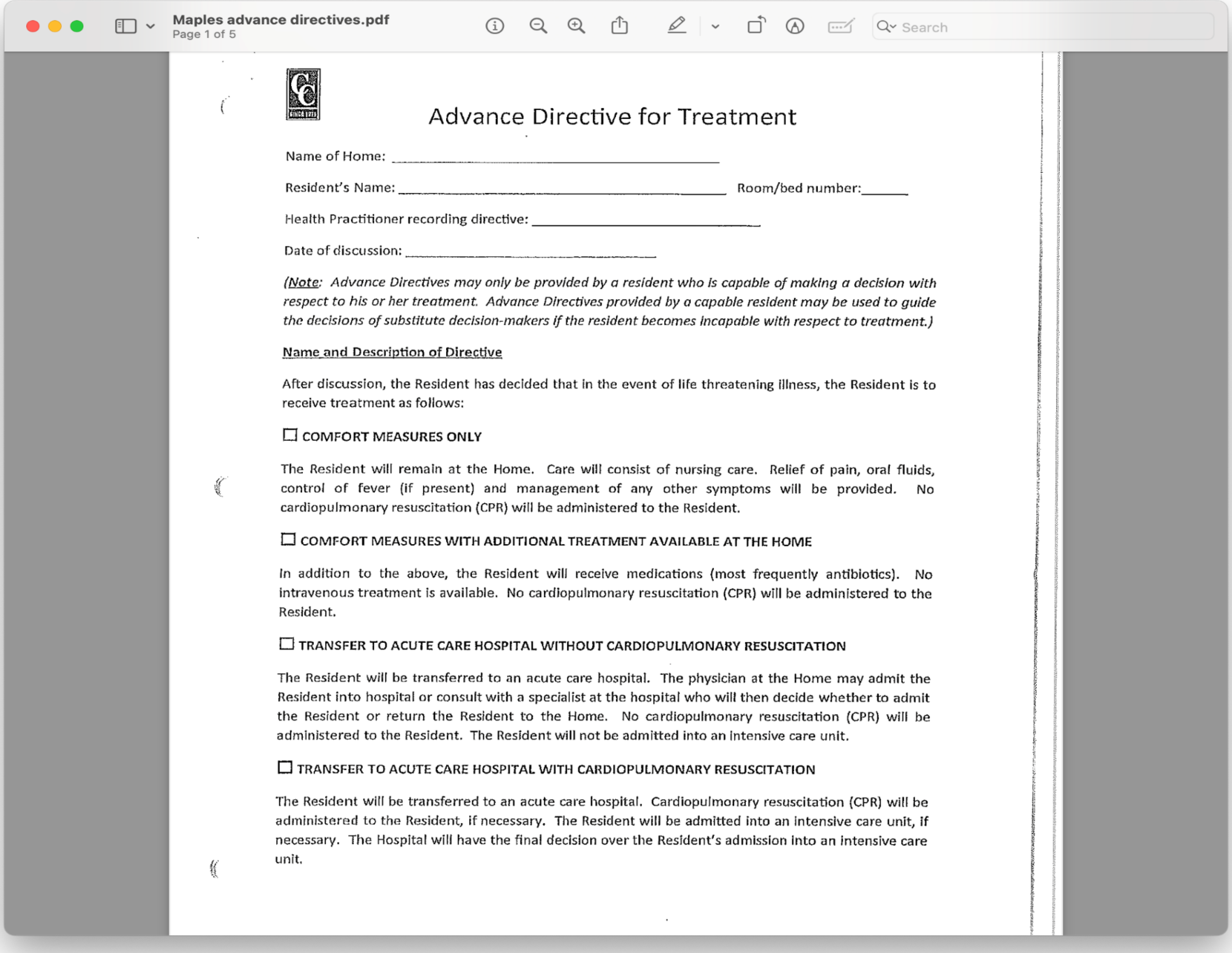
Transitioning from Levels of Care to Goals of Care



Advance Directive for Treatment

Name of Home: ____________________________

Resident's Name: ____________________________ Room/bed number:______

Health Practitioner recording directive: ____________________

Date of discussion: ______________________

(<u>Note</u>: Advance Directives may only be provided by a resident who is capable of making a decision with respect to his or her treatment. Advance Directives provided by a capable resident may be used to guide the decisions of substitute decision-makers if the resident becomes incapable with respect to treatment.)

<u>Name and Description of Directive</u>

After discussion, the Resident has decided that in the event of life threatening illness, the Resident is to receive treatment as follows:

☐ COMFORT MEASURES ONLY

The Resident will remain at the Home. Care will consist of nursing care. Relief of pain, oral fluids, control of fever (if present) and management of any other symptoms will be provided. No cardiopulmonary resuscitation (CPR) will be administered to the Resident.

☐ COMFORT MEASURES WITH ADDITIONAL TREATMENT AVAILABLE AT THE HOME

In addition to the above, the Resident will receive medications (most frequently antibiotics). No intravenous treatment is available. No cardiopulmonary resuscitation (CPR) will be administered to the Resident.

☐ TRANSFER TO ACUTE CARE HOSPITAL WITHOUT CARDIOPULMONARY RESUSCITATION

The Resident will be transferred to an acute care hospital. The physician at the Home may admit the Resident into hospital or consult with a specialist at the hospital who will then decide whether to admit the Resident or return the Resident to the Home. No cardiopulmonary resuscitation (CPR) will be administered to the Resident. The Resident will not be admitted into an intensive care unit.

☐ TRANSFER TO ACUTE CARE HOSPITAL WITH CARDIOPULMONARY RESUSCITATION

The Resident will be transferred to an acute care hospital. Cardiopulmonary resuscitation (CPR) will be administered to the Resident, if necessary. The Resident will be admitted into an intensive care unit, if necessary. The Hospital will have the final decision over the Resident's admission into an intensive care unit.

