

A GUIDE FOR SERIOUS ILLNESS CONVERSATIONS WITH STRUCTURALLY VULNERABLE PATIENTS IN HOSPITAL

1 Prepare for the conversation

Review Health Records for: Substitute Decision-Maker, Emergency Contacts, Indigenous Identifier, previously expressed wishes; recent health care visits.

Who are their trusted community providers? Can you call & consult?

Do you have sufficient background knowledge in principles of cultural safety & humility to engage with Indigenous patients safely? If not, engage with the **VCH Indigenous Patient Experience Team*** for supports and resources.

***VCH Indigenous Patient Experience Team:**

info.aboriginalhealth@vch.ca
intake line: 1-877-875-1131

For information about services provided by this team, go to: <https://one.vch.ca/dept-project/indigenous-cultural-safety/Pages/Aboriginal-Patient-Navigator-Program.aspx>

2 Introduce the conversation safely

- Identify yourself and your role
- Allow ample time for the patient to introduce themselves
- Introduce the purpose of the conversation
- Take time to establish rapport
- Ensure privacy

“I’d like to talk with you about your health and planning for the future. Is now a good time?”

3 Assess & address patient needs

Are their basic needs met?

- Withdrawal
- Pain
- Food
- Clothing

Do they want additional supports involved?*

- Family or friends
- Trusted community providers
- Indigenous Wellness Liaison¹
- Peer support

Offer to use technology to connect (facetime; zoom) or reconvene when person is available.

“I want to start by checking in and seeing if there is anything you need right now to feel more comfortable”

“Is there anyone that you would like included in our conversation, for example...(give options)”*



PAUSE to address any needs / locate supports before resuming.

4

Key questions

- Reflect back what you hear
- Check for accuracy
- Validate their experience
- If sharing a prognosis*, consider using the “wish... worry” framework:



e.g. in terms of uncertainty:
*“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 in terms of time:
*“I **wish** you were not in this situation, but I am **worried** that time may be as short as... (express in range: days to weeks, weeks to months, months to a year).”*

In urgent situations:

“I know it can be scary to talk about. We are working hard to help you feel better but I’m worried things could get worse quickly. It’s important that we know how you want to be cared for if things change.”

- ▼ *“What’s your understanding about your health and why you are in hospital right now?”*
- ▼ *“Would it be ok if I shared our understanding of what’s going on?” (Share medical understanding, any updates, or prognosis*...)*
- ▼ *“What’s most important to you now as you think about your health?”*
- ▼ *“As you think about your health, what worries you?”*
- ▼ *“How much treatment / time in the ICU / time in the hospital (be specific about decisions relevant to their current health) are you willing to go through for the possibility of more time?”*
- ▼ *“Is there anything else you would like us to know so we can treat you the way you want to be treated?”*



The pace of the conversation should be determined by the patient. One or two questions might be all they are able to engage with. Respecting their window of tolerance is an important part of trauma-informed care.

Ask them when you can come back to continue the conversation – and make sure to follow through.

Doing what you say you will do builds trust and rapport.

5

Summarize, Recommend, Document

- Summarize & check for accuracy
- Offer to come back
- Make recommendations, invite feedback
- Offer a written summary
- Document the conversation
- Share discharge summary with primary care team

- ▼ *“Given what you have told me, it sounds like (A, B, and C) are most important to you. Am I hearing that right? (Pause & wait for response)... Because of that, I would recommend (X, Y, and Z). How does that sound to you?”*
- ▼ *“Would you like me to write it down for you to review?”*
- ▼ *“It sounds like you need some time to think about our conversation. Can I check back with you later?”*
- ▼ *“Would it be ok if I share what we talked about today with (eg your primary care provider)?”*

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**