Serious illness & medical decision making: Things to think about, questions to ask

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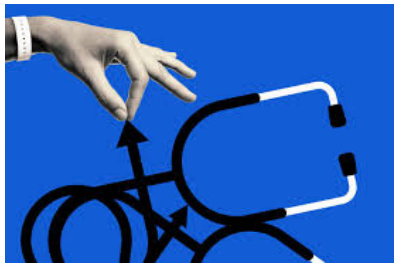
Objectives

- To review important considerations when making medical decisions
- To discuss advance care planning
- To review resources available to help with medical decision making



Medical decision making in serious illness

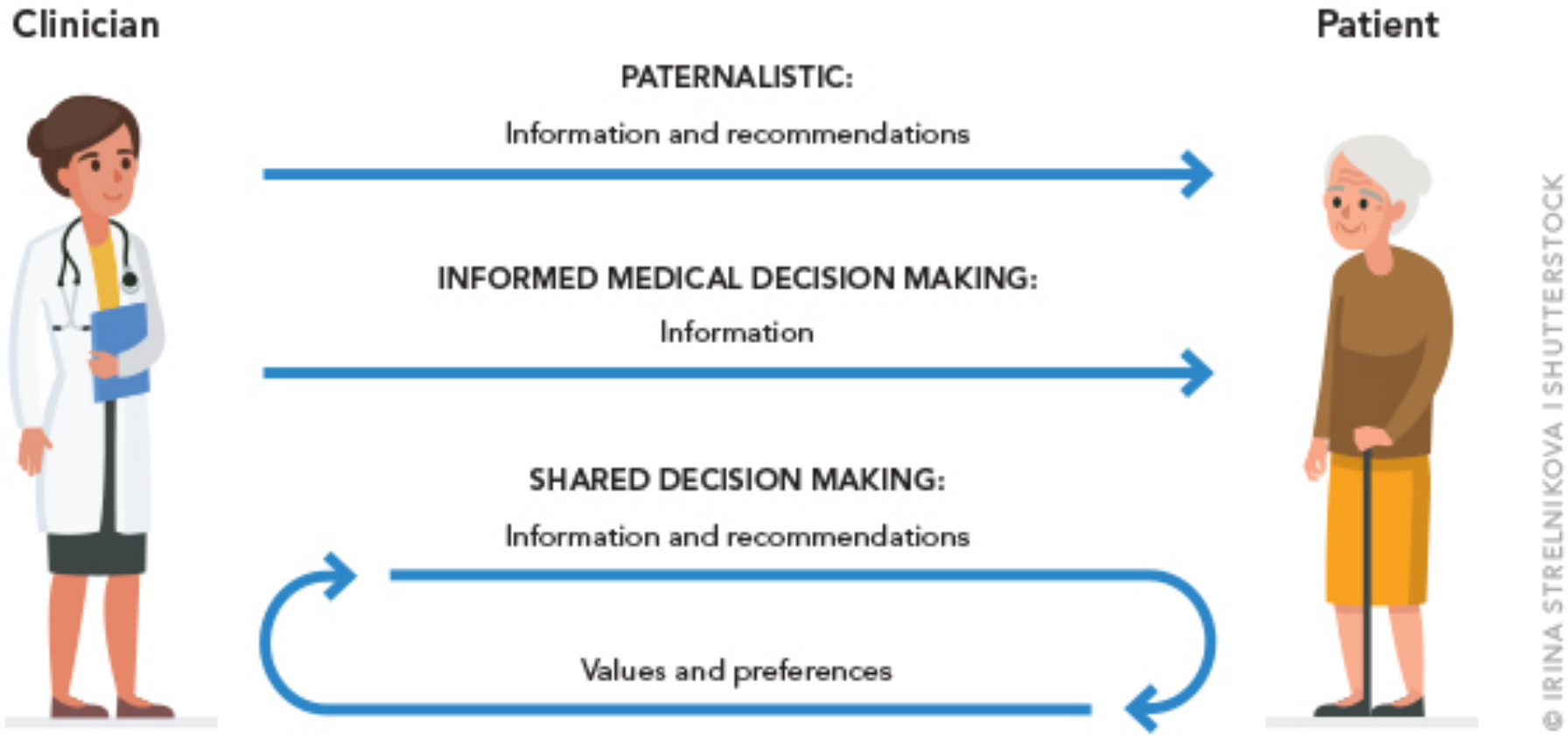
What is serious illness?

- The type of illness that require someone to be in the hospital

- The person may be so sick that they may die, but there is also a chance that they may recover

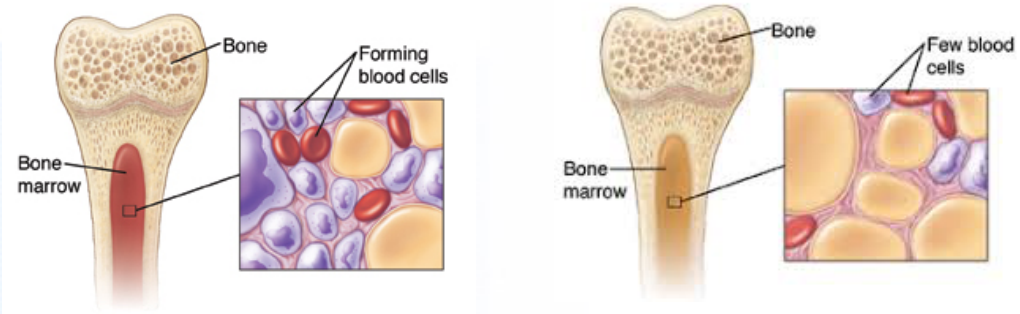
https://planwellguide.com/wp-content/uploads/2019/07/Planwell-guide-short-version-July-2019-web.pdf

Medical decision making

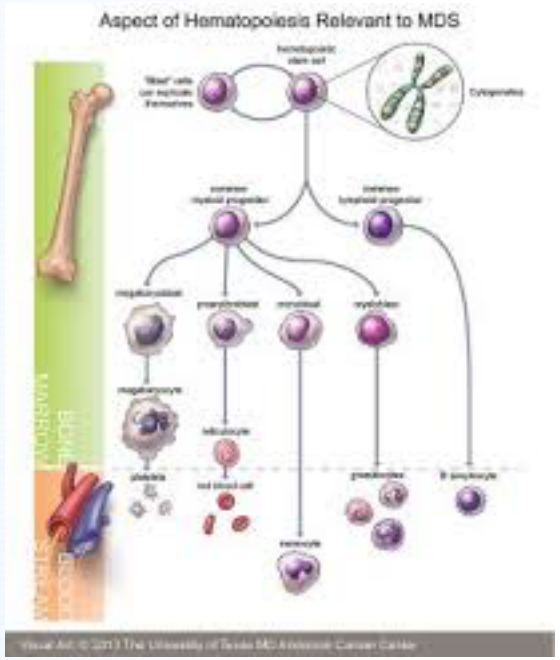


Fam Pract Manag. 2017. 24(3):5-10.