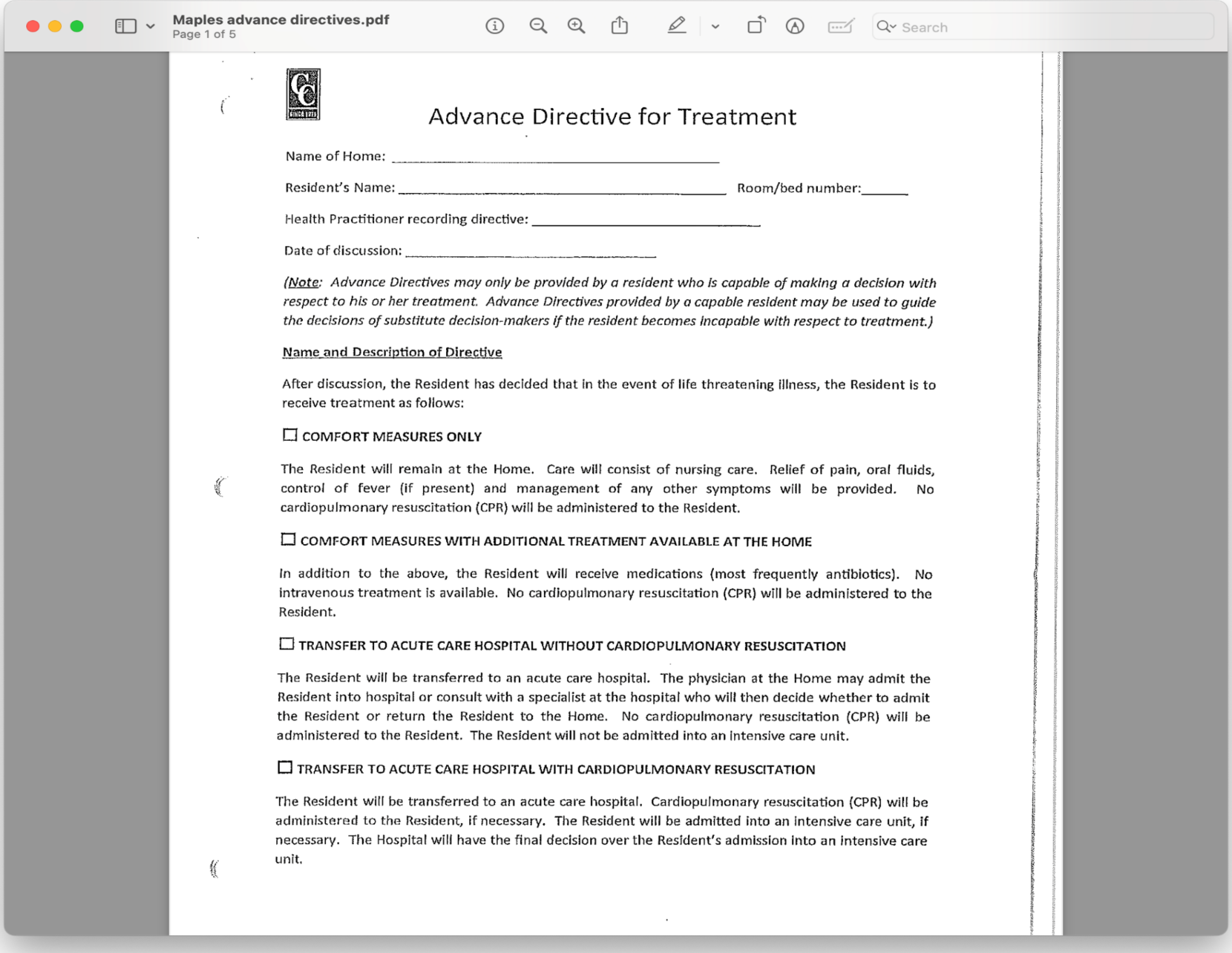
Objectives

- How Ontario laws about healthcare consent impact decisions about patient care
- How we can tell who is capable of their own decisions
- Who is legally able to speak on behalf of another person, and when
- The elements of a Goals of Care conversation
- Where to access LTC admission documents that are legally and clinically better alternatives to Levels of Care forms

Sadie’s story:

- 95 years old, advanced dementia, needing help with most everyday activities, does not understand most things she is told, speech is limited to single words or phrases that make no sense, incontinent.
- Choked on food at dinner
- Now is short of breath and colour is poor “kind of bluish”

- You are called for order to send her to hospital, because….



Advance Directive for Treatment

Name of Home: ______________________________

Resident's Name: ______________________________ Room/bed number:______

Health Practitioner recording directive: ______________________

Date of discussion: ________________________

(<u>Note</u>: Advance Directives may only be provided by a resident who is capable of making a decision with respect to his or her treatment. Advance Directives provided by a capable resident may be used to guide the decisions of substitute decision-makers if the resident becomes incapable with respect to treatment.)

<u>Name and Description of Directive</u>

After discussion, the Resident has decided that in the event of life threatening illness, the Resident is to receive treatment as follows:

☐ COMFORT MEASURES ONLY

The Resident will remain at the Home. Care will consist of nursing care. Relief of pain, oral fluids, control of fever (if present) and management of any other symptoms will be provided. No cardiopulmonary resuscitation (CPR) will be administered to the Resident.

☐ COMFORT MEASURES WITH ADDITIONAL TREATMENT AVAILABLE AT THE HOME

In addition to the above, the Resident will receive medications (most frequently antibiotics). No intravenous treatment is available. No cardiopulmonary resuscitation (CPR) will be administered to the Resident.

☐ TRANSFER TO ACUTE CARE HOSPITAL WITHOUT CARDIOPULMONARY RESUSCITATION

The Resident will be transferred to an acute care hospital. The physician at the Home may admit the Resident into hospital or consult with a specialist at the hospital who will then decide whether to admit the Resident or return the Resident to the Home. No cardiopulmonary resuscitation (CPR) will be administered to the Resident. The Resident will not be admitted into an intensive care unit.

☐ TRANSFER TO ACUTE CARE HOSPITAL WITH CARDIOPULMONARY RESUSCITATION

The Resident will be transferred to an acute care hospital. Cardiopulmonary resuscitation (CPR) will be administered to the Resident, if necessary. The Resident will be admitted into an intensive care unit, if necessary. The Hospital will have the final decision over the Resident's admission into an intensive care unit.

How would you respond?

- Tell the nurse to transfer her and to notify her family, send a copy of Level of Care form so they don’t start CPR at the hospital
- You will come yourself to see her as soon as you can
- Ask for name and phone number of her “Next of kin” and call that person for advice

Transitioning from Levels of Care to Goals of Care- Why?

- Currently in Ontario many long term care homes do use “Advance Directives” or “Level of Care “ forms in which residents or their families are asked to decide in advance about transfer to hospital and CPR for a future medical problem.
- Using these forms to direct treatment is not consistent with the the laws of Ontario, and may not result in the resident getting the treatment they would want
- There are alternatives that will help us- using forms that are easy to find and download

What are those laws?

- **Ontario Substitute Decisions Act, 1992**
- **The Health Care Consent Act 1996**

Health Care Consent in Ontario

In Ontario, the law requires all health care providers to get informed consent, or refusal of consent, before providing a patient with any treatment or care

1. Informed consent requires that prior to treatment we must explain the benefits, risks, side effects, and alternatives to a treatment or proposed plan
2. Consent must come from a mentally capable person- so not from a document.
3. Consent is based on treatment for the current condition, not a future one

This is why consent or withdrawal of consent can NOT come from a document such as a “Living will”, “Advance Directive”, or “Directions” or “Level of Care” form.

Level of Care forms

- So what are those of us who work in those homes that use them supposed to do?

- Let’s look at the details of the laws………….

Who is "mentally capable"?

For decisions about medical treatment, the law assumes you are mentally capable of giving consent, unless there is reasonable evidence otherwise.

Being capable depends on the question being asked. I might not be able to understand medical details of my illness or treatments that the doctor is describing, but I might be perfectly capable of deciding which person in my family I want to have with me or what I want for lunch or what I want to wear. Being capable **depends on the question being asked**. Being capable of a decision can change depending on the time of day.

Who decides if I am mentally capable? That is done by the health care provider who is asking for your consent.

