Critical conversations that inform practice

Are you asking what matters most?

October 18, 2022

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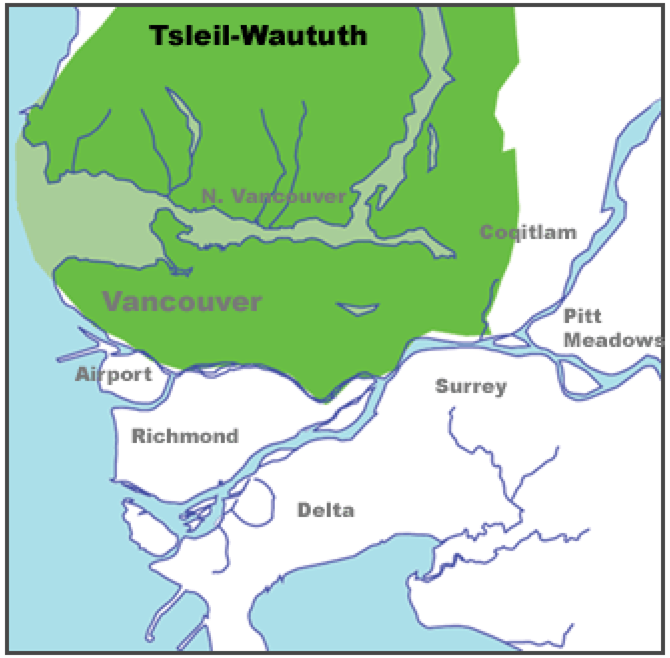
Land Acknowledgement

We would like to acknowledge that we are gathered today on the traditional territories of the Musqueam, Squamish and Tsleil-Waututh peoples.



Source: www.johomaps.net

Learning objectives

- Recognize the benefits of initiating Serious Illness Conversations (SICs) early.
- Identify indicators that suggest the need for an SIC.
- Apply skills from the Serious Illness Conversation Guide into routine practice.
- Conduct code status conversations with greater efficiency and confidence.
- Locate adapted conversation guides that support cultural safety and trauma-informed care.

ACP VS SIC VS MOST – WHAT’S THE DIFFERENCE?

Advance Care Planning

Serious Illness Conversation

Care and Treatment Decisions

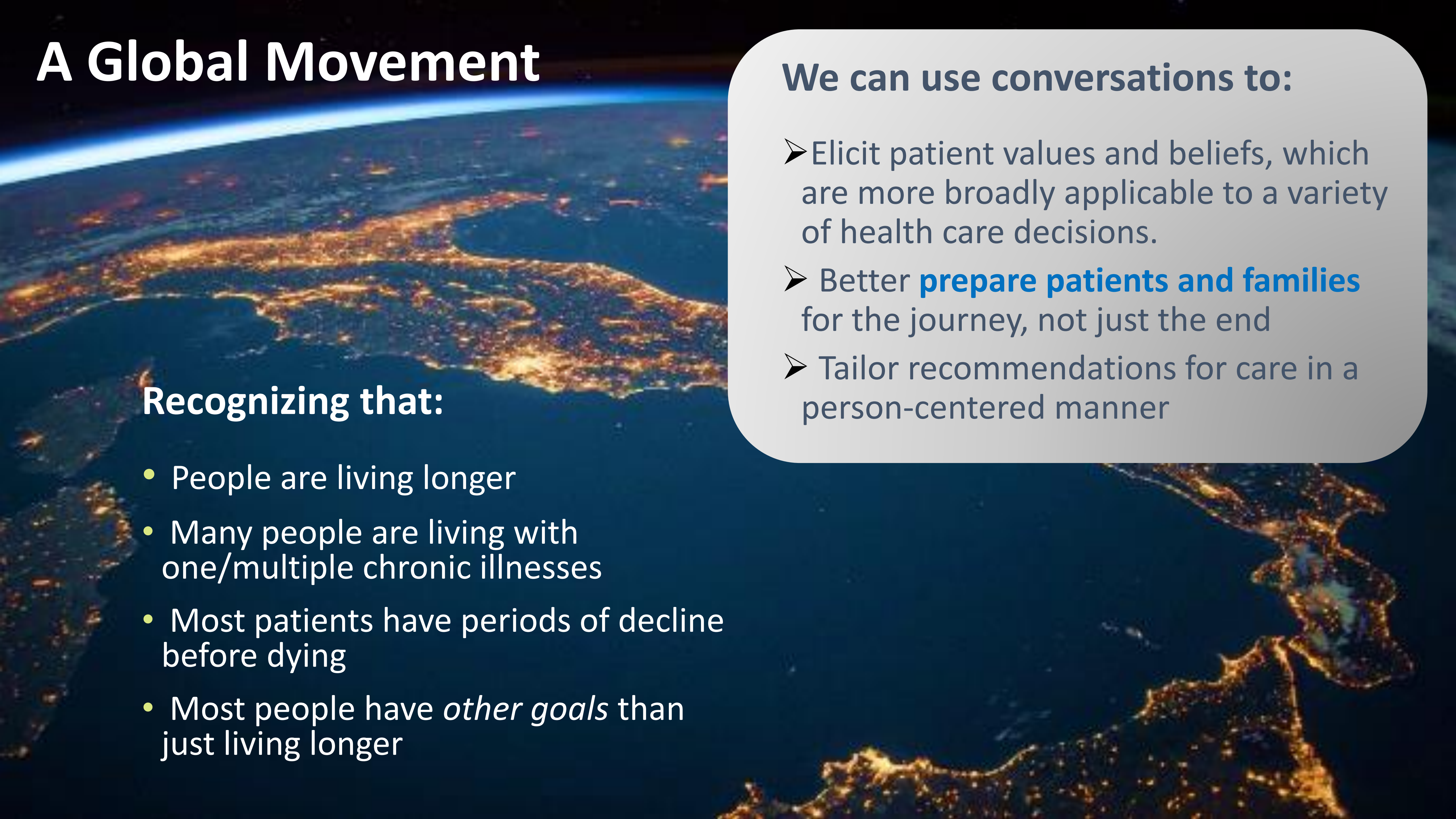
Wishes for **future** care
“What would I want ***if*** *something* happened?”
Encouraged for all adults
Should be revised in context of serious illness

Care preferences in the context of serious illness
“This ***could*** happen”

- Primary aim of medical treatments
  - Cure
  - Life prolongation
  - Comfort
- Personal goals
  - Functional
  - Family
  - Mentation
  - Psychosocial

“This ***is*** happening”
MOST, Code status
Specific treatments and procedures

A Global Movement



Recognizing that:

- People are living longer
- Many people are living with one/multiple chronic illnesses
- Most patients have periods of decline before dying
- Most people have *other goals* than just living longer

We can use conversations to:

- Elicit patient values and beliefs, which are more broadly applicable to a variety of health care decisions.
- Better **prepare patients and families** for the journey, not just the end
- Tailor recommendations for care in a person-centered manner

The unique position of Family Practice

"There's no easy way I can tell you this, so I'm sending you to someone who can."