Understand your diagnosis



- Learn about the specific diagnosis
- Ask health care team questions about the diagnosis
- Use caution when doing research online → use trusted websites (AAMAC, AAMDSIF)



www.mdanderson.org/cancer-types/myelodysplastic-syndrome.html
www.saintlukeskc.org/health-library/when-your-child-has-aplastic-anemia
www.cancer.net/navigating-cancer-care/how-cancer-treated/making-decisions-about-cancer-treatment

Know your options

- Treatment options:
  - disease-directed treatment
  - active surveillance (“watchful waiting”)
  - supportive and palliative care
  - clinical trials

www.cancer.net/navigating-cancer-care/how-cancer-treated/making-decisions-about-cancer-treatment

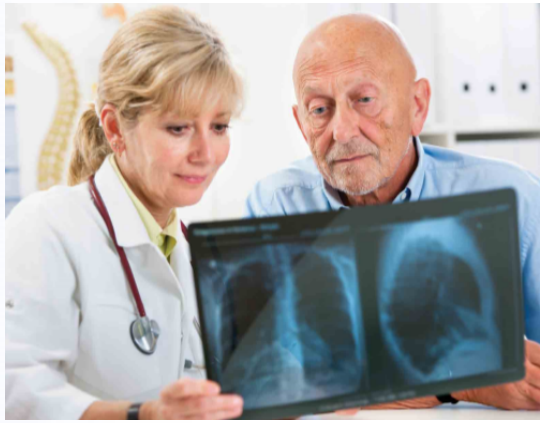
Understand the goals of treatment

- Slow, stop, or eliminate the disease (‘disease-directed’ or ‘disease-modifying’ therapy)
- Manage symptoms and side effects (‘supportive’ or ‘palliative care’)

www.cancer.net/navigating-cancer-care/how-cancer-treated/making-decisions-about-cancer-treatment

Questions to ask:

- What are the ways to treat my condition?
- What are the benefits and risks of each treatment?
- What treatment(s) do you recommend? Why do you think it is best for me?
- When will I need to start treatment?
- Will I need to be in the hospital? If so, for how long?
- How will we know if the treatment is working?
- Would a clinical trial (research study) be right for me?



www.cancer.gov/about-cancer/treatment/questions

Questions to ask about treatment & side effects

Treatment:

- Where will I go for treatment?
- How is the treatment given (pill, injection, etc.)?
- How long will each treatment session take?
- Should a family member or friend come with me to my treatments?

Side-effects:

- What are the possible short and long-term side effects?
- Are there any side-effects that I should call you about right away?
- Who do I call if I need help?
- Are there any lasting effects of treatment?
- How can I prevent/treat side effects?
- What other impacts will there be on everyday life (ex. Visitor restrictions, inability to work, inability to travel, etc.)?

www.cancer.gov/about-cancer/treatment/questions

Questions to ask about clinical trials

- How often will I have to come to the hospital/clinic?
- Will I have to stay in the hospital during the clinical trial? If so, how often and for how long?
- Will I have to travel long distance at all?
- Will I have check-ups/follow-up after the trial?
- How does the treatment I would receive in the trial compare with the other treatment choices?

www.cancer.gov/about-cancer/treatment/clinical-trials/questions

Consider the risks and benefits of each treatment option (*including no disease-directed treatment!*)

Think about:

- The positive and negatives of each treatment option, including:
  - Chance of a cure
  - Possible short- and long-term side effects
  - Likelihood of recurrence of the disease after treatment
  - Chances of living longer with or without the treatment
  - Impact on your quality of life and independence
  - Preferences of you and your family

www.cancer.net/navigating-cancer-care/how-cancer-treated/making-decisions-about-cancer-treatment

Discuss your decision with people you trust

- Family members
- Friends
- Member of your church
- Spiritual advisor
- Social worker
- Someone else with the same condition (peer support, AAMAC)

www.cancer.net/navigating-cancer-care/how-cancer-treated/making-decisions-about-cancer-treatment

Questions to Ask When You Have Finished Treatment

- How long will it take for me to get better and feel more like myself?
- What kind of care should I expect after my treatment?
- What long-term health issues can I expect as a result of my condition and the treatment?
- What is the chance that my condition will return?
- What symptoms should I tell you about?
- Who do I call if I develop these symptoms?
- What can I do to be as healthy as possible?
- Which doctor(s) should I see for my follow-up care? How often?
- What tests do I need after treatment is over? How often will I have the tests?
- What records do I need to keep about my treatment?
- Can you suggest a support group that might help me?

www.cancer.gov/about-cancer/coping/survivorship/questions

Medical decision making and values

Here are some examples of values that you may want to think about:

- I want to live as long as possible
- I want to avoid the use of machines in order to keep me alive if I am seriously ill
- I want to avoid symptoms such as pain and shortness of breath
- I want to live as independently as possible
- I want to continue to be able to participate in activities I like to do
- I want to be able to think clearly and not be in a constant state of confusion

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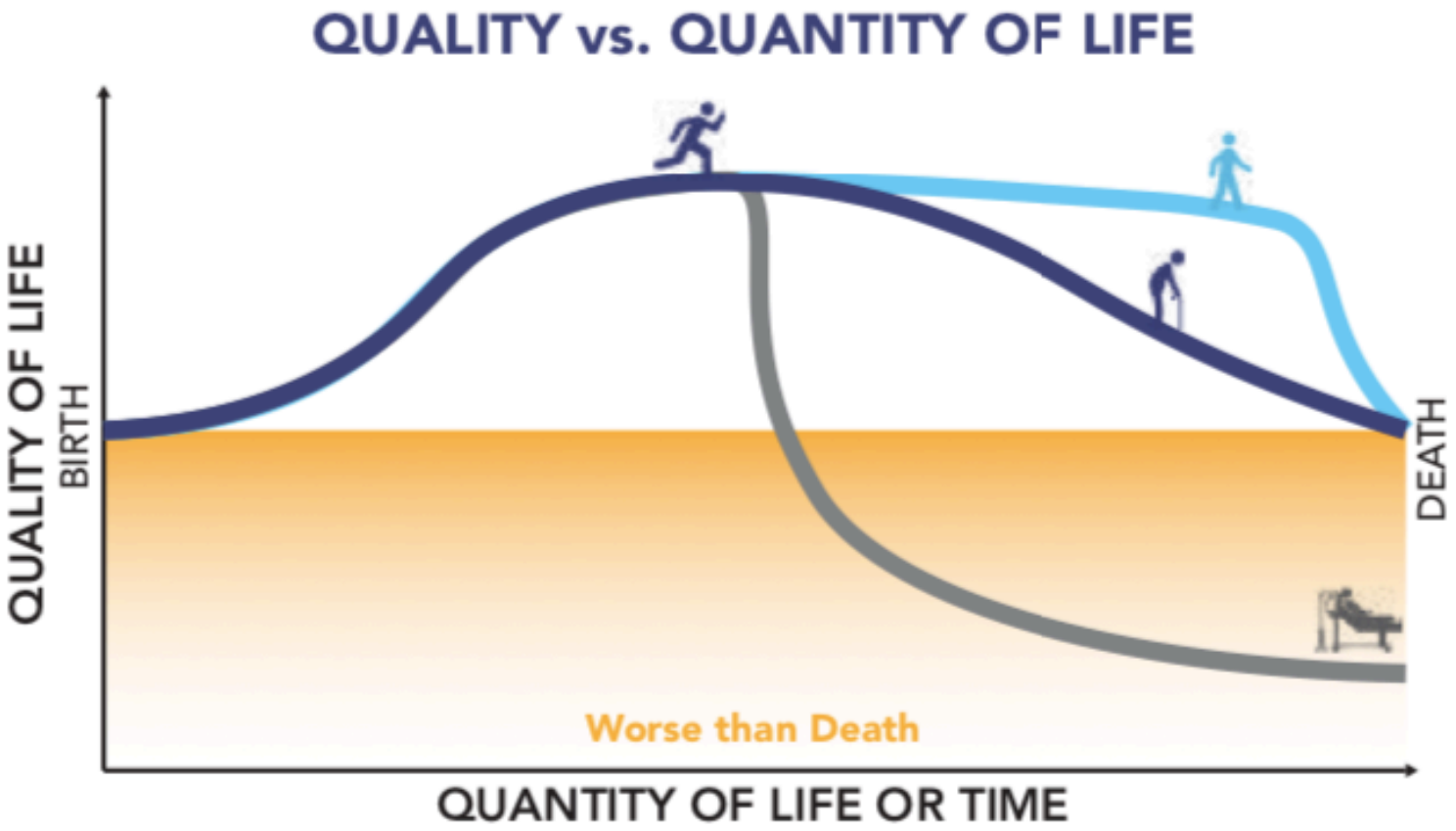
What matters to you?