That's the staff and that's YOU!

Really? How?

How is that decided?

Ontario law defines capacity for medical decisions as:

~Having the ability to **understand information** that has to do with making a decision about treatment, admission, or personal assistance service;

and

~Having the ability to **appreciate the likely consequences** of a decision.

If a resident is mentally incapable for any particular health decision, then the physician or health care provider will turn to someone else to make those health decisions. That person is called a Substitute Decision Maker, or SDM

You need two mental abilities

- Being mentally capable means that for this decision you need to make now, you must have the ability to BOTH:
-
- 1. **Understand the information** you are given about the decision to be made:
- Why is the treatment being recommended?
- What does it involve?
- Are there any other options?
- **AND**
- 2. **Understand the consequences** of that decision what could happen if you say Yes or No to the treatment:
- What are the benefits of saying Yes or No?
- How might it help or harm you?
- What will likely happen if you have it (or decide not to)?

How is that decided?

You do this all the time.

For example, when a hockey player comes to the ER with a knee injury diagnosed as a medial collateral ligament strain, and is fitted for a knee brace, he has many questions :

- Can’t you just operate to fix it?
- How long will I need to wear this brace?
- When should I start physiotherapy?
- Will I have to be off school?
- When can I play hockey again?

His questions tell us he **understands the information** about the treatment and **appreciates the consequences**. He is therefore capable of giving informed consent for his treatment

Determining Mental Capacity

- Back at the nursing home the nurse knows from previous contact with her that Sadie does not have the ability to understand her situation. She tells Sadie she has choked on some food and asks Sadie how she is doing. Sadie grunts and gasps and is hardly able to speak. "I want my mother… Help me," she whispers. Her face displays confusion and worry. The nurse determines that Sadie clearly is not able to **understand the information** she is being given and nor is she able to appreciate the likely **consequences of any treatment decision.**

- **For this decision she is not capable of giving informed consent**. For this decision we need to turn- not to a document signed 3 years ago- but to another person. That person is her Substitute Decision Maker, or SDM

Substitute Decision Makers

- How do we determine who is legally authorized to speak for Sadie?

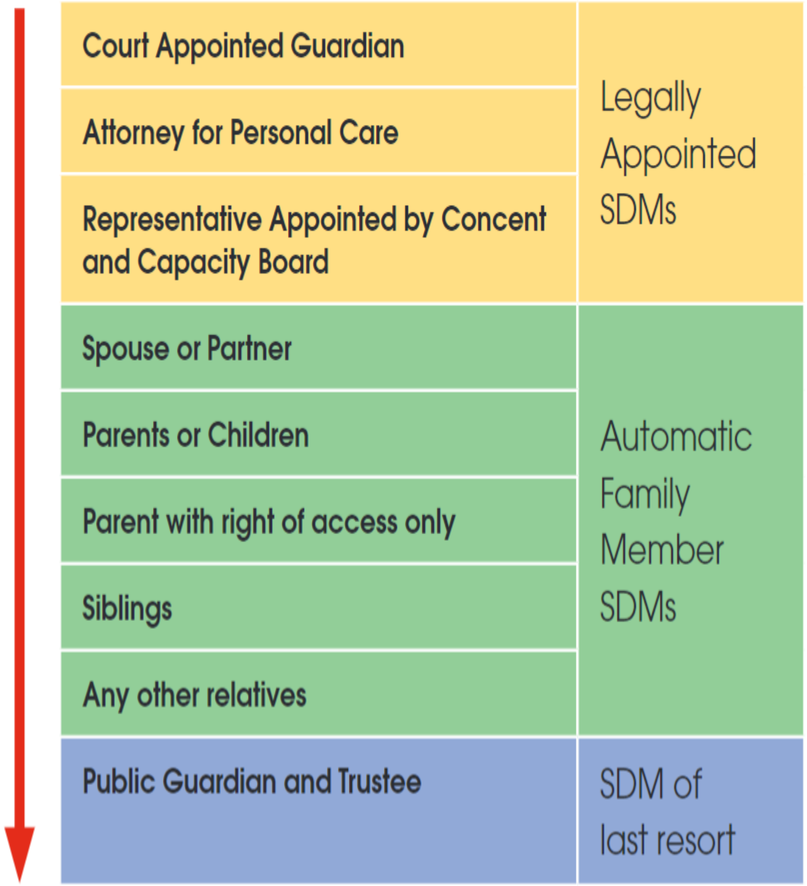
The SDM Hierarchy

- **The Health Care Consent Act** provides a ranked listing (hierarchy) of possible SDMs. They are authorized by law.

- Sadie’s SDM(s) will be the person or persons highest ranked on this list who meet the criteria to be an SDM

SDM Hierarchy

By default, your SDM(s) will be the person or people highest ranked on the hierarchy who meet the criteria to be an SDM



Court Appointed Guardian	Legally Appointed SDMs
Attorney for Personal Care	
Representative Appointed by Concent and Capacity Board	
Spouse or Partner	Automatic Family Member SDMs
Parents or Children	
Parent with right of access only	
Siblings	
Any other relatives	
Public Guardian and Trustee	SDM of last resort

Ontario's Health Care Consent Act, 1996

Legal Requirements to be a Substitute Decision Maker (incl POA)

- Willing to act as SDM
- Have the mental ability to understand the treatment/care being proposed and appreciate the consequences of consenting to or refusing the treatment options.
- Be at least 16 years old (unless you are the parent of the incapable person)
- Not prohibited by court order or separation agreement from acting as SDM
- Available in person, by phone or via electronic communication (email, text)

What if more than one person is entitled to act as the SDM?

- If there are two or more persons (for example two daughters and one son) described in the same subsection of the above hierarchy, and who meet the requirements to be an SDM, they are all equally ranked, and **they** must make decisions together (jointly) and agree, or decide among themselves which one will act as the SDM by **designating a spokesperson.** They must decide the spokesperson amongst themselves- the healthcare provider cannot decide this.

- But…what if they don’t agree?

What if they don’t agree?

- If there is a disagreement among equally ranked decision-makers that cannot be resolved, the Office of the Public Guardian and Trustee may be asked to make the decision.
- Alternatively, the dispute may be referred to the Consent and Capacity Board
- Some family members may say they are no longer willing to act.

