Serious Illness Care:
More, Earlier, Better Conversations

Department *of* Medicine

Faculty/Presenter Disclosure

- **Faculty:** Dr. Daniel Kobewka

- **Relationships with financial sponsors:**
  - **Grants/Research Support:** CIHR (principal investigator)
  - **Speakers Bureau/Honoraria:** OLTCC
  - **Consulting Fees:** N/A
  - **Patents**: N/A
  - **Other:**

Disclosure of Financial Support

- **This program has received financial support from** OLTCC **in the form of** speaker's honorarium
- **This program has received in-kind support from** OLTCC **in the form of** logistical support

- **Potential for conflict(s) of interest:**
  - Daniel Kobewka has no identified conflict of interest.

Faculty/Presenter Disclosure

- **Faculty:** Dr. Celeste Fung
- **Relationships with financial sponsors:**
  - **Grants/Research Support:** CIHR (collaborator); eCampus Ontario (content expert)
  - **Speakers Bureau/Honoraria:** OLTCC
  - **Consulting Fees:** N/A
  - **Patents**: N/A
  - **Other:** Medical Director of St. Patrick's Home; receives a half-day salary support, as the Long-Term Care Lead for the Ontario eConsult Centre of Excellence.

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  - Celesste Fung has no identified conflict of interest.

Mitigating Potential Bias

- The presentation is based on the speaker's personal views and experience
- The objective of the presentation is to support LTC clinicians in Goals of Care Conversations

Objectives

1.Describe the Serious illness conversation program and evidence of benefit for residents.

2. Learn to use the Conversation guide by observing facilitators using the guide.

3. Discuss real world barriers and successes when implementation of the serious illness conversation program in one LTC home

Reflection Exercise

Turn to your neighbour and share a story about a recent experience with a patient with serious illness (or a personal experience) in which a ***conversation*** *about goals of care, or lack thereof, had a positive or negative impact on the patient and/or family.*

What were the aspects of communication that made things either go well or go poorly?

Challenges as LTC Evolves

- Residents are older, more frail and LOS reduced and relationships are shorter
- Often admission is preceded by a period of extreme stress for both resident and caregivers
- Moral distress associated with interventions that did not appear to align with quality of life
- Uncertain benefit to problem-based review at care conference – a missed opportunity
- Disconnect when discussing available treatments vs. recommended treatment

How Do We Define “Serious Illness”

A condition that:

- Carries a high risk of death over the course of a year
- Has a strong negative impact on QOL and functioning in life roles
- Is highly burdensome to a person and his/her family

Kelley, AS Jrl Pall Med 2014

What is a serious illness conversation?

- A Serious Illness Conversation is a clinician-initiated discussion that:
  - Asks patients about values and goals using a structured format
  - Shares prognosis, *when* appropriate
  - De-emphasizes treatments and procedures
  - Occurs early in the course of a serious illness
  - Provides a foundation for making decisions in the future
  - Should be reviewed/revisited over time
  - Is valuable and therapeutic even if medical decisions are not being made

What isn’t a serious illness conversation?

- A Serious Illness Conversation is **not**...
  - A conversation solely focused on medical decisions
  - A code status conversation

BUT

  - Can be used to inform medical decisions and care planning, *when* appropriate
  - Are valuable even if a patient is already DNR/No CPR
  - Can and should come before a "levels of intervention" or code status conversation
  - Can be used even if a patient has a code status as a way of revisiting values, goals, and decisions

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Aggressive care for patients with advanced illness is often harmful:

- For patients:
  - Lower quality of life
  - Greater physical and psychological distress

  Wright, AA JAMA 2008; Mack JCO 2010

- For caregivers:
  - More major depression
  - Lower satisfaction

  Wright, AA JAMA 2008; Teno JM JAMA 2004

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Many patients do not discuss their goals with clinicians

- Fewer than one third of patients with end-stage medical diagnoses discussed EOL preferences with physicians