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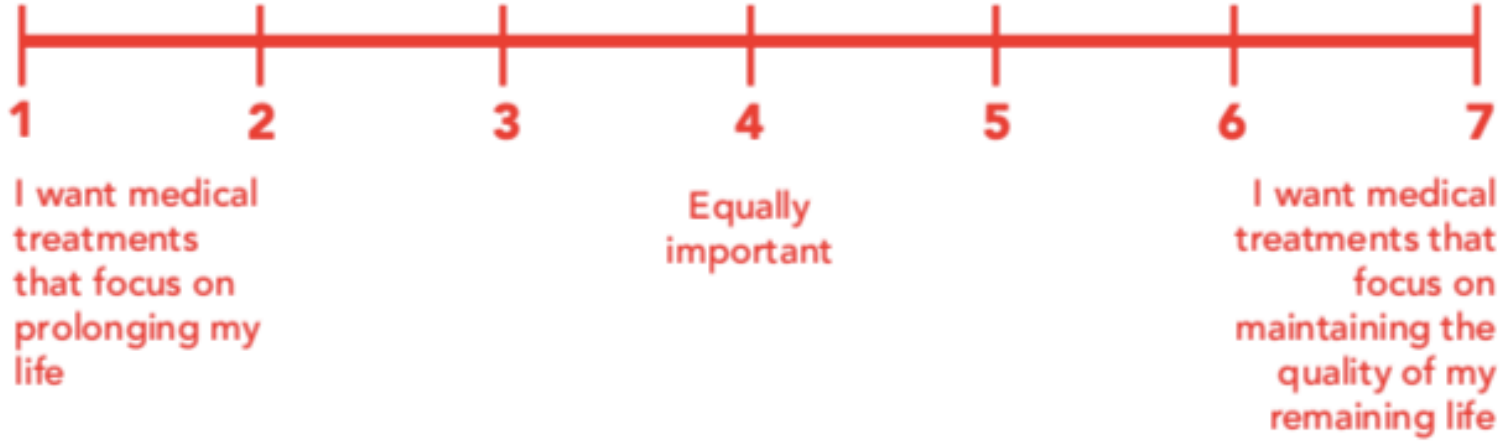
Values Questions:

1. On a scale of 1-7 circle the number to best describe how important the following is to you:



2. On a scale of 1-7 circle the number to best describe how important the following is to you:

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Advance Care Planning & Goals of Care Designation

Advance Care Planning
"…a way to help you think about, talk about and document wishes for health care in the event that you become incapable of consenting to or refusing treatment or other care"

Goals of Care Designation
"…a medical order used to describe and communicate the general aim or focus of care including the preferred location of that care"

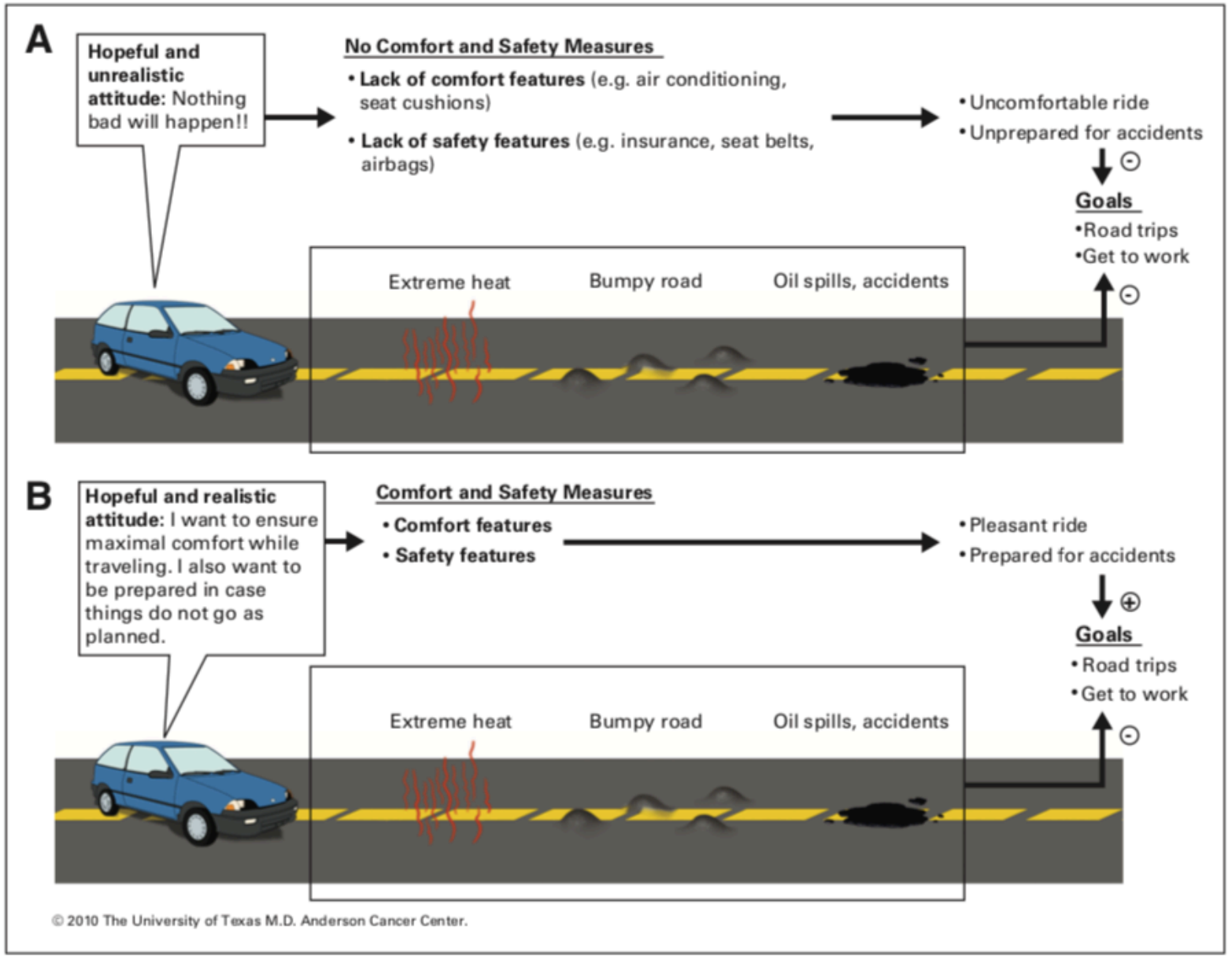
https://www.youtube.com/watch?v=mPtu-FpY1Kw