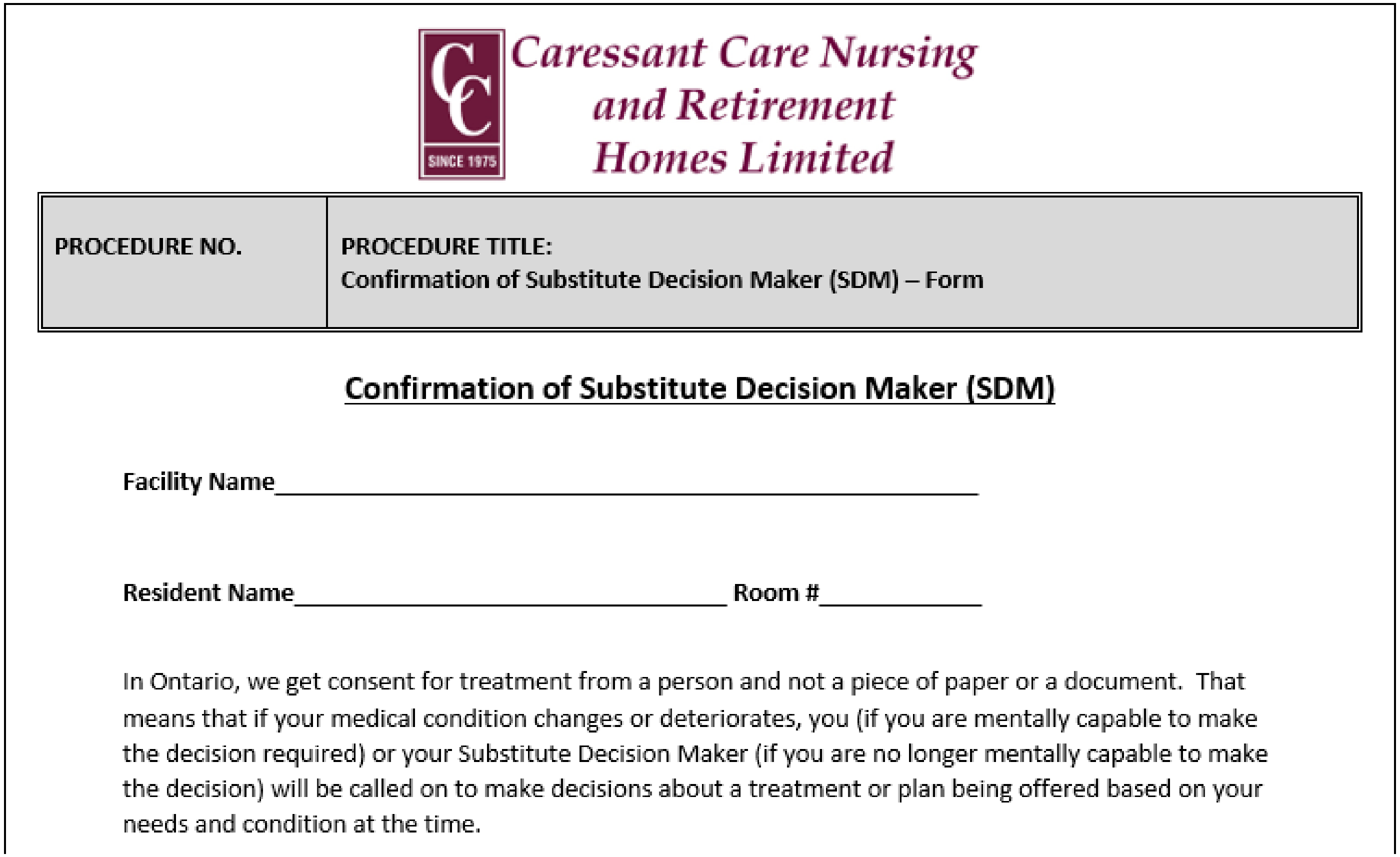
How can I get this information?

- Working with Caressant Care, we have developed forms that have been specially written for long term care homes.
  These forms summarize very simply what is in these laws

- You can find them here: https://www.pcdm.ca/quick-links/resources

~Scroll down to the Long-Term Care section.

Page 1- Confirmation of SDM Form



Caressant Care Nursing and Retirement Homes Limited

SINCE 1975

PROCEDURE NO.	**PROCEDURE TITLE:** **Confirmation of Substitute Decision Maker (SDM) – Form**

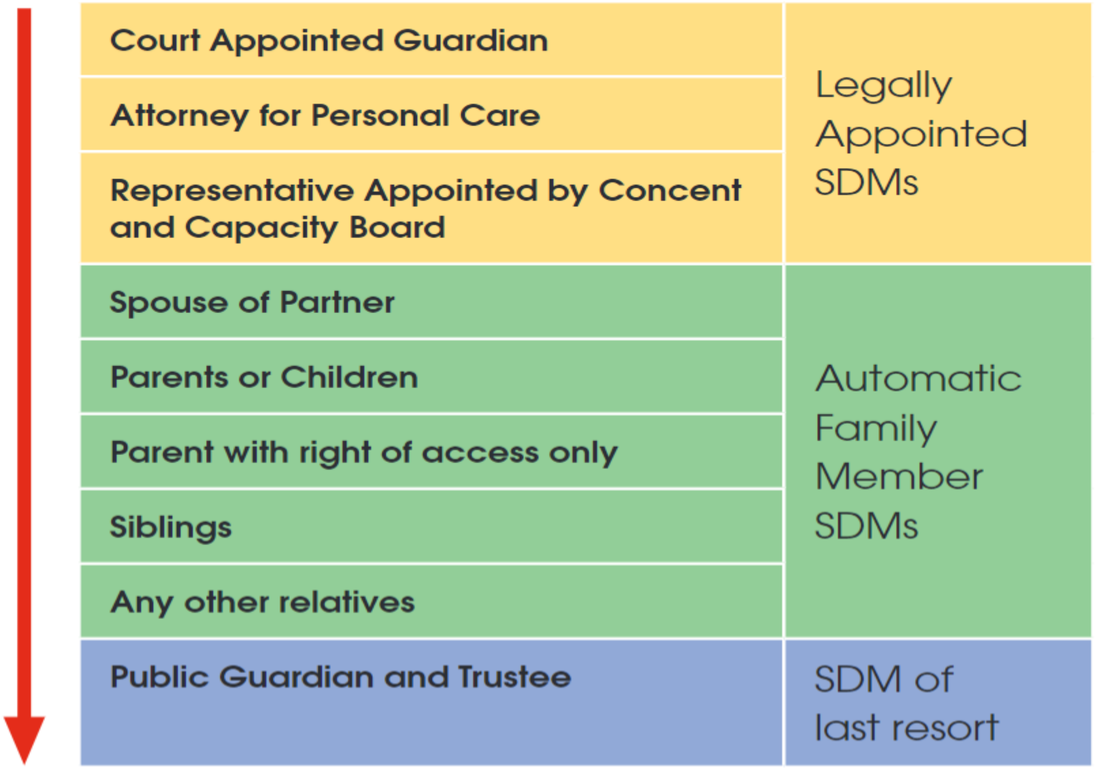
Confirmation of Substitute Decision Maker (SDM)

Facility Name____

Resident Name____________________________ **Room #**__________

In Ontario, we get consent for treatment from a person and not a piece of paper or a document. That means that if your medical condition changes or deteriorates, you (if you are mentally capable to make the decision required) or your Substitute Decision Maker (if you are no longer mentally capable to make the decision) will be called on to make decisions about a treatment or plan being offered based on your needs and condition at the time.

