Advance Care Planning & Goals of Care Discussion Guide for Healthcare Providers

Advance Care Planning

A guide for making healthcare decisions
with loved ones and healthcare providers

CONVERSATIONS MATTER

Plan your healthcare together

August 17, 2015

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Introduction

The purpose of this guide is to provide evidence-based best practices for engaging in ACP and goals of care discussions with older and/or seriously ill patients and their loved ones. The focus is on *functional ACP/GCD talk*. That is, talk that promotes patients/families engagement in and understanding of ACP/GCD through their talk and body language.

This guide is organized into sections of the essential elements or topics of functional ACP/GCD talk. Each section contains:

- main points for discussion
- evidence-based illustrative examples of ACP/GCD talk.

The sequence of the sections allows the essential elements of the ACP process to build upon each other. The sections can be discussed in one or two longer consultations or over a series of shorter consultations.

We recommend the use of ACP, GCD and green sleeve patient information materials as part of the conversations. Information materials provide the patient/family with

- a visual aid to assist them with following along during the conversation,
- a resource to take home to remind them of what was discussed, and
- a guide that can assist them to talk with their family.

This booklet is intended to be a guide for ACP/GCD conversations, not a script. Although examples of talk are provided, conversations with each patient should be organic (i.e., talk should adapt to the patient and the situation).

Appendix A contains general tips for having ACP/GCD conversations and asking questions.

TIP: With practice comes competence.
With competence comes comfort.
With comfort comes confidence.

Introducing Advance Care Planning to Patients

Some patients will provide a natural lead in by telling you about a healthcare experience (s)he or someone (s)he knows had that concerned her/him.

Example of talk:

Patient: My daughter had cancer and it was awful watching them do all those painful things to her. I don't want any of that.

HCP: You don't have to go through your daughter's cancer journey. Most people, when they hear of things like cancer, think about all of the things that people they love went through. What we want to do is make sure that you know what's available to you so you can get back to living as best as you can and have hope for that living. We can help you plan your healthcare with something called advance care planning. We offer advance care planning to everyone 18 years and older. (pause)

I would like to tell you more about advance care planning. Would that be okay with you?

Some patients are in an acute health crisis and they have not done ACP and/or GCD.

Example of talk:
Mr. Jones, as your doctor I want to provide you with the best possible care and make sure that I am giving you the care that *you* want.

In Alberta, we have advance care planning that we offer to everyone 18 years and older. (pause)

Advance care planning helps you to understand what healthcare options are available to you. Then you decide how you want us to care for you if you are not able to speak while you are ill. (pause)

I would like to tell you more about advance care planning. Would that be okay with you?

The ideal is introducing ACP/GCD when the patient is stable.

Example of talk:
As a healthcare provider, it is my goal to provide you with the best possible care and make sure that I am giving you the care that *you* want. One way I do that is by meeting with patients to talk about health planning. In Alberta, we have advance care planning that we offer to everyone 18 years and older. (pause)

Advance care planning helps you to understand what healthcare options are available to you. Then you decide how you want us to care for you if you are ill or injured and not able to speak. (pause)

I would like to tell you more about advance care planning. Would that be okay with you?

Main points:

- You want to provide the patient with the best possible care and you want to give the patient the care (s)he wants
  - These points together reassure the patient that you are there for him/her and that you care about his/her goals for care

- ACP is open to all Albertans 18 years and older
  - This helps to normalize the talk so the patient does not feel targeted

- ACP aids patients in understanding available healthcare options so they can choose care suited to their goals of care

- You want to tell the patient about ACP, followed by a positively worded request for acceptance.
  - Please refer to Appendix A for tips on asking questions

Defining Advance Care Planning

When defining ACP, it would be helpful to give patients/family ACP information materials. You can tell them it is for them to follow along with the main points during your conversation if they wish and to take home to share with their loved ones.

Main points:

- Advance care planning
    - is a process that helps people to think about and talk about their goals for future healthcare should they be unable to speak for themselves.
    - helps people to create and put into place plans to describe the type of care they want.
    - is a gift people give to others. If they are sick or injured and unable to speak, there is a lot less stress if their family, friends and healthcare providers know what care they want rather than having to guess.