- Longitudinal relationships
- Rapport
- Interactions outside of medical crises

Benefits of serious illness conversations

Can reduce anxiety and depression

Improve illness understanding

Support informed decision-making

Improve quality of life

Allow time to weigh decisions that lie ahead

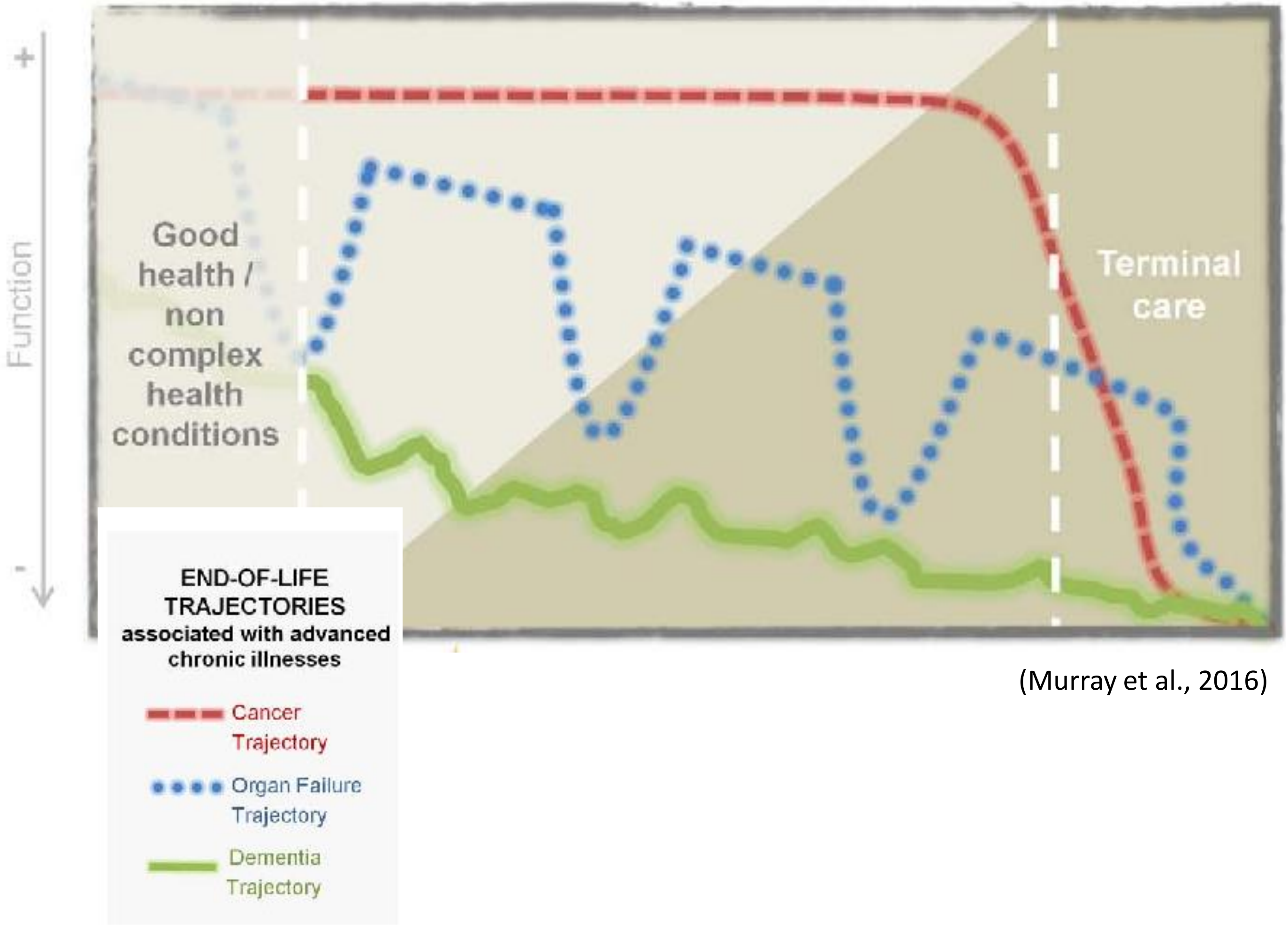
(Detering, Hancock, Reade & Silvester, 2010; Wright et al., 2008)

Timing

When do you typically initiate a conversation with a patient about their illness and their wishes?

Three basic principles of these conversations

- Think broadly
- Think earlier
- Think often



(Murray et al., 2016)

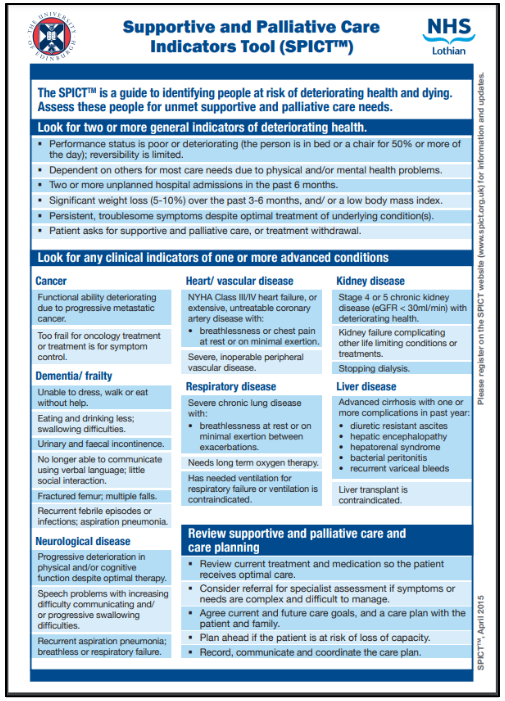
This is typically a **series of conversations.** Many start out very general and become more specific as illnesses progress.

At minimum, prioritize patients at higher risk

1. Surprise question

“Would you be surprised if this patient died in the next year?”

2. SPICT Tool



Supportive and Palliative Care Indicators Tool (SPICT™)

NHS Lothian

The SPICT™ is a guide to identifying people at risk of deteriorating health and dying. Assess these people for unmet supportive and palliative care needs.

Look for two or more general indicators of deteriorating health.

- Performance status is poor or deteriorating (the person is in bed or a chair for 50% or more of the day); reversibility is limited.
- Dependent on others for most care needs due to physical and/or mental health problems.
- Two or more unplanned hospital admissions in the past 6 months.
- Significant weight loss (5-10%) over the past 3-6 months, and/ or a low body mass index.
- Persistent, troublesome symptoms despite optimal treatment of underlying condition(s).
- Patient asks for supportive and palliative care, or treatment withdrawal.

Look for any clinical indicators of one or more advanced conditions

Cancer

Functional ability deteriorating due to progressive metastatic cancer.

Too frail for oncology treatment or treatment is for symptom control.

Dementia/ frailty

Unable to dress, walk or eat without help.

Eating and drinking less; swallowing difficulties.

Urinary and faecal incontinence.

No longer able to communicate using verbal language; little social interaction.

Fractured femur; multiple falls.

Recurrent febrile episodes or infections; aspiration pneumonia.

Neurological disease

Progressive deterioration in physical and/or cognitive function despite optimal therapy.

Speech problems with increasing difficulty communicating and/ or progressive swallowing difficulties.

Recurrent aspiration pneumonia; breathless or respiratory failure.

Heart/ vascular disease

NYHA Class III/IV heart failure, or extensive, untreatable coronary artery disease with:

- breathlessness or chest pain at rest or on minimal exertion.

Severe, inoperable peripheral vascular disease.

Respiratory disease

Severe chronic lung disease with:

- breathlessness at rest or on minimal exertion between exacerbations.

Needs long term oxygen therapy.

Has needed ventilation for respiratory failure or ventilation is contraindicated.