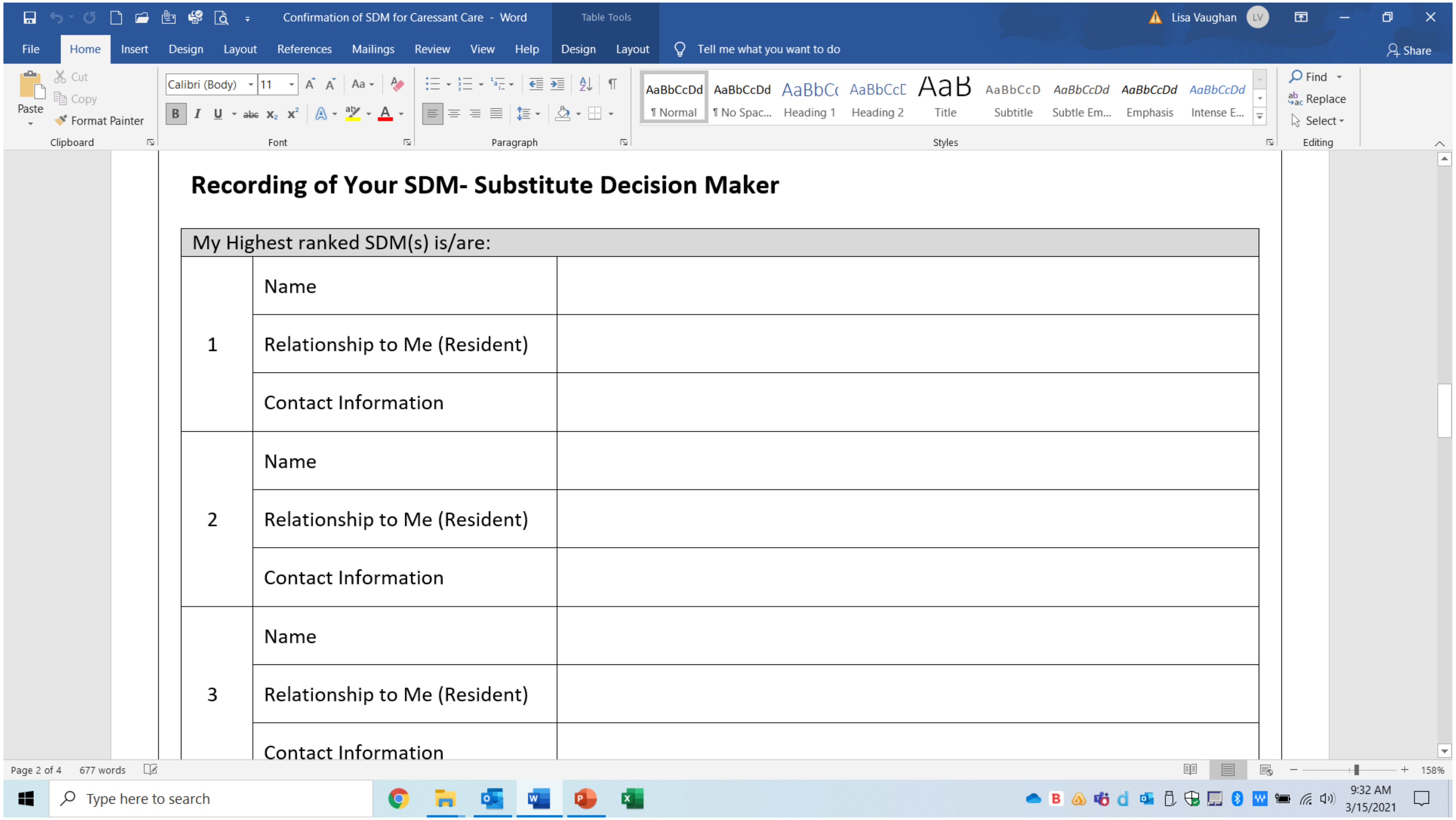
Page 2- **Confirmation of Substitute Decision Maker (SDM)**



Court Appointed Guardian	Legally Appointed SDMs
Attorney for Personal Care	
Representative Appointed by Concent and Capacity Board	
Spouse of Partner	Automatic Family Member SDMs
Parents or Children	
Parent with right of access only	
Siblings	
Any other relatives	
Public Guardian and Trustee	SDM of last resort

Ontario's Health Care Consent Act, 1996

Page 3- Recording of Your SDM- Substitute Decision Maker



Recording of Your SDM- Substitute Decision Maker

My Highest ranked SDM(s) is/are:		
1	Name	
	Relationship to Me (Resident)	
	Contact Information	
2	Name	
	Relationship to Me (Resident)	
	Contact Information	
3	Name	
	Relationship to Me (Resident)	
	Contact Information	

Back to Sadie- using the new forms

- The Nurse checks the form on the chart to see who is correct SDM
- Finds Sadie is a widow with 4 children, one has POA for personal care, another has POA for finances
- Staff call the daughter who is POA for personal care, explains her mother's situation and options for care. Her daughter clearly understands.
- We now are able to get informed consent for Sadie's current situation from a capable person, not from a document, and we know it is the correct SDM

Consent for Sadie

- The nurse explains to Sadie’s daughter her current state, and says she is wondering about sending her to the hospital. Daughter responds by mentioning a prior admission to hospital several months ago that resulted in delirium, the use of restraints, bedsores that ulcerated, and further cognitive decline. She can’t forget hearing her screams.
- Daughter mentions having a previous conversation with the doctor around Goals of Care

What are Goals of Care (GoC) Discussions?

- These discussions are focused on exploring the resident’s and SDM’s understanding of the resident’s illness, the resident’s personal and clinical goals, and prepares the resident and SDM for decision-making.
- The information from these conversations are used for the next discussion about treatment options and to obtain consent.

Elements of a person-centered goals of care (GoC) discussion

- Asking permission to engage in a GoC conversation
- Assessment of the Resident's/SDM(s) understanding of their illness/conditions (diagnosis) and prognosis
- With the permission of the patient, providing information about the trajectory and prognosis for this condition, and what to expect in the future
- Understanding the Resident's values, beliefs, and personal and clinical goals.
- Discussions and information sharing around the available treatment options; and which of them would meet the care goals identified by the Resident
- Developing a plan of treatment that would support the goals of the resident.
- Recognition and respect that the articulation of goals may take some time and thought, and will change with time.
- An understanding that goals can be revisited at any time and especially with a change in health status and may require input from other team members or specialists

How do I have such a discussion?

- A conversation guide has been developed and can be found on the same web site just below the form for identifying the correct SDM

- You can find them here: https://www.pcdm.ca/quick-links/resources

- Scroll down to the Long-Term Care section.

Back to Sadie

- Her daughter explains that during a previous Goals of Care conversation, she and her siblings had learned about the trajectory of their mother's dementia. They had talked about what was important to their Mom- celebrating events and milestones with family, gardening, baking treats, sewing for grandchildren, reading novels. She could not do any of that now. She doesn't recognize her grandchildren anymore. She had suffered a lot the last time she went to hospital.

Sadie's Goals of Care

- Her children had all agreed that the best goal for her now was to minimize her suffering, not living longer- they knew she would not want that if she was able to speak for herself

- The daughter, who has Power of Attorney for Personal Care, said that for this situation her Mom was in now, she would not want her to go to the hospital- Could they ask the doctor what the options were for keeping her comfortable at the nursing home and have the doctor call her with a plan for her mother?