- Some people are able to guide their care right up until they die – other people are not able to speak for a period of time (e.g., they may be unconscious, in a coma, had a stroke, or have advanced Alzheimer's). In situations like these, it is best to have healthcare plans in place to allow someone else to speak for them so their voice is heard.

- It is best to do advance care planning when someone is feeling able rather than during a crisis.

- ACP is voluntary. HCPs are there to give information, answer questions and help with the process.

Example of talk:
Advance care planning helps you to think about, talk about and document your wishes for healthcare so you're an active participant in the planning process. (pause)

We want to see you as an active participant. We don't want you feeling like, 'You know what, this is all going on and people are making decisions about my healthcare without me being involved.' That's why we really like to talk about advance care planning when you're feeling able and not in a health crisis. (pause)

Example of talk:

It's my hope that everyone can make their own healthcare decisions right up until they die, but we can't predict that. I've heard of healthy people who slipped on the ice, hit their head, had a brain bleed and it was just totally unexpected. Advance care planning is a little bit of peace of mind for all of us. (pause)

We can't protect ourselves all the time and walk around in bubble wrap. But if you plan ahead, at least other people know what you want if something happens. That can help relieve some of the stress during a crisis. (pause)

If you have an advance care plan, someone you trust is set to help guide your medical care. Does that make sense? (pause)

No one can make you do advance care planning. I can only give you information, answer your questions and help you with the process. It's something you choose to do. Do you have questions about what I have said so far? (pause)

Outlining the ACP process

Example of talk:
I would like to take a couple of minutes to first give you a brief overview of what’s involved in the advance care planning process. Is that okay with you? (pause)

We’ll meet several times to talk about the different parts of the advance care planning process. Please feel free to invite people important to you to join our talks. (pause)

Each time we meet we’ll build upon what we talked about before. If you have questions about something, please feel free to ask whenever you like. Okay? (pause)

We’ll start by talking about what’s important to you in your life and how those things can influence the type of healthcare you want. (pause)

Then we’ll discuss how to go about deciding on an agent. An agent is someone who will speak for you and help us hear your voice if you can’t speak for yourself. (pause)

We’ll talk about the care options we can offer you and you’ll decide what’s going to be helpful to you to achieve ***your*** goals for a life worth living. (pause)

Over time, we’ll revisit your goals for healthcare to make sure that they still reflect your wishes. Nothing is set in stone. You can change your wishes whenever you want. (pause)

It’s my hope that through this process we’ll build a relationship based on trust and openness. I’ll work to foster your hopes for living as well as you can while you’re ill or injured or until you die.

Do you have questions for me before we get started?

Personal Notes

Learning about patient values and beliefs

Main points:

- Learning about the patient and his/her life is an important part of advance care planning. Possible approaches:
  - Please tell me about the important people in your life.
  - What do you (or did you) do for work?
  - Are there religious beliefs that are important to you?
  - What is important to you in your life?
  - What makes you happy in your life?
  - What do you think makes your life worth living?
- Paraphrasing the patient’s talk and asking for confirmation of your interpretation is a good way to ensure your understanding.
  - It sounds to me like you are a very independent person. AND/OR It sounds to me like you have a strong sense of family that helps to guide your life. Is that how you see yourself?
  - It sounds to me like you are a very sociable person. OR It sounds to me like you are a very private person. Is that how you see yourself?

Example of talk:

Part of advance care planning is thinking about what’s important to you. What gets you out of bed in the morning. Please tell me about the important people and things in your life. (pause)

It sounds to me like you are an independent person and that staying independent is very important to you. Is that how you see yourself? (pause)

It would be good to make sure that your family and healthcare providers understand that. You may want to plan your future care so you can stay as independent as possible. As we go through the advance care planning process, we can talk more about how best to do that for you.

Learning about patient health experiences

Main points:

- Learning how patients interpret their health condition and what questions they have about their health can help you to frame later talk about goals of care. Possible approaches:
  - How have you been doing for the last while?
    - This general approach allows the patient to discuss physical concerns and psychosocial issues (this tells you what is most salient to him/her at the time and aids in understanding the patient’s perspective). The indeterminate time frame allows the patient to set parameters.
  - What concerns do you have about your health?
    - The question assumes the patient has concerns. This is a fair assumption given that you are likely talking to seriously ill and/or older adults. If the patient does not have concerns, he/she will say so.
  - Is there some health information you would find helpful? OR What health information would you find helpful?
    - This approach gives the patient an opportunity to express expectations, such as prognosis and healthcare options.