- Conversations often fail to address key elements of quality discussions

Heyland DK Open Med 2009; Mack AIM 2012; Wright 2008

Early conversations about goals of care benefit patients & families

- **Are associated with**:
  - Enhanced goal-concordant care
  - Improved quality of life
  - Higher patient satisfaction
  - Better patient and family coping
  - Eased burden of decision-making for families
  - More and earlier hospice care
  - Fewer hospitalizations
  - Improved bereavement outcomes

Mack JCO 2010; Wright JAMA 2008; Chiarchiaro AATS 2015; Detering BMJ 2010; Zhang Annals 2009; Temel JCO 2017

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VOLUME 30 · NUMBER 22 · AUGUST 1 2012

JOURNAL OF CLINICAL ONCOLOGY

COMMENTS AND CONTROVERSIES

Reasons Why Physicians Do Not Have Discussions About Poor Prognosis, Why It Matters, and What Can Be Improved

Jennifer W. Mack, *Dana-Farber Cancer Institute and Children's Hospital, Boston, MA*
Thomas J. Smith, *Johns Hopkins Medical Institutions, Baltimore, MD*

- Makes people depressed
- Will take away hope
- Will shorten survival
- We don't really know the patient's prognosis
- We don't like having these discussions

JAMA Internal Medicine | Original Investigation

Effect of the Serious Illness Care Program in Outpatient Oncology

A Cluster Randomized Clinical Trial

Rachelle Bernacki, MD, MS; Joanna Paladino, MD; Bridget A. Neville, MPH; Mathilde Hutchings, MPH; Jane Kavanagh, BA; Olaf P. Geerse, BSc; Joshua Lakin, MD; Justin J. Sanders, MD, MSc; Kate Miller, PhD; Stuart Lipsitz, ScD; Atul A. Gawande, MD, MPH; Susan D. Block, MD

JAMA Oncology | Original Investigation

Evaluating an Intervention to Improve Communication Between Oncology Clinicians and Patients With Life-Limiting Cancer

A Cluster Randomized Clinical Trial of the Serious Illness Care Program

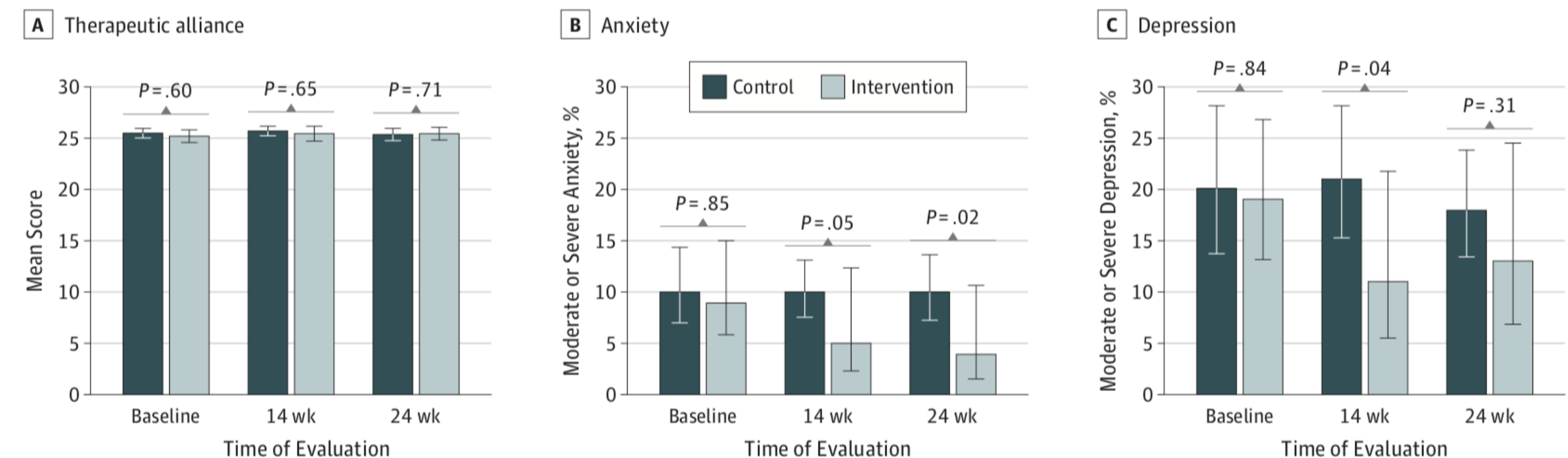
Joanna Paladino, MD; Rachelle Bernacki, MD, MS; Bridget A. Neville, MPH; Jane Kavanagh, BA; Stephen P. Miranda, MD; Marissa Palmor, BS, MBE; Joshua Lakin, MD; Meghna Desai, MPH; Daniela Lamas, MD; Justin J. Sanders, MD, MSc; Jonathon Gass, MPH; Natalie Henrich, PhD, MPH; Stuart Lipsitz, ScD; Erik Fromme, MD; Atul A. Gawande, MD, MPH; Susan D. Block, MD