Kidney disease

Stage 4 or 5 chronic kidney disease (eGFR < 30ml/min) with deteriorating health.

Kidney failure complicating other life limiting conditions or treatments.

Stopping dialysis.

Liver disease

Advanced cirrhosis with one or more complications in past year:

- diuretic resistant ascites
- hepatic encephalopathy
- hepatorenal syndrome
- bacterial peritonitis
- recurrent variceal bleeds

Liver transplant is contraindicated.

Review supportive and palliative care and care planning

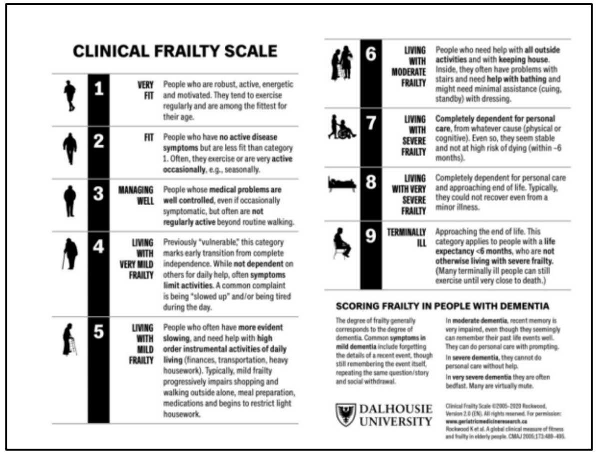
- Review current treatment and medication so the patient receives optimal care.
- Consider referral for specialist assessment if symptoms or needs are complex and difficult to manage.
- Agree current and future care goals, and a care plan with the patient and family.
- Plan ahead if the patient is at risk of loss of capacity.
- Record, communicate and coordinate the care plan.

Please register on the SPICT website (www.spict.org.uk) for information and updates.

SPICT™, April 2015

spict.org.uk

3. Clinical Frailty Scale



CLINICAL FRAILTY SCALE

1	VERY FIT	People who are robust, active, energetic and motivated. They tend to exercise regularly and are among the fittest for their age.
2	FIT	People who have **no active disease symptoms** but are less fit than category 1. Often, they exercise or are very **active occasionally**, e.g., seasonally.
3	MANAGING WELL	People whose **medical problems are well controlled**, even if occasionally symptomatic, but often are **not regularly active** beyond routine walking.
4	LIVING WITH VERY MILD FRAILTY	Previously “vulnerable,” this category marks early transition from complete independence. While **not dependent** on others for daily help, often **symptoms limit activities**. A common complaint is being “slowed up” and/or being tired during the day.
5	LIVING WITH MILD FRAILTY	People who often have **more evident slowing**, and need help with **high order instrumental activities of daily living** (finances, transportation, heavy housework). Typically, mild frailty progressively impairs shopping and walking outside alone, meal preparation, medications and begins to restrict light housework.
6	LIVING WITH MODERATE FRAILTY	People who need help with **all outside activities** and with **keeping house**. Inside, they often have problems with stairs and need **help with bathing** and might need minimal assistance (cuing, standby) with dressing.
7	LIVING WITH SEVERE FRAILTY	**Completely dependent for personal care**, from whatever cause (physical or cognitive). Even so, they seem stable and not at high risk of dying (within ~6 months).
8	LIVING WITH VERY SEVERE FRAILTY	Completely dependent for personal care and approaching end of life. Typically, they could not recover even from a minor illness.
9	TERMINALLY ILL	Approaching the end of life. This category applies to people with a **life expectancy <6 months**, who are **not otherwise living with severe frailty.** (Many terminally ill people can still exercise until very close to death.)

SCORING FRAILTY IN PEOPLE WITH DEMENTIA

The degree of frailty generally corresponds to the degree of dementia. Common **symptoms in mild dementia** include forgetting the details of a recent event, though still remembering the event itself, repeating the same question/story and social withdrawal.

In **moderate dementia**, recent memory is very impaired, even though they seemingly can remember their past life events well. They can do personal care with prompting.

In **severe dementia**, they cannot do personal care without help.

In **very severe dementia** they are often bedfast. Many are virtually mute.

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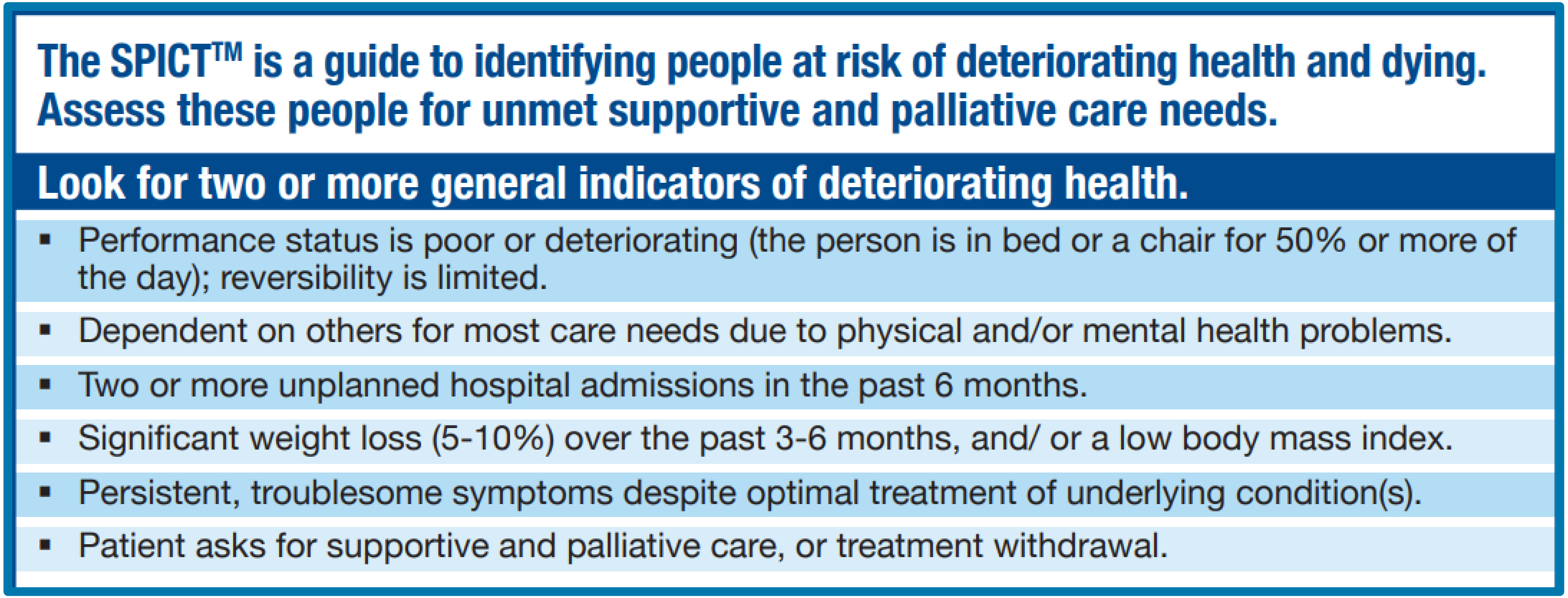
Rockwood K et al. A global clinical measure of fitness and frailty in elderly people. CMAJ 2005;173:489–495.