Example of talk:

Thank you for sharing that information about your life and what is important to you. It helps me to get to know you better. (pause)

It’s also important for me to learn about your health. How have you been doing for the last while? (pause)

It sounds to me like you have concerns about (XXXX). Please tell me more about that. (pause)

Is there some health information you’d find helpful?

- Helping patients to equate past personal healthcare experiences and/or those of others to some more specific healthcare options can help them to start (or continue) formulating their goals for care.

Example of talk:
I believe that the life experiences that you’ve had are the most powerful things because you’ve lived them and you may have seen what choices other people have made in different situations. (pause)

So I suggest you look to your past, your family, your friends, anyone who’s had health challenges or been in situations, and say, ‘I want this because I think that makes sense to me,’ or ‘I don’t want this because that was what happened here, and I don’t want to go down that road.’ I think that’s what gives people the most insight into their own choices – what you’ve lived. Those situations can inform you about what you might want for your care. Does that make sense to you? (pause)

What life experiences make you think about the type of healthcare you’d want?

- Sometimes patients' healthcare experiences and/or those of others cause them to feel anxious or afraid. Take time to reassure patients that they will be provided with care and that healthcare providers will work to help them achieve their goals for care.

Example of talk:
It can be distressing thinking about what your friend went through. You don't have to be afraid of dying an uncomfortable death. We have very good comfort care. For example, if you're very uncomfortable with your breathing, then we give you some more medication to keep you comfortable until you naturally die. You don't have to worry about that. We'll take care of you by giving you the care that best fits your goals for care. (pause)

Example of talk:
Most people become anxious or afraid when they think about things like cancer. But it's important to know that you can live with cancer, even cancer we can't cure. You've got some living left to do. I don't know when I'm going to die. I don't know for sure when anybody's going to die. (pause)

It's important to know that you can be healthy even in the face of illness. To me, being healthy means having strong, healthy relationships, being in control of what happens to you, being able to talk about the things that make you afraid or angry. It also means being able to talk about the things that are important for living and life worth living. That's what we're going to work on. (pause)

Talking about an Agent

Main points:

- An agent can be anyone over the age of 18 years who has capacity to make decisions
- Agents can be a family member or a friend and there can be more than one agent
- If they do not want a family member or friend to be their agent, they can get a public guardian
- An agent should be someone they can count on to share their health information and wishes for care with healthcare providers if they cannot speak

Example of talk:

Most people automatically go to family when considering who to ask to be their agent. But I like to say to people, if you’re going to name this family member, it’s good to consider if he or she does well in a crisis or if he or she is going to fall apart.

Sometimes it’s better to go even one step outside your immediate family circle, like a cousin or friend or someone who will support your decisions and your family. You want someone who can make the tough decisions, because sometimes people have to make tough decisions. (pause)

You want an agent you can trust to follow your wishes and not their own. Does that make sense? (pause)

Do you have someone in mind who you would like to be your agent? (pause)

Encouraging patients to communicate with family/friends

Main points:

- It is good to stress to patients that it is very important to make sure the person (or people) they wish to be their agent(s) is/are aware of that and that their healthcare wishes are known to their agent(s) before a health crisis.

Example of talk:
I encourage people who've done advance care planning to have a good chat with their agent or agents and their family. It's important to make sure these people know what you want and that they have copies of your documents if they need them. (pause)

When talking with the agent you want, you can say something like, 'I've given it a lot of thought and if something happens to me and I can't talk, I'd really like you to be my agent. That's the person who tells my doctors what type of care I want. Are you willing to be my agent?'

Do you feel comfortable talking with the person you want to be your agent?

- Encourage patients to let the people in their life know who their agent is and their wishes for healthcare.

Example of talk:
Talking about your healthcare wishes with people important to you can be difficult. But I really encourage you to let them know so they aren't surprised if something happens.

I recommend that when you pick your agent that you're transparent with everyone else in your life so that if something happens, there's no fighting.