Goals of Care Discussions

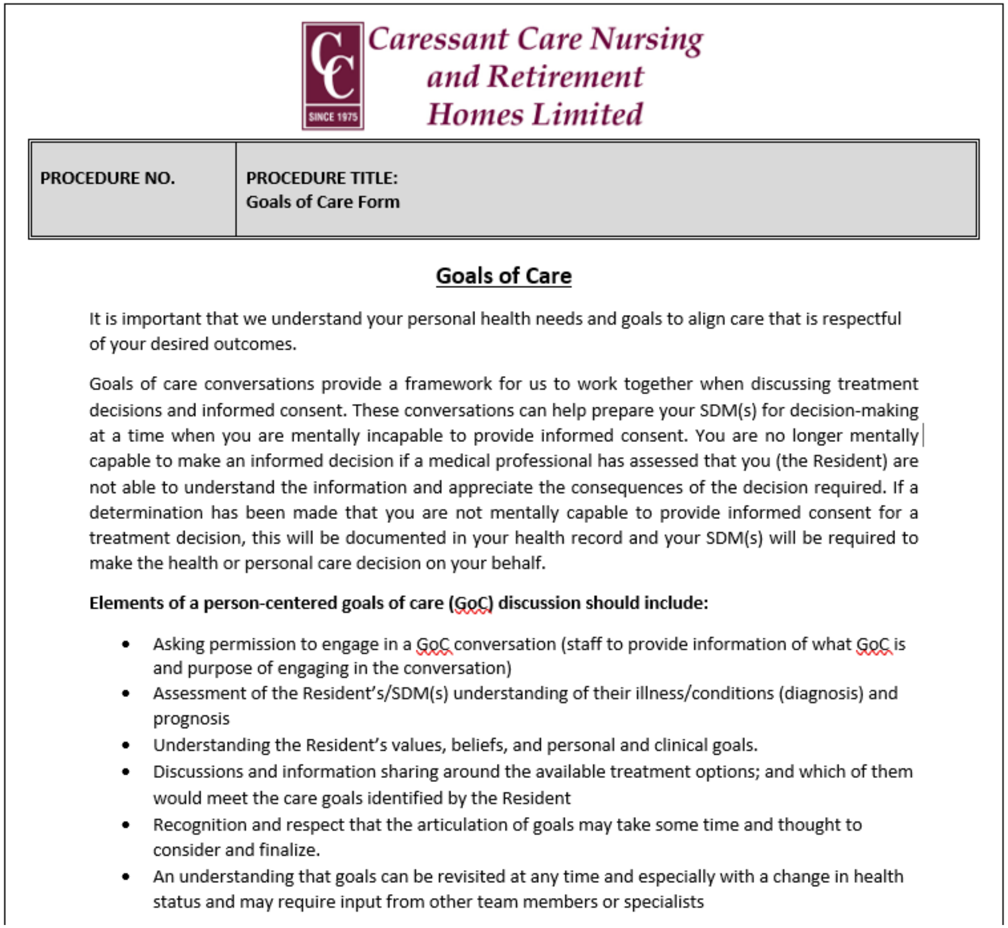
For health care staff: There are four components to document:

1. Illness understanding of resident/SDM
2. Information given about this illness
3. Goals/values of the resident
4. Treatment recommendations and consent for a Plan of Treatment

- Admission forms for long term care

https://www.pcdm.ca/quick-links/resources scroll down to LTC section

Page 1- Goals of Care Form



Caressant Care Nursing and Retirement Homes Limited

SINCE 1975

PROCEDURE NO.	**PROCEDURE TITLE:** Goals of Care Form

Goals of Care

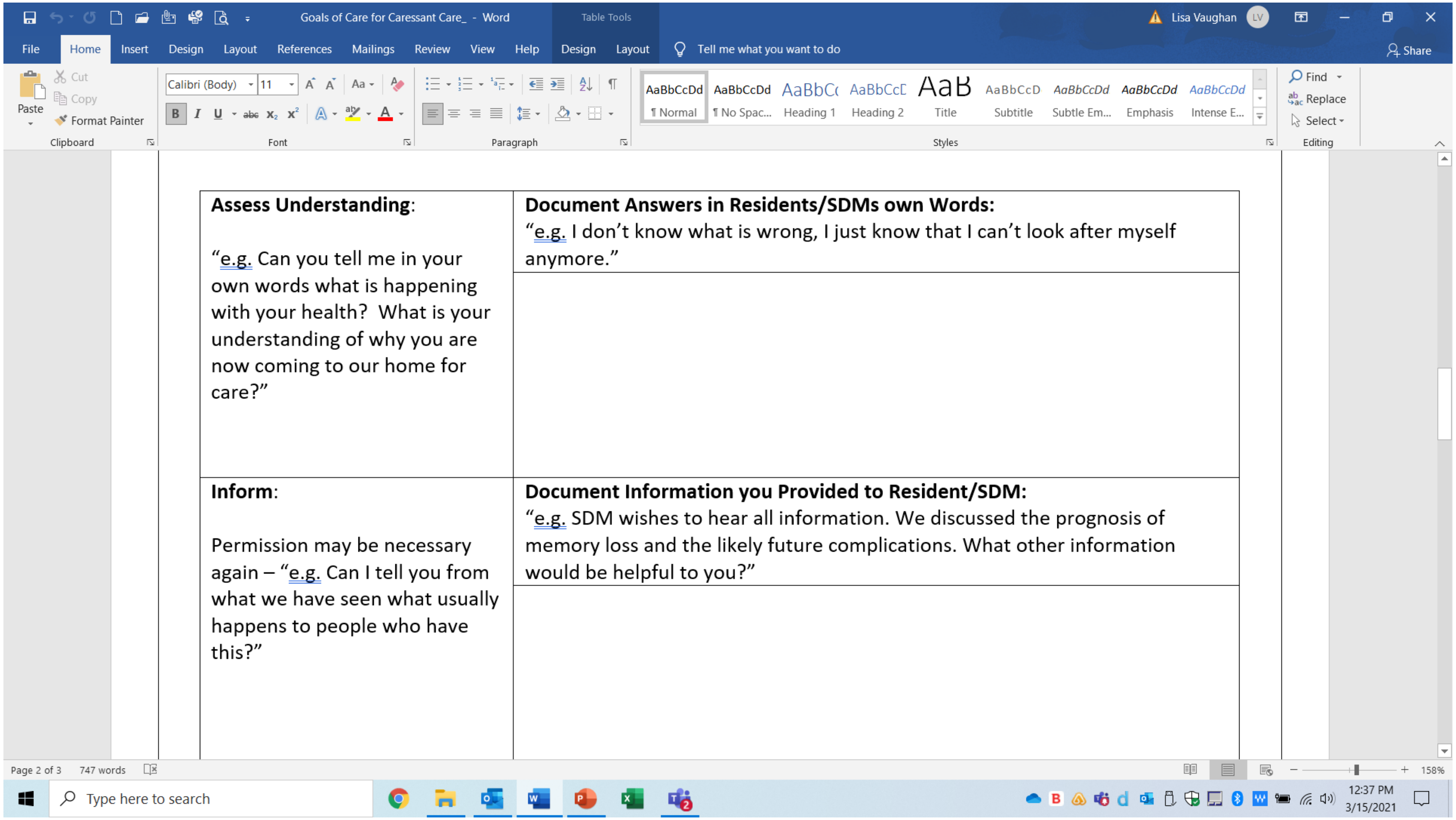
It is important that we understand your personal health needs and goals to align care that is respectful of your desired outcomes.