SPICT Tool: General indicators of deteriorating health



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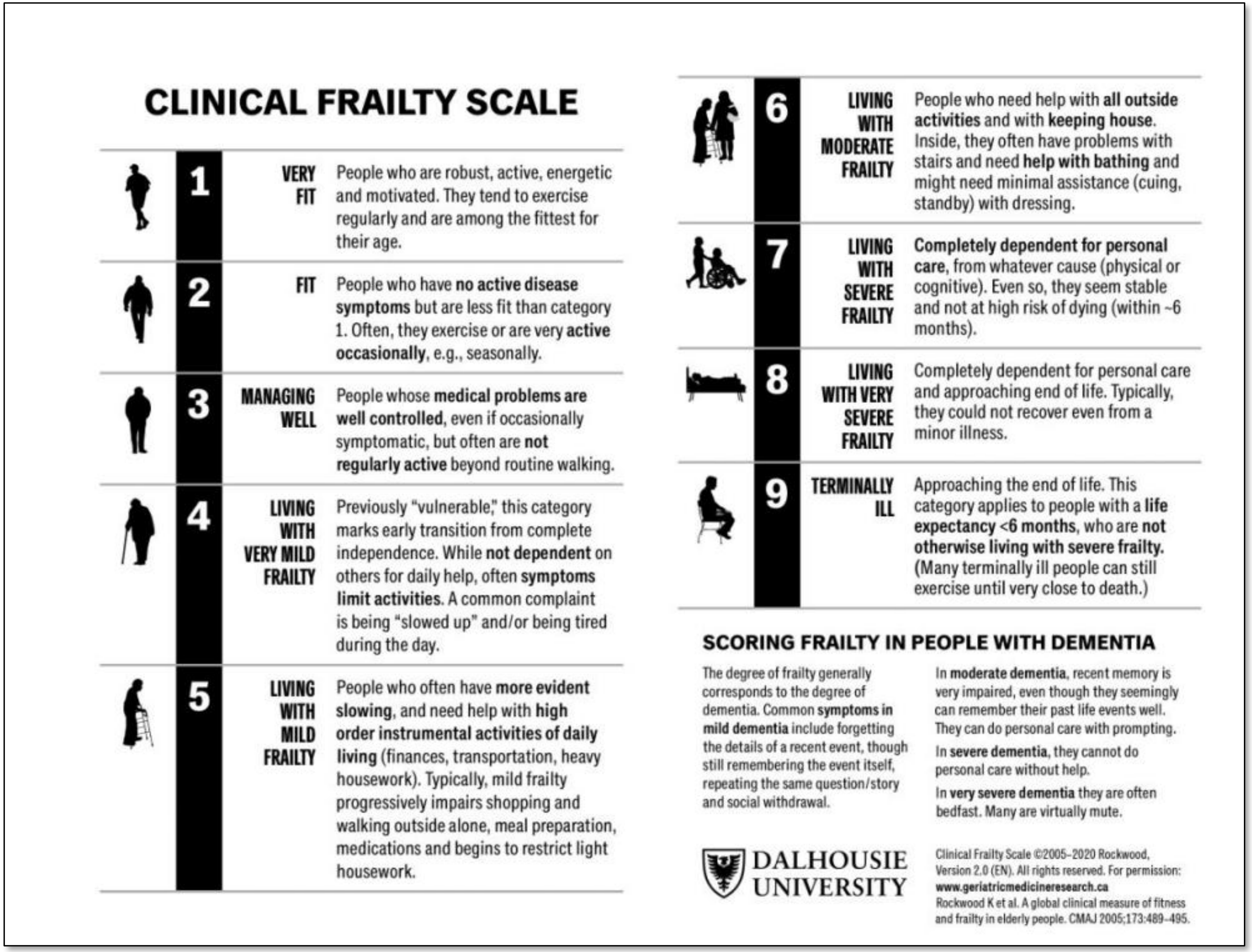
spict.org.uk



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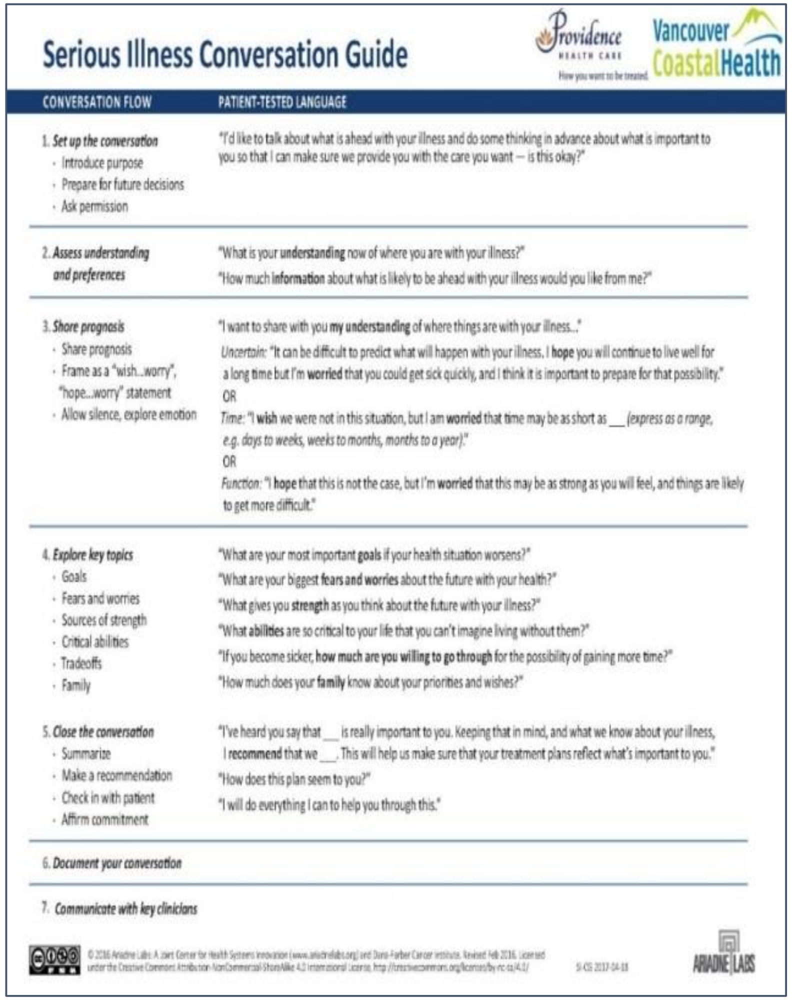
Clinical Frailty Scale ©2005–2020 Rockwood, Version 2.0 (EN). All rights reserved. For permission: www.geriatricmedicineresearch.ca
Rockwood K et al. A global clinical measure of fitness and frailty in elderly people. CMAJ 2005;173:489–495.

A helpful framework for these conversations:

The Serious Illness Conversation (SIC) Guide

- Research-based out of Ariadne Labs
- Patient-tested language
- Uses logical flow
- Both exploratory and informative



Serious Illness Conversation Guide

Providence HEALTH CARE How you want to be treated.