There are always lots of emotions in a crisis and if everyone knows who will speak for you if you can't speak, that relieves some of the stress. (pause)

Are you comfortable doing that?

Example of talk:
When talking with people you could say something like, 'If I'm no longer able to walk or do the things that I enjoy in life, I don't want my life prolonged unnecessarily.'

Or something like, 'If I have a bad stroke and the doctors don't feel I will recover to where I was before but I still know who you are, I want everything done to keep me alive. But if I'm in a coma and I'm not going to recover, please let me go. (pause)

Are you comfortable having this kind of conversation?

- Encourage patients to keep the conversations going over time – keep those people important to them updated on changes to their wishes.

Example of talk:
I highly recommend that you keep the conversations going over time, especially if your health or something important changes in your life.

For example, let people know what 'life support' means to you in different situations. When people know what you want, it's easier for them to be supportive of you and to make the tough decisions if needed. (pause)

Grief is never easy, but I think when everyone knows your wishes and respects them at the end of life, there is more of a sense of peace that what was done was what you wanted.

I think when people feel like they're guessing about someone's wishes, the grief after death can be longer or more difficult to come to terms with because you're always wondering, 'Did I make the right choice? Should I have done something different?' So just having that conversation can make a big difference to the people important to you. (pause)

Does that make sense?

Personal directive

You may wish to have a copy of the Personal Directive form to show patients while you are talking.

Main points:

- A personal directive is a legal document but they do not need a lawyer to complete it. As long as they sign it in front of witnesses and the witnesses sign it, it is legal.
- A personal directive does not come into effect unless they are not able to communicate their healthcare choices.
- It has nothing to do with finances or property. That is a Power of Attorney.
- It gives their agent, loved ones and healthcare providers direction.
- The personal directive forms can be found at http://humanservices.alberta.ca/guardianship-trusteeship/opg-personal-directives.html

Example of talk:
A personal directive is a legal document that tells your healthcare providers and loved ones who you want to be your agent and what type of care you want. You can write down the cultural, spiritual and personal beliefs that guide you on what care you want. (pause)

I'll give you a scenario when it would be really important to have this legal document. Say you got very sick, couldn't talk any more, you're unable to move back to your home, and a decision was made that you had to go to a care facility, a nursing home or something. Before you could go to a care facility, if you didn't have a personal directive naming who can speak for you, we'd have to keep you in the hospital until your family went to court to become your guardian. And that takes time and there are court costs. But if you have a signed personal directive, your agent can legally speak for you and the court process is avoided. (pause)

Example of talk:
When filling in the personal directive, you can be as detailed as you want.

For example, you can say something like, ‘If I’m expected to make a full recovery in the intensive care unit I’d like all treatments, but if I’m not expected to live, I don’t want my life prolonged unnecessarily.’

You can list things like feeding tubes, machine to help you breath, those kinds of things, whether you would want them or not want them. (pause)

These are *your* decisions. We respect those decisions. You look at your health and what you think is important to you in your life and you make the decisions.

Do you have questions for me about the personal directive?

Personal Notes

Defining goals of care

When defining goals of care, it would be good to give patients/family GCD information materials and a GCD form.

Main points:

- ➢ Goals of care has two parts.
    1. A conversation with a healthcare provider about ***their*** goals for what healthcare they want provided if they cannot speak.
    2. A doctor or nurse practitioner completes a Goals of Care Designation Medical Order form and signs it.
- ➢ The Goals of Care Designation Order form complements the Personal Directive.

Example of talk:

Part of advance care planning is deciding your goals of care. Goals of care is our way saying the healthcare that best fits with how you want to be cared for. You can talk about goals of care with any healthcare provider. You don't have to wait for a healthcare provider to start the conversation. (pause)

The reason that talking about goals of care is important is that we want to make sure that you know what's available to you. That way you'll be able to choose care that helps you to live as best you can and have hope for that living when you're ill, injured or near the end of your life. (pause) Does that make sense?

Part of goals of care is talking with a doctor or nurse practitioner about completing what we call a goals of care designation medical order form (show patient the form). This form tells healthcare providers what care you want if you can't speak for yourself and your agent is not with you. The goals of care designation medical order form goes along with your personal directive. It's really important to have both forms. (pause)

I'm going to tell you about our goals of care next, but first I wanted to see if you have questions about what I've said?