www.albertahealthservices.ca/info/page12585.aspx

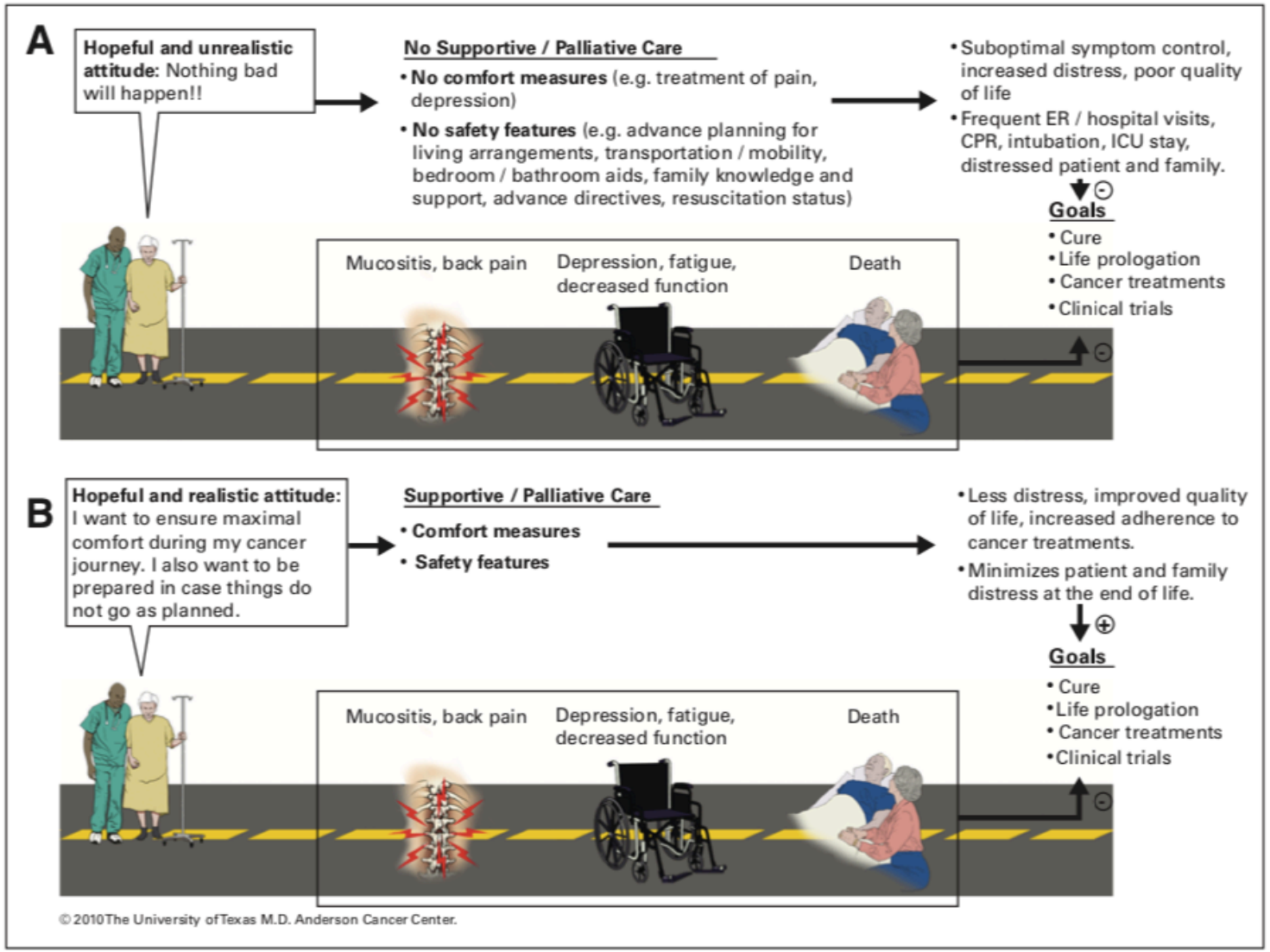
Advance care planning – Why?

- ACP is a gift…for everyone (individuals, caregivers/family members, clinicians)

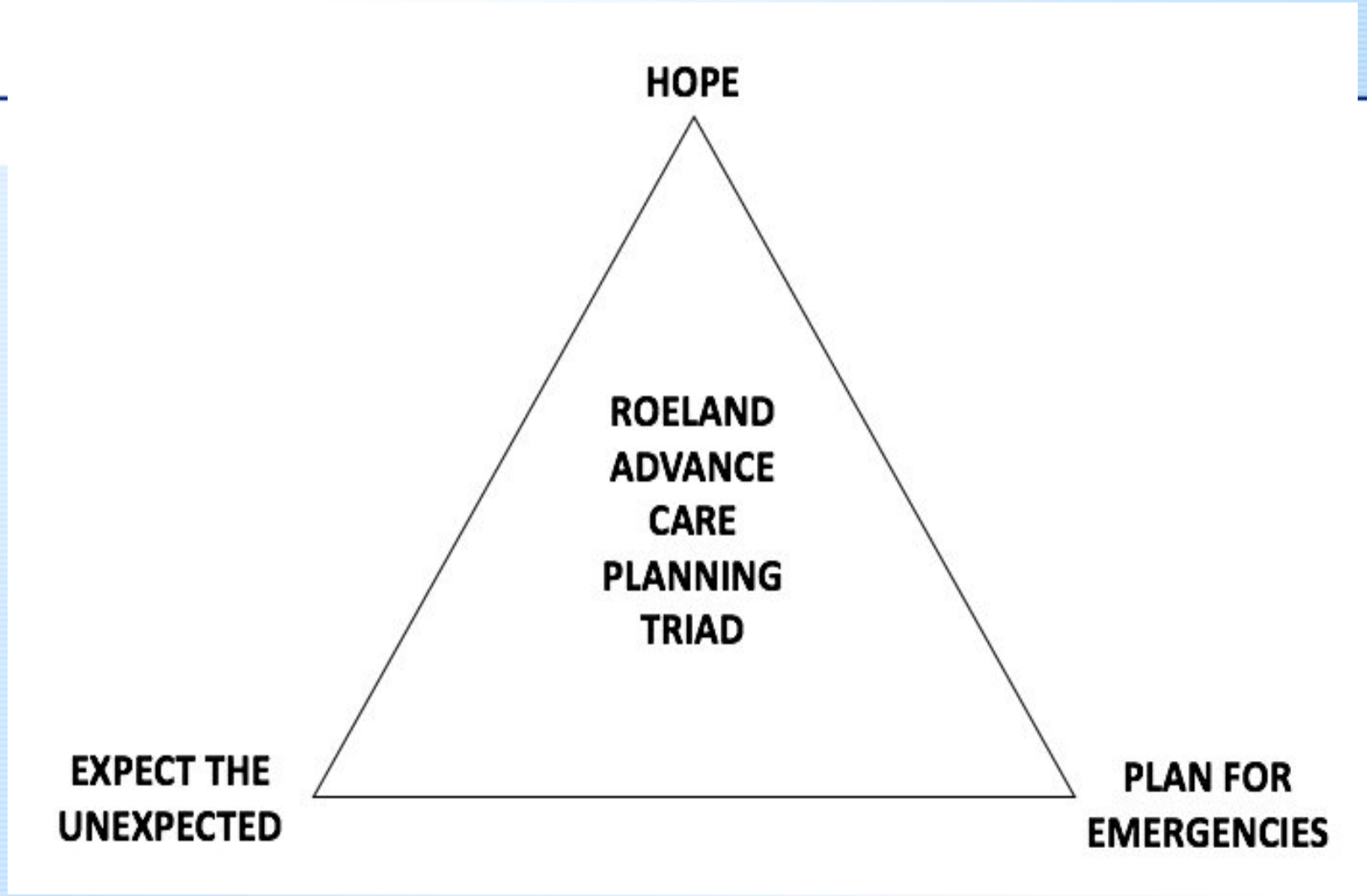
- Health wishes are made known
  - Improved EOL care
  - Less aggressive treatment at EOL
  - Removes ambiguity for fam members → can lead to improved bereavement outcomes



Bruera & Hui, 2010, *JCO, 28*(25), 4013-4017



Bruera & Hui, 2010, *JCO, 28*(25), 4013-4017


HOPE
ROELAND
ADVANCE
CARE
PLANNING
TRIAD
EXPECT THE
UNEXPECTED
PLAN FOR
EMERGENCIES

ACP: The Status Quo

2012 Ipsos-Reid poll:

- 86% of Canadians had not heard of ACP
- <50% had discussed health care treatments with a fam member or friend to express what they would want if they were ill and unable to communicate
- 9% had spoken to a HCP about their wishes for care
- >80% did not have a written plan

www.advancecareplanning.ca/wp-content/uploads/2015/09/acp_cancer_booklet_-_oncologist_final-web.pdf

The prevalence of medical error related to end-of-life communication in Canadian hospitals: results of a multicentre observational study

Daren K Heyland,[1] Roy Ilan,[2] Xuran Jiang,[3] John J You,[4] Peter Dodek[5]

▸ Additional material is published online only. To view please visit the journal online (http://dx.doi.org/10.1136/bmjqs-2015-004567).