Vancouver CoastalHealth

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***	
7. ***Communicate with key clinicians***	

SI-CG 2017-04-18

ARIADNE | LABS

(Ariadne Labs, 2016)

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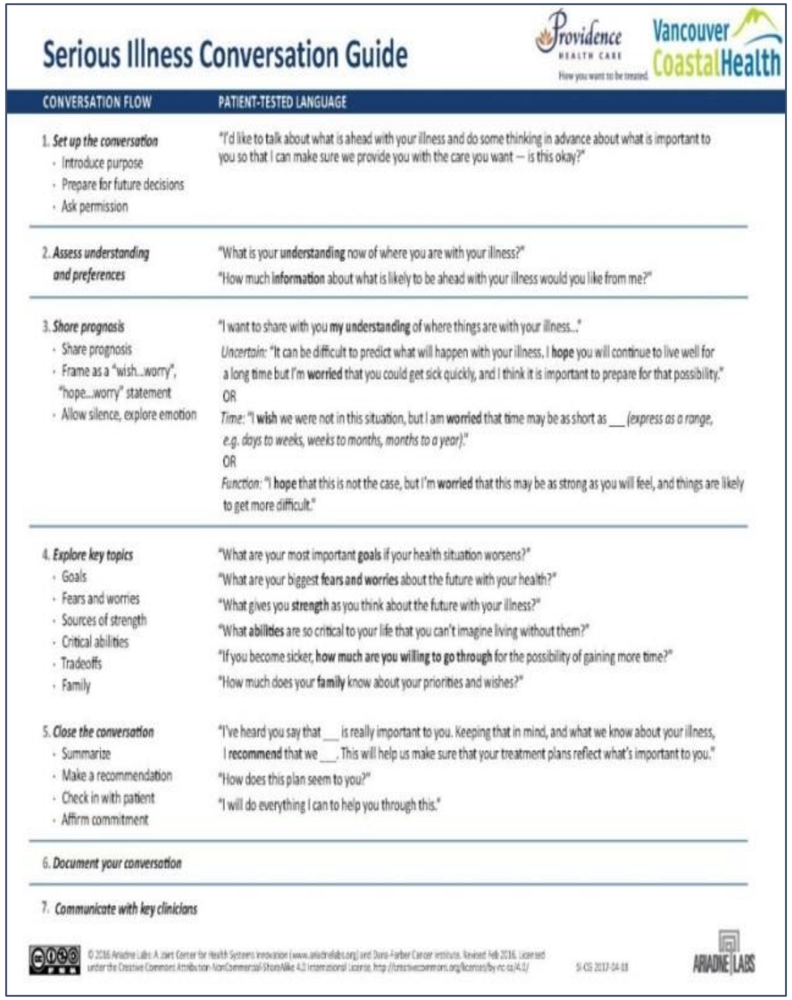
Overview of the SIC Guide

1. **Open** the conversation.

2. **Explore** Understanding
3. **Share** Concerns and Prognosis
4. **Explore** what matters

5. **Summarize** the Conversation

You don't have to ask it all.
Start with a few questions.



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6. ***Document your conversation***	
7. ***Communicate with key clinicians***	

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First steps of the SIC Guide

I'd like to talk to you about your illness and get a better understanding of **what matters to you** so I can provide you with the care you want. Is that ok?

1. **Open** the conversation.
2. **Explore** Understanding
3. **Share** Concerns and Prognosis
4. **Explore** what matters
5. **Summarize** the Conversation

Can you share with me **your understanding** of what's happening with your health/illness?

Framing concerns about future

1. **Open** the conversation.
2. **Explore** Understanding
3. **Share Concerns and Prognosis**
4. **Explore** what matters
5. **Summarize** the Conversation

Align with their hope, but plant the seeds of change

"I'd like to share with you **my understanding** of your illness… [*very brief summary]"*

*Then use **Wish/worry, hope/worry framework***

> ***E.g. Uncertainty:*** "I hope that you continue to stay well, but I worry that you could get sick quickly and I think it's important to prepare for that possibility…"

Exploring what matters and summarizing

1. **Open** the conversation.
2. **Explore** Understanding
3. **Share** Concerns and Prognosis
4. **Explore what matters**

- **Goals/hopes**
- **Worries** about future
- **Unwilling to sacrifice** [these abilities]
- **Willing to go through** [tests, hospital, CPR…]

5. **Summarize** the Conversation

"**I've heard** you say ________ are important to you. With that and what we know about your illness, **I recommend** that we ___________."

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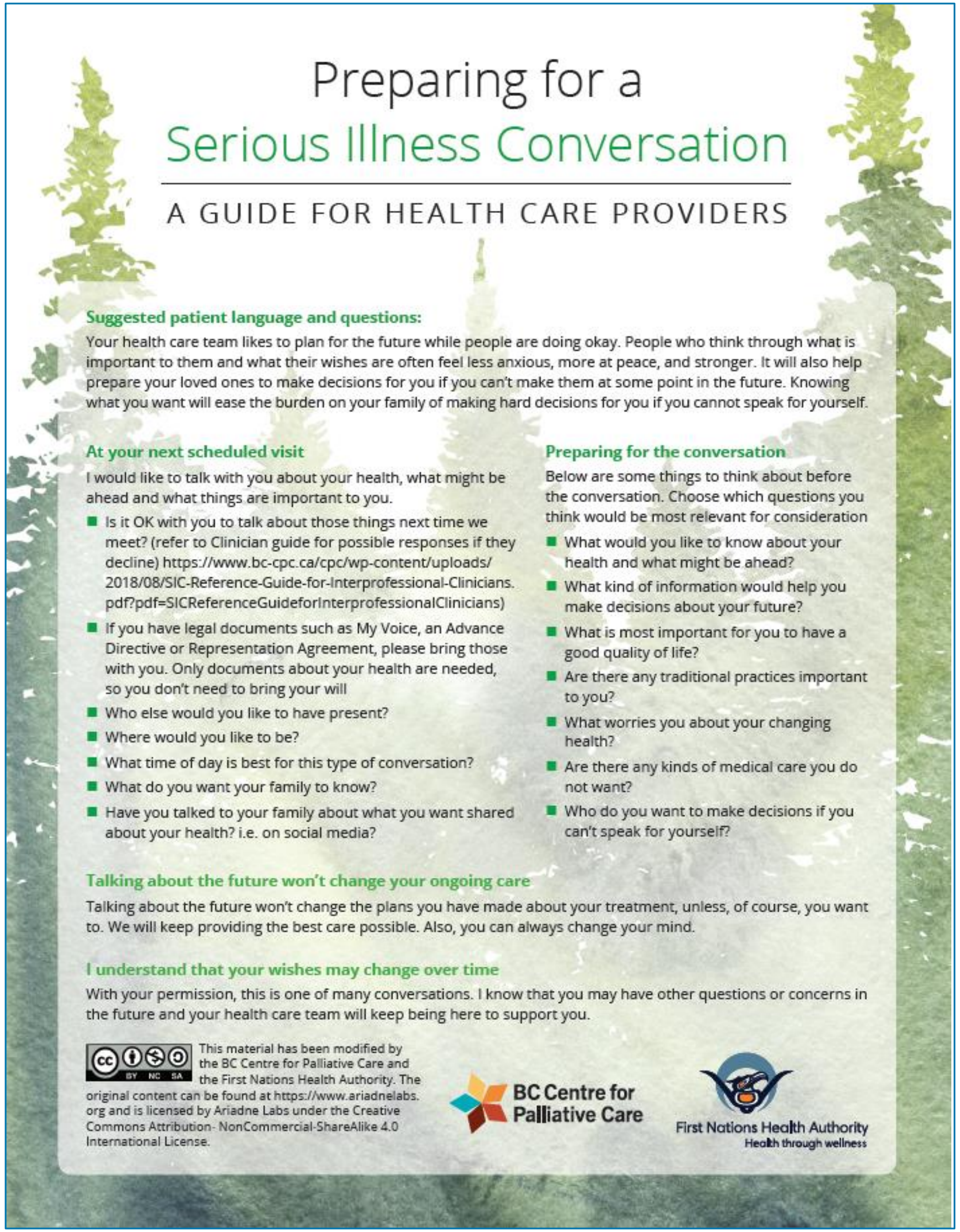
Conversations that are culturally safe and trauma-informed

- Prepare the patient in advance
  - –Who would they like present?
  - –Do they have an ACP?
  - –Family awareness?