Goals of care conversations provide a framework for us to work together when discussing treatment decisions and informed consent. These conversations can help prepare your SDM(s) for decision-making at a time when you are mentally incapable to provide informed consent. You are no longer mentally capable to make an informed decision if a medical professional has assessed that you (the Resident) are not able to understand the information and appreciate the consequences of the decision required. If a determination has been made that you are not mentally capable to provide informed consent for a treatment decision, this will be documented in your health record and your SDM(s) will be required to make the health or personal care decision on your behalf.

Elements of a person-centered goals of care (GoC) discussion should include:

- Asking permission to engage in a GoC conversation (staff to provide information of what GoC is and purpose of engaging in the conversation)
- Assessment of the Resident's/SDM(s) understanding of their illness/conditions (diagnosis) and prognosis
- Understanding the Resident's values, beliefs, and personal and clinical goals.
- Discussions and information sharing around the available treatment options; and which of them would meet the care goals identified by the Resident
- Recognition and respect that the articulation of goals may take some time and thought to consider and finalize.
- An understanding that goals can be revisited at any time and especially with a change in health status and may require input from other team members or specialists

Page 2- Goals of Care Form



Assess Understanding: “e.g. Can you tell me in your own words what is happening with your health? What is your understanding of why you are now coming to our home for care?”	**Document Answers in Residents/SDMs own Words:** “e.g. I don’t know what is wrong, I just know that I can’t look after myself anymore.”
Inform: Permission may be necessary again – “e.g. Can I tell you from what we have seen what usually happens to people who have this?”	**Document Information you Provided to Resident/SDM:** “e.g. SDM wishes to hear all information. We discussed the prognosis of memory loss and the likely future complications. What other information would be helpful to you?”

The New Forms Now:

- Ensure consent is compliant with Ontario laws, and in doing so are simply more respectful of the wishes of the resident and their SDM's
- Facilitate discussions to prepare the resident and SDM for decision-making.
- Encourage that the decisions about health care treatment are aligned with the goals of the resident

Transitioning from Levels of Care to Goals of Care

- These documents have been reviewed and edited by HPCO legal experts to ensure they meet their standards.
- The documents have been vetted through the legal department of Caressant Care and have been approved for use
- These documents are available for anyone to download, copy, modify, and use.
- Go to pcdm.ca web site and under resources, scroll down to the LTC section

What to do with Advance Directives & Levels of Care Forms

- **Levels of Care forms and Advance Directives are** for the future- In Ontario they can be used as wishes, but not for consent, and should not be used to direct care. They could be used by the SDM to guide them in decisions about the treatments for which they would give consent.
- Consent for treatment for a current condition comes from the patient or the SDM, not a document.

- **Goals of Care** are to be used by staff to develop a plan of treatment that aligns with patient's goals
- Transfer to hospital decisions are part of the treatment plan for the current condition, and a previous decision would not necessarily apply to a new medical problem (e.g. Sadie)

Legally correct forms for LTC

For any home interested in moving from using Advance Directives to identifying the correct SDM and using Goals of Care:

https://www.pcdm.ca/quick-links/resources

Scroll down to Resources for Long Term Care

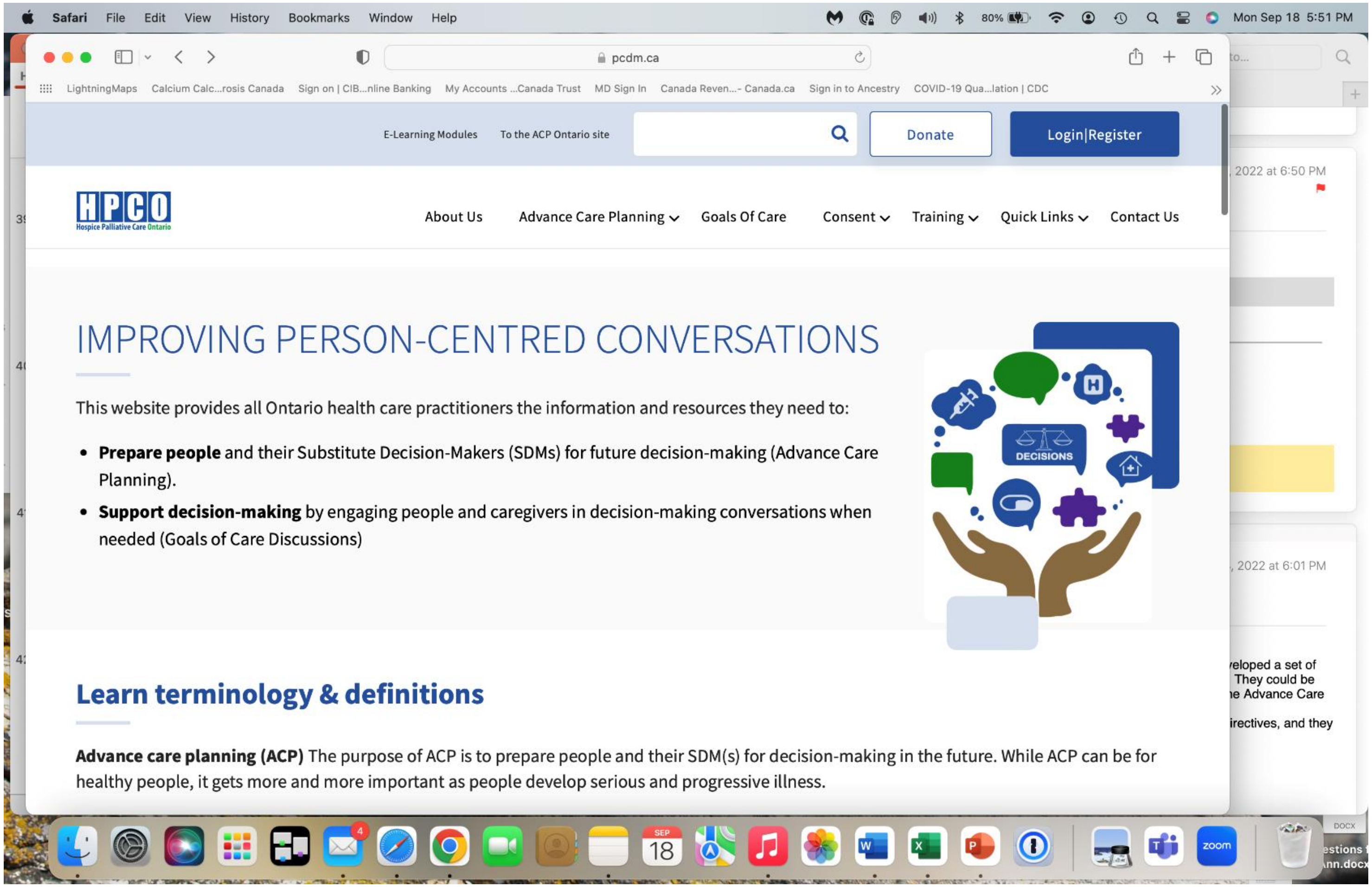
For more information on the problems with Level of Care forms

https://www.pcdm.ca/acp/clinician-primer/level-of-care-forms

For Long Term Care (LTC) ACP Education Modules :

