support. If she seems uncomfortable, we will provide medications to ensure her comfort...**

**MD: Does this kind of suggestion make sense? How do you feel about what I've just said?**

*Sheila replies that the recommendation makes a lot of sense – that although it is so hard to think about, that this is probably what her mother would want. The physician explains more about what is involved to keep Sheila's mother comfortable...what medication are used and how she would be monitored – CCAC visits, the MD availability, etc.*

*They agree to a plan and the MD arranges a palliative care CCAC visit. At the next visit, the MD discussed other issues that will likely arise at end of life, and begins educating Sheila about what to expect. For example, they discuss hydration, treatment of infections, equipment that might be needed, etc. The MD gives Sheila the Last Hours Document and organizes community hospice to support Sheila.*

### **References and additional information:**

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