“What do I need to know about you to give you the best care possible?”



Preparing for a Serious Illness Conversation

A GUIDE FOR HEALTH CARE PROVIDERS

Suggested patient language and questions:

Your health care team likes to plan for the future while people are doing okay. People who think through what is important to them and what their wishes are often feel less anxious, more at peace, and stronger. It will also help prepare your loved ones to make decisions for you if you can't make them at some point in the future. Knowing what you want will ease the burden on your family of making hard decisions for you if you cannot speak for yourself.

At your next scheduled visit

I would like to talk with you about your health, what might be ahead and what things are important to you.

- Is it OK with you to talk about those things next time we meet? (refer to Clinician guide for possible responses if they decline) https://www.bc-cpc.ca/cpc/wp-content/uploads/2018/08/SIC-Reference-Guide-for-Interprofessional-Clinicians.pdf?pdf=SICReferenceGuideforInterprofessionalClinicians)
- If you have legal documents such as My Voice, an Advance Directive or Representation Agreement, please bring those with you. Only documents about your health are needed, so you don't need to bring your will
- Who else would you like to have present?
- Where would you like to be?
- What time of day is best for this type of conversation?
- What do you want your family to know?
- Have you talked to your family about what you want shared about your health? i.e. on social media?

Preparing for the conversation

Below are some things to think about before the conversation. Choose which questions you think would be most relevant for consideration

- What would you like to know about your health and what might be ahead?
- What kind of information would help you make decisions about your future?
- What is most important for you to have a good quality of life?
- Are there any traditional practices important to you?
- What worries you about your changing health?
- Are there any kinds of medical care you do not want?
- Who do you want to make decisions if you can't speak for yourself?

Talking about the future won't change your ongoing care

Talking about the future won't change the plans you have made about your treatment, unless, of course, you want to. We will keep providing the best care possible. Also, you can always change your mind.

I understand that your wishes may change over time

With your permission, this is one of many conversations. I know that you may have other questions or concerns in the future and your health care team will keep being here to support you.

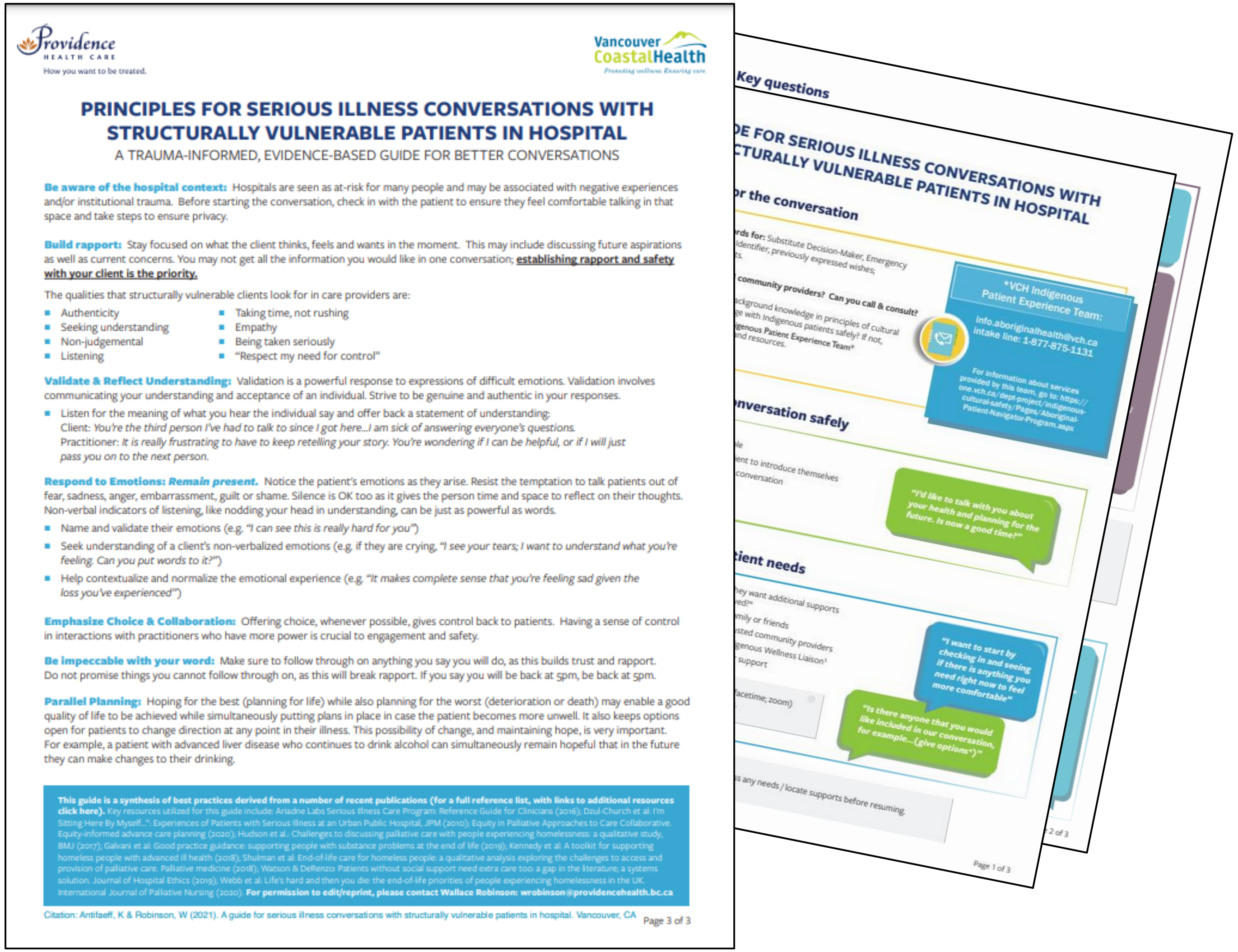
BC Centre for Palliative Care

First Nations Health Authority
Health through wellness

Vancouver CoastalHealth

Conversation Guide for Patients with Structural Vulnerabilities

- Rapport and connection (in the moment) are key
- First, assess and address basic needs
- Use a parallel planning approach
  - –Plan for more than one possible path (eg current path and possibility of making an expressed change)
- Guide for use in community settings under development



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Promoting wellness. Ensuring care.

PRINCIPLES FOR SERIOUS ILLNESS CONVERSATIONS WITH STRUCTURALLY VULNERABLE PATIENTS IN HOSPITAL

A TRAUMA-INFORMED, EVIDENCE-BASED GUIDE FOR BETTER CONVERSATIONS

Be aware of the hospital context: Hospitals are seen as at-risk for many people and may be associated with negative experiences and/or institutional trauma. Before starting the conversation, check in with the patient to ensure they feel comfortable talking in that space and take steps to ensure privacy.