For numbered affiliations see end of article.

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ABSTRACT

Background In the hospital setting, inadequate engagement between healthcare professionals and seriously ill patients and their families regarding end-of-life decisions is common. This problem may lead to medical orders for life-sustaining treatments that are inconsistent with patient preferences. The prevalence of this patient safety problem has not been previously described.

Methods Using data from a multi-institutional audit, we quantified the mismatch between patients' and family members' expressed preferences for care and orders for life-sustaining treatments. We recruited seriously ill, elderly medical patients and/or their family members to participate in this audit. We considered it a

INTRODUCTION

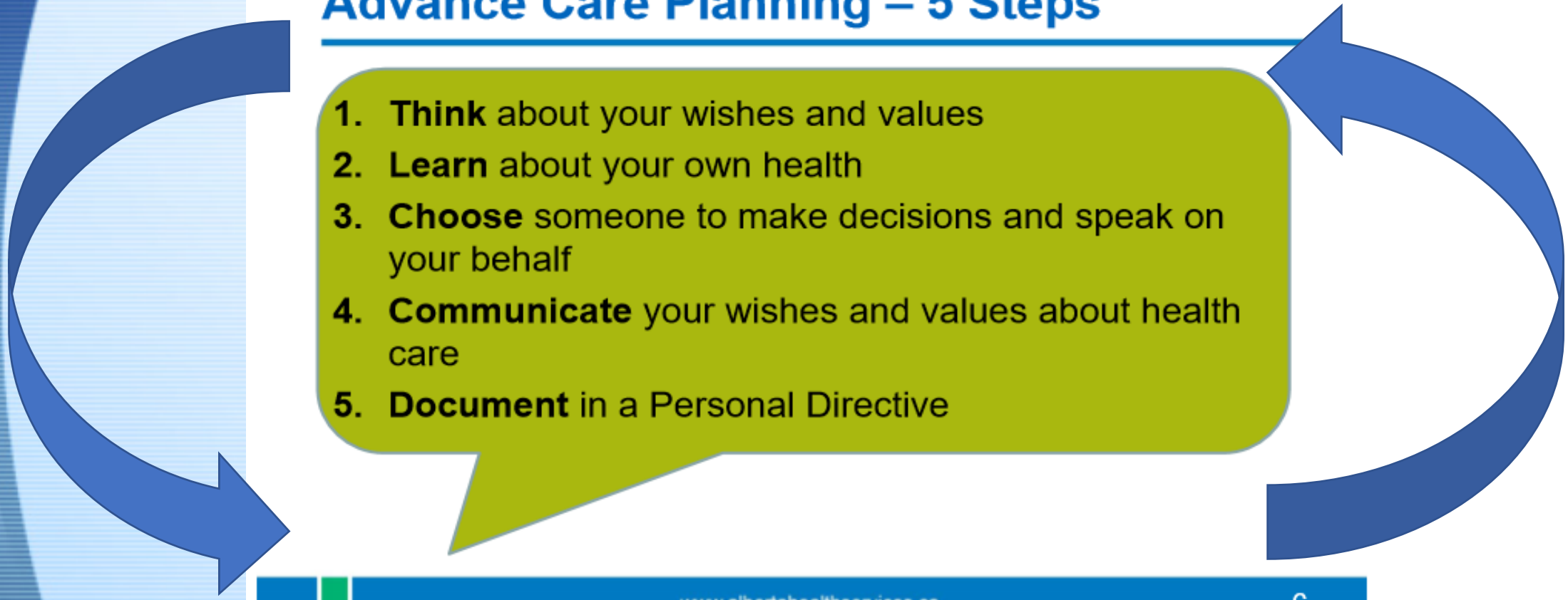
From the perspective of seriously ill, hospitalised elderly patients and their family members, effective communication and decision-making and open relationships with their healthcare providers are central to their construct of quality of end-of-life (EOL) care.[1] There are great opportunities for the improvement of these practices.[2] In a multicentre audit of communication practices in 12 hospitals in Canada, we used a validated questionnaire to interview patients and family members shortly after hospital admission to determine their perspectives about whether healthcare professionals engaged them in key processes of communication

- 16 hospitals in Canada
- N= 808 patients, 631 family members

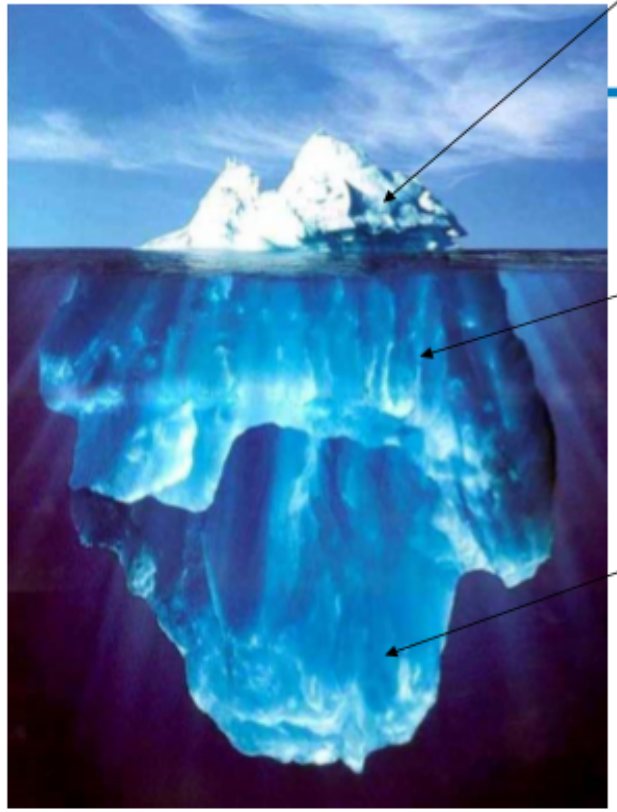
- Compared expressed preferences and documented orders for use of CPR
  - 35% of patients had orders to receive CPR when they wouldn’t have wanted it
  - 2% of patients had orders for NO CPR when they would have wanted it

BMJ Qual Saf 2016 25: 671-679

Advance Care Planning – 5 Steps



Alberta Health Services



Goals of Care Designation Order

- Medical order written by doctor/NP
- M, R, C

Goals of Care Conversations

- Conversations with the healthcare team (prognosis, appropriate treatment options, expected outcomes)

Advance Care Planning

- Conversations with agent, loved ones, healthcare provider (values, wishes, fears, health status)
- Personal Directive

Medical Care

In this approach to care, a patient is expected to benefit from and is accepting of any appropriate medical tests and/or interventions that can be offered, excluding ICU and resuscitative care. Additionally, locations for care (home, hospital, and care facility) are considered depending on what is medically appropriate and in keeping with the patient's wishes and values. Medical care is an appropriate approach when resuscitative care therapies are unlikely to work.