Learning Modules Waterloo/Wellington

pcdm.ca



IMPROVING PERSON-CENTRED CONVERSATIONS

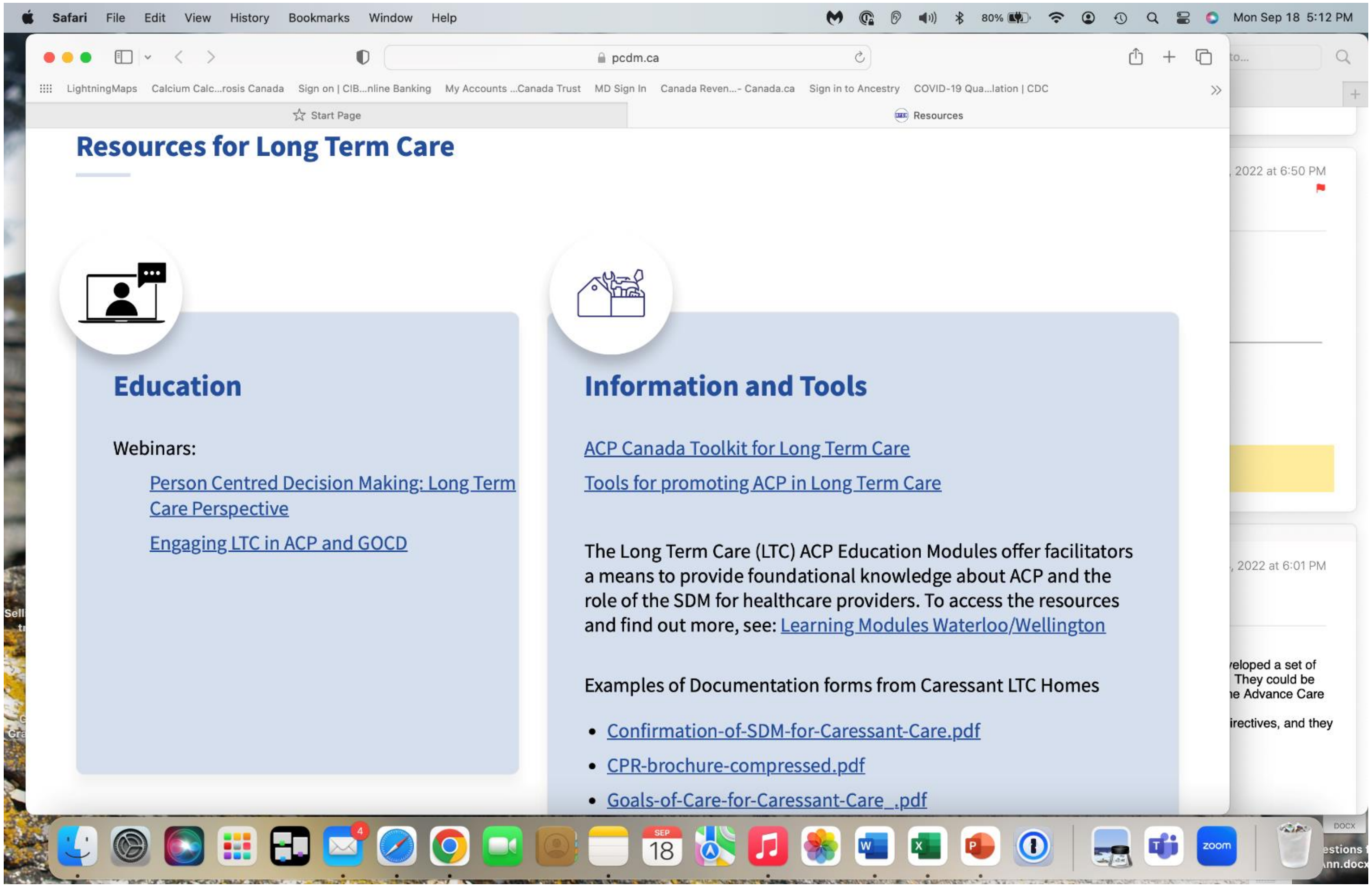
This website provides all Ontario health care practitioners the information and resources they need to:

- **Prepare people** and their Substitute Decision-Makers (SDMs) for future decision-making (Advance Care Planning).
- **Support decision-making** by engaging people and caregivers in decision-making conversations when needed (Goals of Care Discussions)

Learn terminology & definitions

Advance care planning (ACP) The purpose of ACP is to prepare people and their SDM(s) for decision-making in the future. While ACP can be for healthy people, it gets more and more important as people develop serious and progressive illness.

Resources for Implementation page



Resources for Long Term Care

Education

Webinars:

- Person Centred Decision Making: Long Term Care Perspective
- Engaging LTC in ACP and GOCD

Information and Tools

ACP Canada Toolkit for Long Term Care

Tools for promoting ACP in Long Term Care

The Long Term Care (LTC) ACP Education Modules offer facilitators a means to provide foundational knowledge about ACP and the role of the SDM for healthcare providers. To access the resources and find out more, see: Learning Modules Waterloo/Wellington

Examples of Documentation forms from Caressant LTC Homes

- Confirmation-of-SDM-for-Caressant-Care.pdf
- CPR-brochure-compressed.pdf
- Goals-of-Care-for-Caressant-Care_.pdf

Acknowledgments

For Advance Care Planning, laws about health care consent and substituted decision making-

Thanks to:

- Ontario law (Health Care Consent Act 1966 and Substitute Decisions Act 1992)
- the Hospice Palliative Care Ontario Health Care Consent and Advance Care Planning working group

For Advance Care Planning conversation guide, Goals of Care and Serious Illness Conversations-

Thanks to:

- Dr. Nadia Incardona, Dr. Leah Steinberg, Dr. Jeff Myers
- Ariadne Labs, Harvard Medical School
- Vital Talk

- For sharing forms for implementation, thanks to Caressant Care

Thank you!

Questions?

Comments?

Stories?

Legally correct forms for LTC

For any home interested in moving from using Advance Directives to identifying the correct SDM and using Goals of Care:

https://www.pcdm.ca/quick-links/resources

Scroll down to Resources for Long Term Care

For more information on the problems with Level of Care forms

https://www.pcdm.ca/acp/clinician-primer/level-of-care-forms

For Long Term Care (LTC) ACP Education Modules :

Learning Modules Waterloo/Wellington