- There are three goals of care designations with some variation within each.
- **Medical Care** has two designations:

  M1: For patients who do not want to have intensive treatments or when those treatments would not help them to achieve a way of living that is important to them. The patient goes to the hospital to get treatment for illness and injury, but does not want to go to the intensive care unit and have more aggressive treatments (e.g., CPR, which can be explained as a machine that breathes for them, pushing on the chest and/or shocking their heart if it stops beating).

  M2: For patients who live in supportive living, a nursing home, rural hospitals akin to tertiary care, or their own home. These patients prefer to be treated by a healthcare provider where they live and avoid further hospital visits. If they do not respond to the medical treatments possible where they live, then their healthcare team would likely switch to a focus on comfort care. They can go to the hospital for minor things, like stitches for deep cuts, but would go home afterwards.

Example of talk:
The first area of care I want to talk with you about is what we call Medical Care. In this pamphlet (show the patient a resource that explains Medical Care) it describes Medical Care as (read the description). (pause)

Another way to think about this is that some people say to us, ‘I’ve been to the intensive care unit and I don’t want that again. I want to go to hospital for minor treatment, tests and may be to have surgery, but if things don’t do well, let me go. Try to help me as best you can, but I don’t want aggressive treatments.’

Do you have questions about Medical Care?

- **Comfort Care** has two designations.
  C1: For patients who have an incurable illness but who still have a fair bit of life left to live. They likely live at home. They want any treatable problems taken care of, but they do not want any aggressive treatments. They want as much support as possible to help relieve symptoms like pain, and to make sure that they are as comfortable as possible through their illness journey until they die.
  C2: For patients who are very near the end of their life (in the final hours, days or weeks). All their care is focused on helping them to be comfortable until they die.

Example of talk:
The next area of care is what we call Comfort Care. The pamphlet describes Comfort Care as (read description). (pause)

Another way to think about Comfort Care is that some people say, ‘I’ve lived a long life. I’ve had enough of all of the treatments that aren’t working. Just treat my symptoms, keep me stable, but don’t aggressively treat me.’ Others say, ‘I want you to focus more on me being comfortable and me having as good a quality of life as possible and no pain if possible until the end of my life. I want to die as peaceful as possible.’ (pause)

Comfort care doesn’t mean less care, it means the focus is on care and comfort and having a quality of life for the time remaining. It’s about keeping people comfortable and helping them towards a comfortable death, a comfortable and dignified death in a place that they want. They can go to the hospital for care if they want. (pause)

Comfort Care can involve hospice care. Many people think hospice is the place you go to die, but it is really the place you go to live near the end of your life. The focus is on helping you to live the way you want to, as best as you can, with you being in control of your care.

Do you have questions about Comfort Care?

- **Resuscitative Care** has three designations.
  R1: For patients who want to be kept alive as long as possible by any reasonable and appropriate means. This includes going to the intensive care unit, CPR and all life-sustaining machines and treatments deemed appropriate.
  R2: For patients who want to be kept alive as long as possible using all appropriate aggressive treatments *except* chest compressions because that would not help them to achieve a way of living that is important to them.
  R3: For patients who want to be kept alive as long as possible using all appropriate aggressive treatments *except* chest compressions and intubation. Defibrillation can be used to correct an irregular heartbeat, but is not used to restart the heart.

Example of talk:
The next area of care is what we call Resuscitative Care. The pamphlet describes Resuscitative Care as (read description). (pause)

If we don't know what you want, we do everything, that is R1. So if your heart were to stop, we'd push on your chest, hook you up to a machine to help you breath, shock your heart to try to restart it, all the aggressive treatments we think are appropriate to keep you alive as long as possible. (pause)

But some people say to us, 'I don't want you pushing on my chest because you're going to break some ribs and it's not likely that I'm going to do well or survive.

So if there are things you don't want, that's when it's really important that we know, because we're wired to do everything deemed appropriate for your situation.

Do you have questions about Resuscitative Care?