Resuscitative Care

In this approach to care, a patient is expected to benefit from and is accepting of any appropriate medical tests and/or interventions that can be offered and may include intensive care (ICU) and resuscitation.

Comfort Care

In this approach to care, the aim of medical tests and interventions are for optimal symptom control and maintenance of function when cure or control of an underlying condition is no longer possible or desired. Transfer to a hospital may occur in order to better understand or control symptoms.

www.albertahealthservices.ca/info/page12585.aspx

Goals of Care Designation (GCD) Order

Affix patient label within this box

Date *(yyyy-M-dd)*	Time *(hh:mm)*

Goals of Care Designation Order

To order a Goals of Care Designation for this patient, check the appropriate Goals of Care Designation below and write your initials on the line below it. *(See reverse side for detailed definitions)*

Check ▸	☐ R1	☐ R2	☐ R3	☐ M1	☐ M2	☐ C1	☐ C2
Initials ▸	_____	_____	_____	_____	_____	_____	_____

Check ✓ here ☐ if this GCD Order is an Interim Order awaiting the outcome of a Dispute Resolution Process. Document further details on the ACP/GCD Tracking Record.

Specify here if there are specific clarifications to this GCD Order. Document these clarifications on the ACP/GCD Tracking Record as well.

_____

_____

_____

_____

Patient's location of care where this GCD Order was ordered *(Home; or clinic or facility name)*

Indicate which of the following apply regarding involvement of the Patient or alternate decision-maker (ADM)

☐ This GCD has been ordered after relevant conversation with the patient.

☐ This GCD has been ordered after relevant conversation with the alternate decision-maker (ADM), or others. *(Names of formally appointed or informal ADM/s should be noted on the ACP/GCD Tracking Record)*

☐ This is an Interim GCD Order prior to conversation with patient or ADM.

History/Current Status of GCD Order

Indicate one of the following

☐ This is the first GCD Order I am aware of for this patient.

☐ This GCD Order is a revision from the most recent prior GCD *(See ACP/GCD Tracking Record for details of previous GCD Order)*.

☐ This GCD Order is unchanged from the most recent prior GCD.

Name of Physician/Designated Most Responsible Health Practitioner who has ordered this GCD	Discipline
Signature	**Date** *(yyyy-M-dd)*

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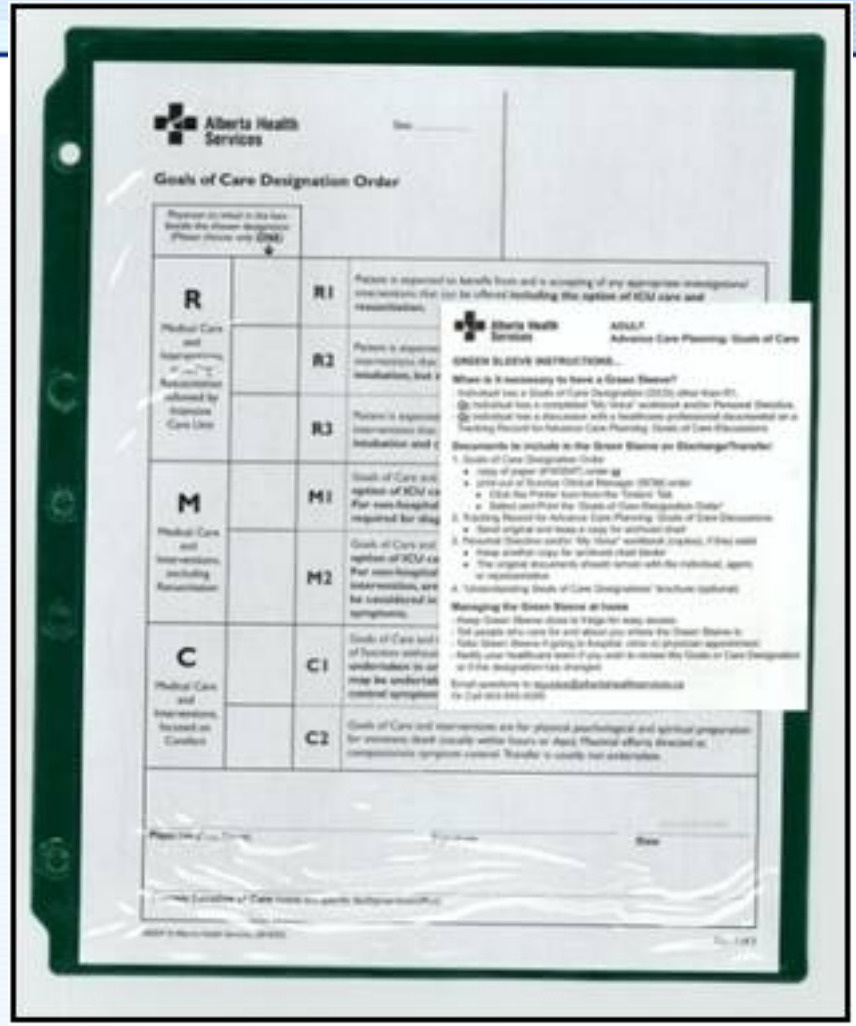
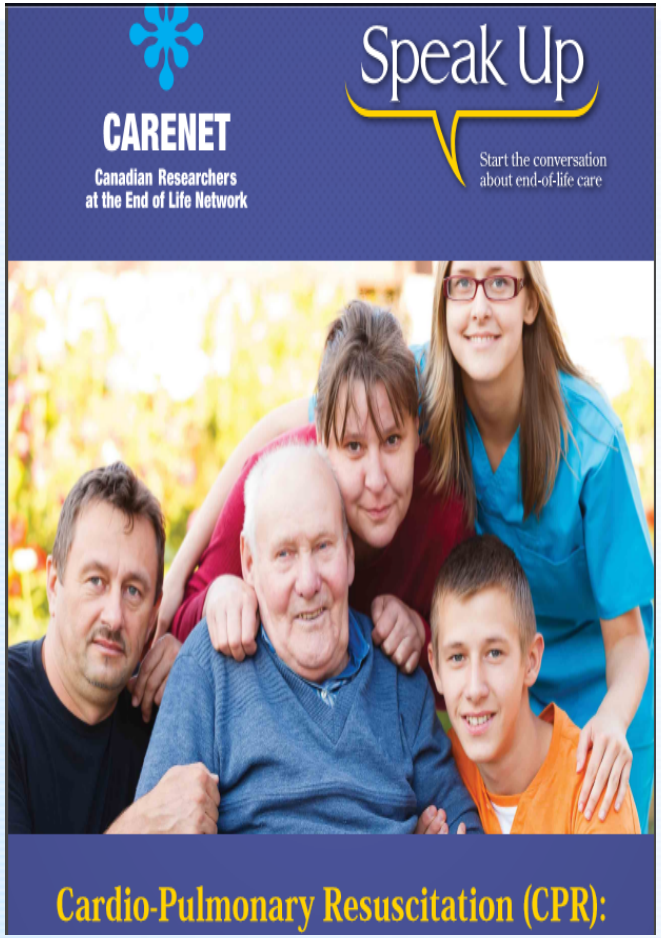


www.albertahealthservices.ca/info/page12585.aspx

Example: CPR



www.advancecareplanning.ca/wp-content/uploads/2015/10/ACP-CPR-Tool_FINAL-web.pdf

CPR Success Rates

In the overall population:
82 out of 100 will die
18 will survive and leave the hospital

People with serious illnesses like cancer, heart or kidney disease:
90 out of 100 will die
10 will survive CPR

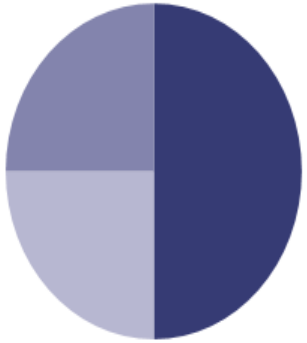
People who have critical illness and are in the intensive care unit:
98 out of 100 will die
2 out of 100 will survive CPR

In the overall population over age 75:
85 out of 100 will die
15 out of 100 will survive CPR

www.advancecareplanning.ca/wp-content/uploads/2015/10/ACP-CPR-Tool_FINAL-web.pdf

Outcomes after CPR

What is the chance of survivors going home from hospital?