Outcome	Intervention (n=76)	Control (n=85)
Patients with at least 1 documented SIC, No. (%)	73 (96)	68 (89)
Patients with documentation of a discussion about values or goals, No. (%)	67 (79)	37 (44)
Patients with documentation of a discussion about prognosis or illness understanding, No (%)	69 (91)	41 (48)
Patients with documentation of a discussion about end-of-life care planning, No. (%)	61 (80)	58 (68)
Patients with documentation of a discussion about life-sustaining treatment preferences,	48 (63)	27 (32)
Timing of first documented serious illness conversation before death, median (IQR) days	143 days (71-325)	71 days (33-166)
Documented serious illness conversations per patient	3.1 (2.5-3.6)	2.1 (1.4-2.8)

Table 3. Achievement of Goal-Concordant Care and Peacefulness Near the End of Life

Outcome	Intervention Arm No.	Intervention Arm Mean (95% CI)	Intervention Arm Median (95% CI)	Control Arm No.	Control Arm Mean (95% CI)	Control Arm Median (95% CI)	Differences (95% CI)[a]
Goal-concordant care[b]							
No. of goals met	38	1.4 (1.0 to 1.7)	0.8 (0.6 to 1.1)	26	1.5 (1.0 to 2.1)	1.2 (0.3 to 2.1)	Median, −0.4 (−1.5 to 0.7)
Sensitivity analysis	29	1.3 (1.0 to 1.6)	0.8 (0.5 to 1.1)	17	1.5 (0.9 to 2.2)	1.2 (0.1 to 2.3)	Median, −0.3 (−1.2 to 0.6)
PEACE							
PA scale	47	16.9 (16.1 to 17.6)	NA	47	16.8 (15.9 to 17.6)	NA	Mean, 0.1 (−1.0 to 1.2)
SI scale	44	14.0 (12.9 to 15.1)	NA	42	14.4 (12.7 to 16.0)	NA	Mean, −0.3 (−2.2 to 1.5)

Figure 2. Outcomes of Assessments of Therapeutic Alliance, Anxiety, and Depression



What do checklists or guides do?

- Bridge gap between evidence & “real world” implementation
- Assure adherence to key processes
- Achieve higher level of baseline performance
- Ensure completion of necessary tasks during complex, stressful situations

Also:

- Reduce clinician anxiety
- More content and focus
- Better listening

Serious Illness Conversation Guide for the Substitute Decision Maker

https://www.fraserhealth.ca/employees/clinical-resources/advance-care-planning/serious-illness#.Y0I1-HbMLIU