Build rapport: Stay focused on what the client thinks, feels and wants in the moment. This may include discussing future aspirations as well as current concerns. You may not get all the information you would like in one conversation; **establishing rapport and safety with your client is the priority.**

The qualities that structurally vulnerable clients look for in care providers are:

- Authenticity
- Seeking understanding
- Non-judgemental
- Listening
- Taking time, not rushing
- Empathy
- Being taken seriously
- "Respect my need for control"

Validate & Reflect Understanding: Validation is a powerful response to expressions of difficult emotions. Validation involves communicating your understanding and acceptance of an individual. Strive to be genuine and authentic in your responses.

- Listen for the meaning of what you hear the individual say and offer back a statement of understanding:
  Client: *You're the third person I've had to talk to since I got here...I am sick of answering everyone's questions.*
  Practitioner: *It is really frustrating to have to keep retelling your story. You're wondering if I can be helpful, or if I will just pass you on to the next person.*

Respond to Emotions: *Remain present.* Notice the patient's emotions as they arise. Resist the temptation to talk patients out of fear, sadness, anger, embarrassment, guilt or shame. Silence is OK too as it gives the person time and space to reflect on their thoughts. Non-verbal indicators of listening, like nodding your head in understanding, can be just as powerful as words.

- Name and validate their emotions (e.g. *"I can see this is really hard for you"*)
- Seek understanding of a client's non-verbalized emotions (e.g. if they are crying, *"I see your tears; I want to understand what you're feeling. Can you put words to it?"*)
- Help contextualize and normalize the emotional experience (e.g. *"It makes complete sense that you're feeling sad given the loss you've experienced"*)

Emphasize Choice & Collaboration: Offering choice, whenever possible, gives control back to patients. Having a sense of control in interactions with practitioners who have more power is crucial to engagement and safety.

Be impeccable with your word: Make sure to follow through on anything you say you will do, as this builds trust and rapport. Do not promise things you cannot follow through on, as this will break rapport. If you say you will be back at 5pm, be back at 5pm.

Parallel Planning: Hoping for the best (planning for life) while also planning for the worst (deterioration or death) may enable a good quality of life to be achieved while simultaneously putting plans in place in case the patient becomes more unwell. It also keeps options open for patients to change direction at any point in their illness. This possibility of change, and maintaining hope, is very important. For example, a patient with advanced liver disease who continues to drink alcohol can simultaneously remain hopeful that in the future they can make changes to their drinking.

This guide is a synthesis of best practices derived from a number of recent publications (for a full reference list, with links to additional resources click here). Key resources utilized for this guide include: Ariadne Labs Serious Illness Care Program: Reference Guide for Clinicians (2016); Dzul-Church et al: I'm Sitting Here By Myself...": Experiences of Patients with Serious Illness at an Urban Public Hospital, JPM (2010); Equity in Palliative Approaches to Care Collaborative. Equity-informed advance care planning (2020); Hudson et al.: Challenges to discussing palliative care with people experiencing homelessness: a qualitative study, BMJ (2017); Galvani et al: Good practice guidance: supporting people with substance problems at the end of life (2019); Kennedy et al: A toolkit for supporting homeless people with advanced ill health (2018); Shulman et al: End-of-life care for homeless people: a qualitative analysis exploring the challenges to access and provision of palliative care. Palliative medicine (2018); Watson & DeRenzo: Patients without social support need extra care too: a gap in the literature; a systems solution. Journal of Hospital Ethics (2019); Webb et al: Life's hard and then you die: the end-of-life priorities of people experiencing homelessness in the UK. International Journal of Palliative Nursing (2020). **For permission to edit/reprint, please contact Wallace Robinson: wrobinson@providencehealth.bc.ca**

Citation: Antifaeff, K & Robinson, W (2021). A guide for serious illness conversations with structurally vulnerable patients in hospital. Vancouver, CA

Page 3 of 3

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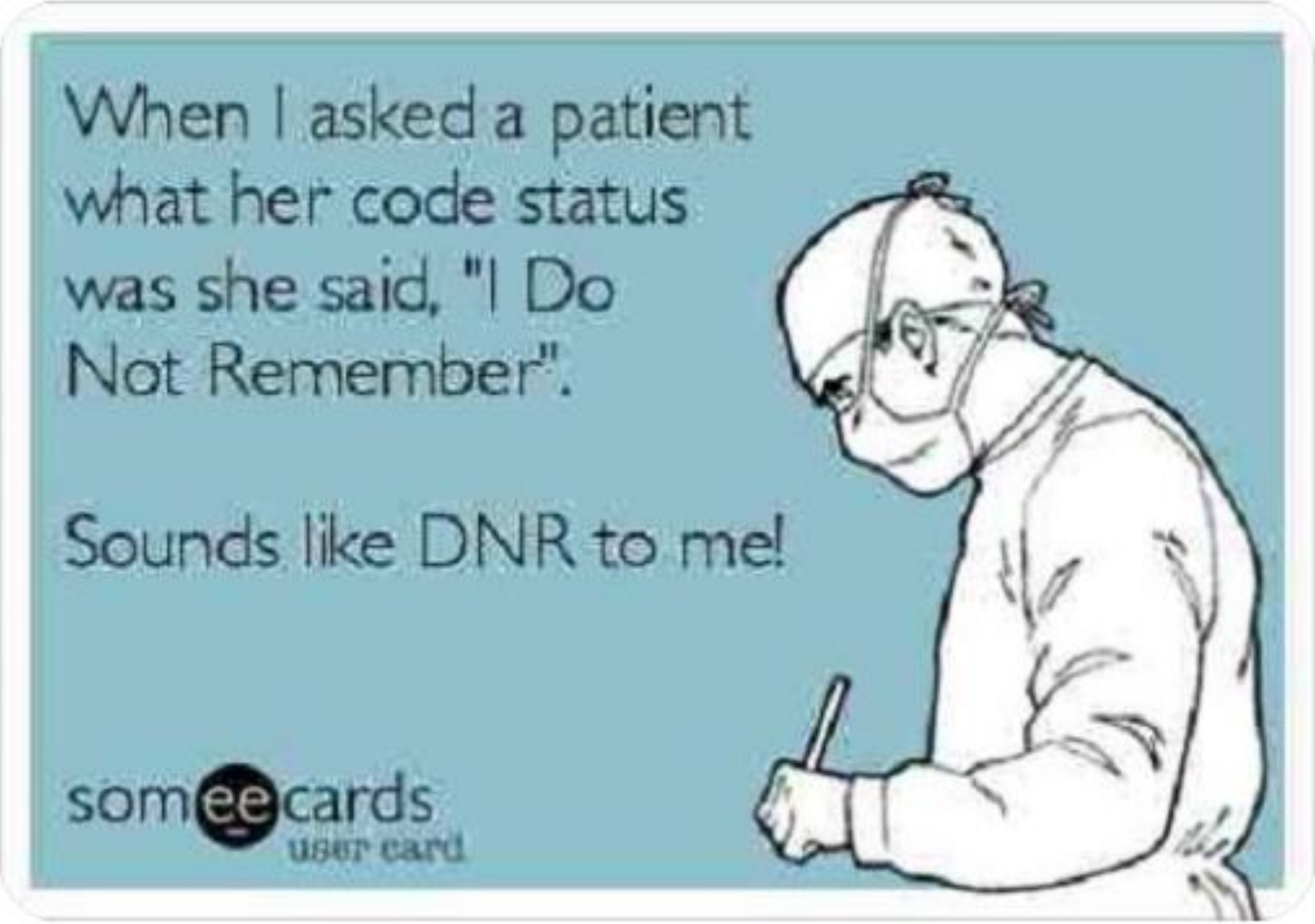
Wise words from Wendy



When I asked a patient what her code status was she said, "I Do Not Remember".