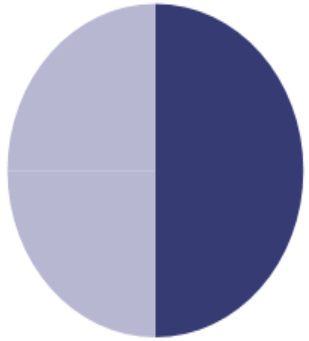


About ¼ will go home independently.

Another ¼ will go home but require help at home.

About ½ will need to live in an institution – like a nursing home or rehab centre

What is the chance that survivors will have thinking or communication difficulties?



About ½ will have problems such as memory loss, problems with attention and problems getting things done.

www.advancecareplanning.ca/wp-content/uploads/2015/10/ACP-CPR-Tool_FINAL-web.pdf

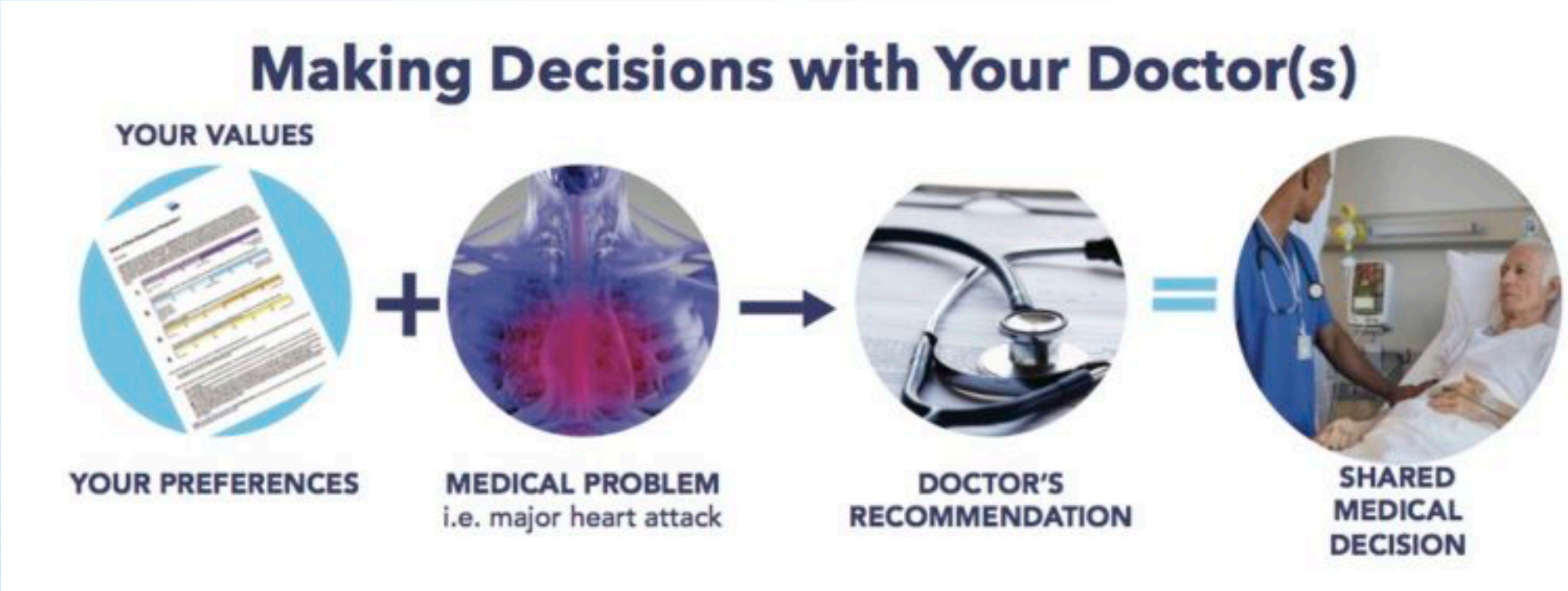
Choice	What's Involved	Possible Advantages	Possible Disadvantages
CPR	Chest compression Electric shocks to restart heart Tube down your throat to breathe for you Transfer to ICU on life supports	May prevent immediate death Chance of returning to near previous function (even if small).	High rate of stroke and brain injury Risk of broken breast bone or ribs and bruised lung Does not improve other health issues You may need a lot of care from your family or home care services in order to return home.
NO CPR	Other medical treatments such as antibiotics or going to an ICU may be given depending on your treatment choices Comfort measures may be the main treatment. These are treatments to keep you comfortable but not to keep you artificially alive or cure illness.	May be less traumatic for family members at the time your heart stops beating Death with less likelihood of discomfort from tubes, procedures or fractured ribs	Death occurs when your heart stops beating Some people worry that 'No CPR' means that no other treatments will be provided. This is not true. Lose out on small chance of prolonging life

www.advancecareplanning.ca/wp-content/uploads/2015/10/ACP-CPR-Tool_FINAL-web.pdf

	Survival to Discharge	Discharge Disposition	Chance That Survivors Will Have Thinking or Communication Difficulties
Overall Population	24.7% (range 20-27%)[1] 23%[3] 18%[4,5] 13%[7]	30% going home (Self care)[1] 14% going home (home care)[1] 55% will go to an institutionalized setting[1,4] 11% discharged home (care not specified)[7]	Among survivors, approximately 55% to 75% will be able to think and write clearly.[5,8] A systematic review of 28 studies examining cognitive impairment ≥3 months after out-of-hospital cardiac arrest found impairment (mainly memory, attention, and executive function) in 6% to 100% of patients.[6] In the same report, the three largest prospective studies showed high rates of impairment, ranging from 42% to 60% at three months.
Serious chronic illnesses like heart or kidney disease	7-18%[2,4]		
Terminal Cancer	6%-15%[2] 2% if in the ICU[2]		
Overall population over age 65	11-22%; lower if older (11% for patients 90+)[2,4]		

www.advancecareplanning.ca/wp-content/uploads/2015/10/ACP-CPR-Tool_FINAL-web.pdf

Shared decision making



https://planwellguide.com/serious-illness-decision-making/

Resources

What's Important to Me (patient version)
https://planwellguide.com/wp-content/uploads/2019/07/GVHT-Pt-Orig-June-2018.pdf