SERIOUS ILLNESS CONVERSATION GUIDE

SUBSTITUTE DECISION-MAKERS
A CONVERSATION TOOL FOR CLINICIANS

CONVERSATION FLOW	PATIENT-TESTED LANGUAGE
1. Set up the conversation • Introduce ideas and benefits • Prepare of future decisions • Ask permission	"I'd like to talk about what is ahead with your ______'s illness and do some thinking in advance about what is important to him/her so that I can make sure we provide him/her with the care that they'd want - **is that okay?"**
2. Explore prior advance care planning conversations and documentation	"How much has your ______ discussed with you about about his/her priorities and wishes, especially about his/her health and illness?" "Does he/she have any previous advance care planning documents?"
3. Assess illness understanding and information preferences	"What is your current **understanding** of your ______'s illness now and how it might change over time?" "How much **information** about what is likely to be ahead with your ______'s illness would you like from me?"
4. Share prognosis and medical information • Tailor information to expressed preferences • Allow silence, explore emotions • Provide a warning: "I have some bad news.", or "The news is not good." • Frame as "wish..., worry..."	"I want to share with you **my understanding** of where things are with your ______'s illness..." *Uncertain:* "It can be difficult to predict what will happen with your ______'s illness. I **hope** he/she will continue to live well for a long time but I'm **worried** that he/she could get sick quickly, and I think it is important to prepare for that possibility." **OR** *Time:* "I wish we were not in this situation, but I am **worried** that time may be as short as ____ *express as a range, eg. days to weeks, weeks to months, months to a year)*" ***OR*** *Function:* "I **hope** that this is not the case, but I'm **worried** that this may be as strong as your ______ will feel and things are likely to get more difficult.
5. Explore key topics • Goals • Fears • Strengths • Functions • Trade-offs	"What would your ______ say would be his/her most important **goals** if/when his/her health worsens? "What would your ______ say are his/her **biggest fears and worries** about his/her health?" "What gives your ______ and you **strength** as you think about the future and your ______'s illness?". "What do you think your ______ would say are **abilities** that are so critical to him/her that he/she couldn't imagine living without them?" "If your ______ becomes sicker, how much would he/she say he/she would be **willing to go through** for the possibility of gaining more time?
6. Close the conversation • Summarize what you've heard • Make a recommendation • Check for alignment • Affirm commitment	"It sounds like ______ (sumarize goals and fears) is very important to your ______." "Given your ______'s goals and priorities and what we know about his/her illness at this stage, I **recommend**.... "How does this plan seem to you?" **"We're in this together."**
7. Document your conversation on the ACP record	
8. Communicate with key clinicians	

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Serious Illness Conversation Guide

Updated – Version 3

Organized as 2 parts: Checklist & Language

Serious Illness Conversation Guide

CONVERSATION FLOW	PATIENT-TESTED LANGUAGE
1. ***Set up the conversation*** · Introduce purpose · Prepare for future decisions · Ask permission	"I'd like to talk about what is ahead with your illness and do some thinking in advance about what is important to you so that I can make sure we provide you with the care you want — **is this okay?**"
2. ***Assess understanding and preferences***	"What is your **understanding** now of where you are with your illness?" "How much **information** about what is likely to be ahead with your illness would you like from me?"
3. ***Share prognosis*** · Share prognosis · Frame as a "wish…worry", "hope…worry" statement · Allow silence, explore emotion	"I want to share with you **my understanding** of where things are with your illness…" *Uncertain:* "It can be difficult to predict what will happen with your illness. I **hope** you will continue to live well for a long time but I'm **worried** that you could get sick quickly, and I think it is important to prepare for that possibility." OR *Time:* "I **wish** we were not in this situation, but I am **worried** that time may be as short as ___ *(express as a range, e.g. days to weeks, weeks to months, months to a year).*" OR *Function:* "I **hope** that this is not the case, but I'm **worried** that this may be as strong as you will feel, and things are likely to get more difficult."
4. ***Explore key topics*** · Goals · Fears and worries · Sources of strength · Critical abilities · Tradeoffs · Family	"What are your most important **goals** if your health situation worsens?" "What are your biggest **fears and worries** about the future with your health?" "What gives you **strength** as you think about the future with your illness?" "What **abilities** are so critical to your life that you can't imagine living without them?" "If you become sicker, **how much are you willing to go through** for the possibility of gaining more time?" "How much does your **family** know about your priorities and wishes?"
5. ***Close the conversation*** · Summarize · Make a recommendation · Check in with patient · Affirm commitment	"I've heard you say that ___ is really important to you. Keeping that in mind, and what we know about your illness, I **recommend** that we ___. This will help us make sure that your treatment plans reflect what's important to you." "How does this plan seem to you?" "I will do everything I can to help you through this."
6. ***Document your conversation***	
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1. Set up the conversation

- Setting up the conversation builds trust
  - Introduce purpose and prepare for future decisions:
    "I'd like to talk about what is ahead with your illness and do some thinking in advance about what is important to you so that I can make sure we provide you with the care you want"
  - Ask permission:
    "Is this ok?"
  - Offer rationale:
    "The goal is to make sure that I have all of the information I need about what matters most to you so I can provide you with the care you want, and so I can best support your family if they ever have to make decisions for you."