Sounds like DNR to me!

Retrieved from Pinterest

We need to *normalize* these conversations

“I have this conversation with everyone who has [*a chronic or serious health condition*].”

Sharing prognosis or medical updates

- Hope, honesty and hopefulness
  - speak in the third person to soften
  - instead of “you have cancer” → use “tests show you have cancer”
- “Wish, worry, wonder”
- Pause… wait out the silence

“I **wish** ___… but I **worry** ___…
and I **wonder** ___ …”

When decisions are needed urgently…

Share either:

1. "The expectation is that this is treatable and you will get better. However, ***if*** you become very sick…"
2. "We are going to do *everything* we can to manage your symptoms and hope for improvement… However, we need to have a plan **in case you become *sicker***."

Then, explore these 3 key topics:

1) Do you have an advanced care plan?
2) Have you ever thought about treatments that you would never want?
3) Who would know your wishes if you were unable to speak for yourself? (SDM)

Making recommendations for care:

Focus on what we WILL do

Principle: First focus your recommendations on appropriate treatments being offered, not on CPR.

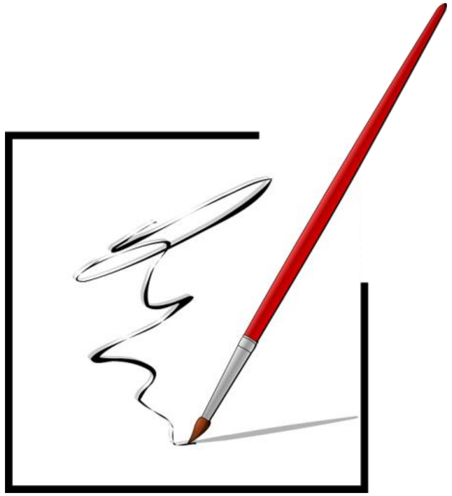
- “We can focus on what we **can** treat to help you to feel better…”
- “You will get the best care possible even if we can’t fix everything…”
- “We will help you and your family to live meaningfully in the time you have left…”

Tips when hearing “I want everything done”

- “Yes, we will do everything we can to **treat what we can**.”
- “If we cannot treat for cure, there is plenty that we can treat to prolong a good quality of life.”

May need to engage in a detailed conversation about <u>what everything would entail</u>. Most people do not know that dying in an ICU entails…

- Sedation
- Restraints
- minimizing pain meds
- being unable to communicate with family
- little chance of returning to previous level of functioning
- requiring long-term care



Painting the picture

CPR and critical care discussions

- Frame discussion in context of patient’s wishes, values and prognosis

  e.g. “You told me that the most important thing was time with your family, and to not suffer, so what we should focus on is the most appropriate care for you.”

- “Some people become so ill that they need CPR, transfer to the ICU to be kept alive with a breathing tube and a breathing machine. Is that something you have thought about?”

- If CPR is not appropriate…there is a lot that can be treated before we get to CPR. Describe the escalating care that goes through DNR levels M3-C2 as appropriate to prognosis. E.g. “If you became septic and needed to be in a HAU setting, for pressors, etc, I think that would be appropriate in your case.”

- CPR in this type of condition would lead to a traumatic painful undignified death.

Group discussion

How is this framework *different* or *similar* to your current approach?

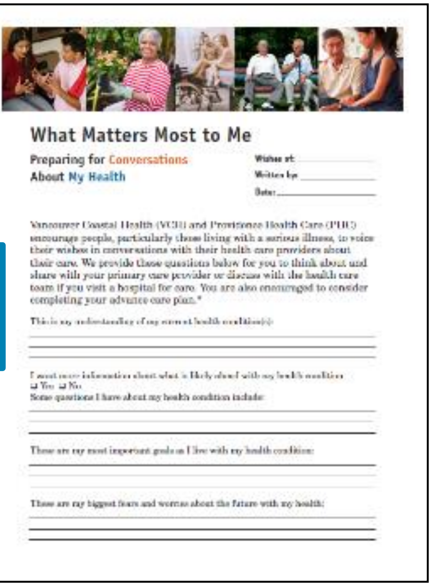
What challenges have you experienced in having these conversations?

Resources to support your practice

- RPACE webpage on internal and external VCH websites
  - Adapted conversation guides
  - Translated materials
  - Screening tools

- CME accredited workshops for physicians
  - 5 workshops over the coming year presenting the original SICG and three other adaptations dates TBA
  - Watch for an announcement coming to an inbox near you!

rpace@vch.ca



What Matters Most to Me

Preparing for Conversations
About My Health

Wishes of: ____________
Written by: ____________
Date: ____________

Vancouver Coastal Health (VCH) and Providence Health Care (PHC) encourage people, particularly those living with a serious illness, to voice their wishes in conversations with their health care providers about their care. We provide these questions below for you to think about and share with your primary care provider or discuss with the health care team if you visit a hospital for care. You are also encouraged to consider completing your advance care plan.*

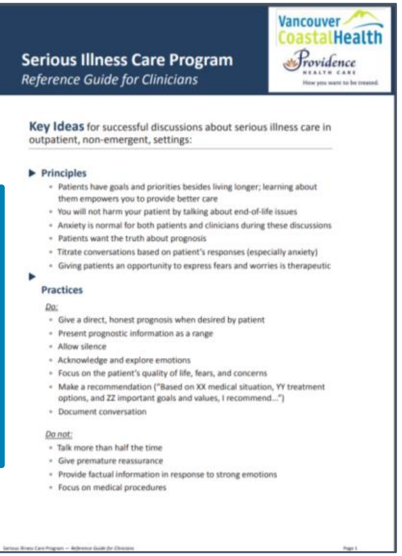
This is my understanding of my current health condition(s):

I want more information about what is likely ahead with my health condition:
☐ Yes ☐ No
Some questions I have about my health condition include:

These are my most important goals as I live with my health condition:

These are my biggest fears and worries about the future with my health:

Translations available!



Serious Illness Care Program
Reference Guide for Clinicians

Vancouver CoastalHealth
Providence HEALTH CARE
How you want to be treated.

Key Ideas for successful discussions about serious illness care in outpatient, non-emergent, settings:

Principles
- Patients have goals and priorities besides living longer; learning about them empowers you to provide better care
- You will not harm your patient by talking about end-of-life issues
- Anxiety is normal for both patients and clinicians during these discussions
- Patients want the truth about prognosis
- Titrate conversations based on patient's responses (especially anxiety)
- Giving patients an opportunity to express fears and worries is therapeutic

Practices

Do:
- Give a direct, honest prognosis when desired by patient
- Present prognostic information as a range
- Allow silence
- Acknowledge and explore emotions
- Focus on the patient's quality of life, fears, and concerns
- Make a recommendation ("Based on XX medical situation, YY treatment options, and ZZ important goals and values, I recommend…")
- Document conversation

Do not:
- Talk more than half the time
- Give premature reassurance
- Provide factual information in response to strong emotions
- Focus on medical procedures

Serious Illness Care Program — Reference Guide for Clinicians Page 1

SICG Clinician Reference Guide -- Tips for navigating strong emotions or resistance

Thank you for having us

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