What's Important to Me (substitute decision maker version)

https://planwellguide.com/wp-content/uploads/2019/07/GVHT-SDM_Orig-June-2018.pdf

My ICU Guide: www.myicuguide.ca

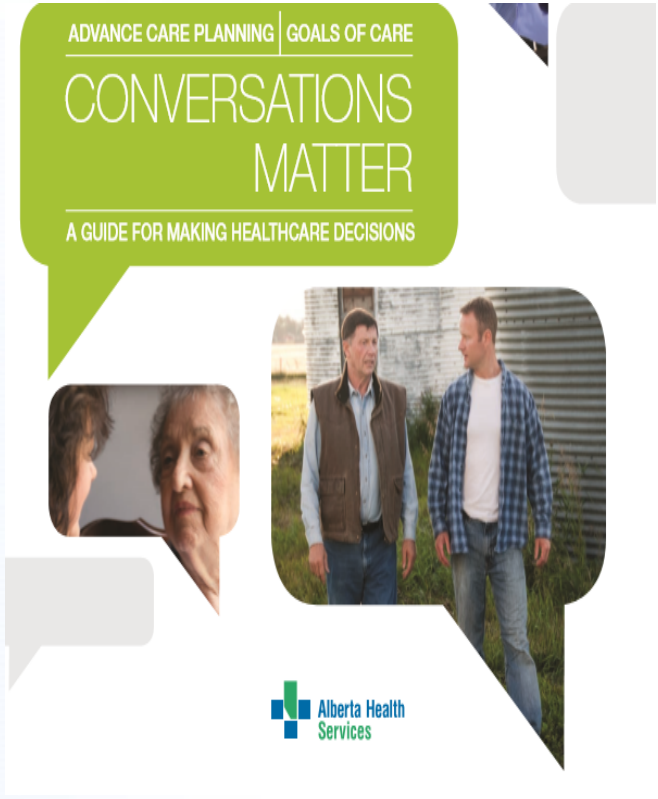
Legal terms in each province: https://planwellguide.com/legal-terms/

Speak Up Canada: www.advancecareplanning.ca

Resources: Conversations Matter

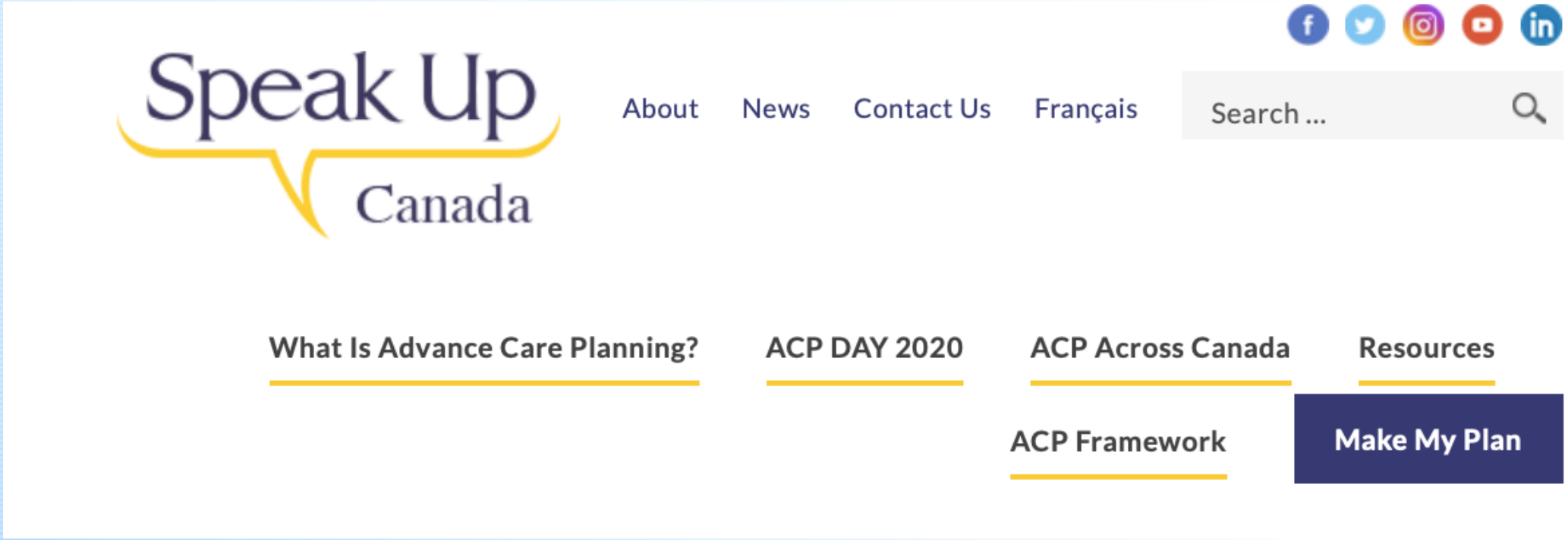
- Goal of care designation – only one component of ACP

- Conversations:
  - GCD
  - but also, more broadly…about serious illness, goals, care, wishes



https://myhealth.alberta.ca/Alberta/Pages/advance-care-planning-conversation-matters.aspx

Advance Care Planning (ACP)



www.advancecareplanning.ca

Ottawa Personal Decision Guide

For People Making Health or Social Decisions

1 Clarify your decision.

What decision do you face?

What are your reasons for making this decision?

When do you need to make a choice?

How far along are you with making a choice?

- ☐ Not thought about it
- ☐ Thinking about it
- ☐ Close to choosing
- ☐ Made a choice

2 Explore your decision.

Knowledge

List the options and benefits and risks you know.

Values

Rate each benefit and risk using stars (★) to show how much each one matters to you.

Certainty

Choose the option with the benefits that matter most to you. Avoid the options with the risks that matter most to you.

	Reasons to Choose this Option Benefits / Advantages / Pros	How much it matters to you: 0★ not at all 5★ a great deal	Reasons to Avoid this Option Risks / Disadvantages / Cons	How much it matters to you: 0★ not at all 5★ a great deal
Option #1				
Option #2				
Option #3				

Which option do you prefer? ☐ Option #1 ☐ Option #2 ☐ Option #3 ☐ Unsure

Support

Who else is involved?						
Which option do they prefer?						
Is this person pressuring you?	☐ Yes	☐ No	☐ Yes	☐ No	☐ Yes	☐ No
How can they support you?						

What role do you prefer in making the choice?

- ☐ Share the decision with…
- ☐ Decide myself after hearing views of…
- ☐ Someone else decides…

3 Identify your decision making needs.

Adapted from The SURE Test © 2008 O'Connor & Légaré.

Knowledge	Do you know the benefits and risks of each option?	☐ Yes	☐ No
Values	Are you clear about which benefits and risks matter most to you?	☐ Yes	☐ No
Support	Do you have enough support and advice to make a choice?	☐ Yes	☐ No
Certainty	Do you feel sure about the best choice for you?	☐ Yes	☐ No

If you answer 'no' to any question, you can work through steps two 2 and four 4, focusing on your needs.
People who answer "No" to one or more of these questions are more likely to delay their decision, change their mind, feel regret about their choice or blame others for bad outcomes.

4 Plan the next steps based on your needs.

Decision making needs	✓ Things you could try
Knowledge If you feel you do NOT have enough facts	☐ Find out more about the options and the chances of the benefits and risks. ☐ List your questions. ☐ List where to find the answers (e.g. library, health professionals, counsellors):
Values If you are NOT sure which benefits and risks matter most to you	☐ Review the stars in step two 2 to see what matters most to you. ☐ Find people who know what it is like to experience the benefits and risks. ☐ Talk to others who have made the decision. ☐ Read stories of what mattered most to others. ☐ Discuss with others what matters most to you.
Support If you feel you do NOT have enough support	☐ Discuss your options with a trusted person (e.g. health professional, counsellor, family, friends). ☐ Find help to support your choice (e.g. funds, transport, child care).
If you feel PRESSURE from others to make a specific choice	☐ Focus on the views of others who matter most. ☐ Share your guide with others. ☐ Ask others to fill in this guide. (See where you agree. If you disagree on facts, get more information. If you disagree on what matters most, consider the other person's views. Take turns to listen to what the other person says matters most to them.) ☐ Find a person to help you and others involved.
Certainty If you feel UNSURE about the best choice for you	☐ Work through steps two 2 and four 4, focusing on your needs.

Other factors making the decision DIFFICULT

List anything else you could try:

https://decisionaid.ohri.ca/docs/das/opdg.pdf

Thank you!