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2. Assess illness understanding and preferences

- *"What is your understanding now of where you are with your illness?"*
- *"How much information about what is likely to be ahead would you like from me?"*
  - Some people want to know about time; others want to know what to expect; others like to know both

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3. Share Prognosis – Wish/Worry, Hope/ Worry Framework

*"I want to share with you **my understanding** of where things are with your illness…*

1. Uncertain:

- *"It can be difficult to predict what will happen with your illness. I **hope** you will continue to live well for a long time but I'm **worried** that you could get sick quickly, and I think it is important to prepare for that possibility."*

2. Time

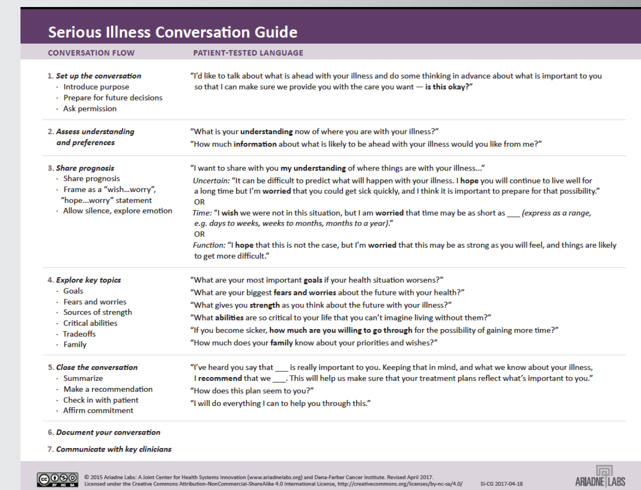
- *"I **wish** we were not in this situation, but I'm **worried** that time may be as short as______ (express as a range, e.g. days to weeks, weeks to months, months to a year."*

3. Function:

- *"I **hope** that this is not the case, but I'm **worried** that this may be as strong as you feel, and things are likely to get more difficult."*

4. Explore previously disclosed prognosis:

- *"Dr. B talked about his worry that you might have weeks to a few months."*



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Some Specific Communication Tips

3 W's: Wish (or Hope), Worry, and Wonder

Patient: *"Will I make it to my granddaughter's graduation in 1 year?"*

Clinician:

- *"I wish that things were different; I worry that that's not likely."*
- *"I hope that you can, but I worry that it may not be possible."*
- *"I wonder if there are things you can do to prepare in the event you can't be there."*
- *"I know you've said that you don't want information about prognosis, my dilemma is that you might be making different decisions if you had that information."*

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Helpful phrases

- I'm concerned that in spite of the treatment we're giving you I might have to share some more difficult information with you soon."
- I'm worried that even with aggressive treatment we may be getting to a place where we can't control this disease and time may be short.
- We need a Plan B
- We're in a different place now
- Hope for the best but plan for the worst

Expect emotion

- Allow silence immediately after giving prognosis
  - It is therapeutic to give a patient time to process emotions after hearing difficult news.

- Respond to emotion by naming it and exploring:
  - *"You seem really upset. Tell me more about what you are feeling."*
  - *"You seem surprised. Tell me about what you were expecting to hear."*
  - *"This is really hard to hear. Tell me what you're thinking about."*

4. Explore key topics

- *“What are your most important goals if your health situation worsens?”*
- *“What are your biggest fears and worries about the future with your health?”*

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6. ***Document your conversation***	
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THE OTTAWA HOSPITAL L'HÔPITAL D'OTTAWA

uOttawa

Explore sources of strength

- *“What gives you strength as you think about the future with your illness?”*
  - For some patients, it is their religious faith, or family and community support

Serious Illness Conversation Guide

CONVERSATION FLOW	PATIENT-TESTED LANGUAGE
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Explore function, tradeoffs and family

- *“What abilities are so critical to your life that you can’t imagine living without them?”*
- *“If you become sicker, how much are you willing to go through for the possibility of gaining more time?”*
- *“How much does your family know about your priorities and wishes?”*

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5. Close the conversation

1. Summarize & Recommend:

“I’ve heard you say that____is really important to you. Keeping that in mind, and what we know about your illness, I recommend that we ___. This will help us make sure that your treatment plans reflect what’s important to you.”

2. Check in with patient:

“How does this plan seem to you?”

3. Affirm commitment:

“I will do everything I can to help you through this.” Don’t make promises you can’t keep though

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6. Document the conversation and Communicate with key clinicians

- Document the conversation in the medical record
- Inform members of the team

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Adaptations

- Substitute Decision Maker Conversation Guide

- SICG and Patient/ Family Guide translated to over 10 languages
  - French, Spanish, Vietnamese, Cantonese, Arabic, Punjabi, Korean

Courtesy of Fraser Health, British Columbia

Most common missteps

- Not discussing prognosis

- Getting off track (not following the Guide)

Common misstep: Not discussing prognosis

The purpose of prognostication is…	To help patients begin a planning process 'just in case,' not to be right or wrong
Discussing prognosis is hard; clinicians are afraid of…	• Being wrong/losing patient trust • Provoking anger, anxiety or sadness
Research on prognostication demonstrates that...	• Most patients want to know their prognosis • Patients realize that clinicians are not perfect prognosticators • Prognostic information can reduce anxiety & depression (*knowledge is power*) • Patients do not "die sooner" after receiving prognostic information

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Common misstep: Getting off track

The order of the questions is important…	• Conversation Guide questions & order of the questions are based on research
The topics addressed might not feel right at first…	• Reverting to what you are comfortable talking about is natural
The first priority is learning about the patient's values & goals…	• Discussion of treatments, interventions and the care plan comes *after* the serious illness conversation rather than in the middle

Resist the urge to...

- Provide premature reassurance
- Talk more than listen, fear silence
- Avoid addressing the patient's emotions
- Solve problems

SICG in LTC

- Individual provider comfort
- Access to training, feedback and mentorship
- Standardized documentation
- Aligns well with palliative philosophy of care/person-centred care initiatives
- Well suited for legislated admission and annual care conference

Goals of care

Resident:	Effective Date:	Location:
Initial Admission:	Admission:	Date of Birth:
Score: NA	Category: NA	Physician:

A. Resuscitation Decision

In the event of witnessed cardiac or respiratory arrest, the resident wishes to have:

1.
- 1. FULL Resuscitation in event of witnessed cardiac or respiratory arrest
- 2. NO CPR (Ensure a DO Not Resuscitate Confirmation Form (MOH LTC Ontario) is completed)

B. Considerations in the event of change in condition

*NB - unless emergent treatment or care is required due to imminent harm or suffering, in the event of a change in condition, treatment or care will be discussed with the resident / SDM (if the resident is incapable) before treatment is initiated

In the event of a change in condition the resident or their SDM on their behalf would:

1.
- 1. Determine a course of action at the time a treatment decision is required
- 2. Continue to consider transfer to acute care hospital for further investigation or treatment
- 3. Prefer to remain in St Patrick and may consider to life prolonging treatment
- 4. Prefer to remain in St Patrick for treatment to be focused on symptom control and to be comfortable

Name and Designation

2. Signature

Date

3. Date

C. Goals of care discussion

1. Date and time of Discussuion
2. Individuals participating
3. Resident capacity:
   - 1. Full
   - 2. Limited
   - 3. Incapable
4. Primary Diagnosis
5. Additional important diagnosis:
6. Functional Abilities:
7. Prognosis

Page 1 of 2

Thank you

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