Example of talk:
We want to provide you with the best possible care, but we don't want to do things that won't help you or that may harm you. (pause)

Most people believe that pushing on the chest and shocking the heart always work and that they'll be as they were before their heart stopped. Unfortunately, that's not the case. Pushing on the chest and shocking the heart only works about three percent of the time with people who have a serious existing health issue. And the people who are revived usually suffer from broken ribs, punctured lungs, they may be in a coma, and they usually end up with disabilities that seriously affect their quality of life. (pause)

I would like to help you find the care that's most likely to let you live the life you want. But nothing is written in stone. You can change your mind at any time. We want you to be directing us to giving you the care that meets your goals on living a life worth living for you. (pause)

Do you have some questions for me?

- Patients should tell all healthcare providers caring for them that they have a personal directive and a goals of care.

Example of talk:
Any doctor can do the goals of care designation medical order form. But if your family doctor doesn't know you did it with a specialist, the family doctor may ask you to do it again. You just have to bring a copy of the documents and say 'I'm organized!' Because the more people who understand what your healthcare wishes are, the better it is for you and us. We can then manage your care the way you want. (pause)

Do you feel comfortable doing that?

It's also important for us to know who you want us to talk to. Is it all of your family or are there some people in your family you don't want us to talk to? So we should see a copy of your personal directive too.

Personal Notes

Defining the green sleeve

When defining the green sleeve, it would be good to give patients/family one to see what it looks like.

Main points:

- The green sleeve is a portable document holder to help patients manage their advance care planning and goals of documents.
- It usually contains a copy of their personal directive, signed goals of care designation medical order form, the advance care planning tracking record and if possible an up-to-date list of medications.

Example of talk:
The green sleeve is your health passport that you own and manage. It’s a portable gateway to tell healthcare providers the type of healthcare you want – without it, unwanted care may be given. (pause)

You write your name and phone number on the front sticker. You take it with you to medical appointments with healthcare providers who haven’t seen it. They may wish to make a copy of your documents. (pause)

It’s very important that you keep your green sleeve somewhere on or very near your fridge because that’s where emergency response people are trained to look for it to take with you to the hospital. You can put it on the top, the side, on the front or beside the fridge just as long as it’s easy to find. (pause)

If an ambulance takes you to the hospital, your green sleeve should go with you. If emergency response people can’t find your green sleeve, healthcare providers at the hospital may give you care you don’t want. (pause)

The hospital will make copies for your chart so everyone knows your wishes for care. If your green sleeve gets left at the hospital when you’re discharged, it will be mailed back to you. (pause)

Advance care planning tracking record

You may wish to show the patient a copy of the ACP tracking record.

Main point:

- The purpose of the tracking record is to document what ACP and GCD conversations the patient has had with healthcare providers so everyone is not always starting from scratch each time

Example of talk:
I am going to fill in your advance care planning tracking record. The purpose of the Tracking Record is to document the Advance Care Planning and Goals of Care conversations you've had with healthcare providers. It is a way for us to keep your healthcare plans living and active because we know the most recent plans you want us to follow.

Ongoing maintenance

Main points:

- Patients can see you or any healthcare provider if they have questions about ACP and/or GCD
- They can change any of the ACP/GCD documents at any time and any number of times

Example of talk:

If your health changes or you change your mind about your goals for care, you may think ‘Hey, this isn’t what I want. I want this instead.’ You just have to bring in your green sleeve and we can get the documents fixed up to what you want. Then you throw away the old one so you only have one version. (pause)

Personal Notes

Appendix A

Tips for ACP/GCD Conversations and Asking Questions

Key message:

Older and seriously ill patients and families tend to be more involved/engaged in the ACP process when the communication style is conversational rather than an interview or an information session.

TIP: **Imagine that you are having a conversation with a family member**

Conducting an ACP/GCD conversation is a skill that can be learned.

Points to consider are:

- Take a few minutes at the beginning of the conversation to establish a relationship with the patient/family. Ask a few questions about him/her as a person in the context of his/her core network of family/friends, not just a patient.
- If culturally appropriate:
  - Make eye contact as much as possible.
  - Sit facing the patient at a reasonably close distance.
  - When appropriate, gently touch the patient’s arm or shoulder to demonstrate that you care.
- Speak in a tone that is friendly and comforting rather than business-like.
- Frequently insert pauses in your talk (count to four to yourself) to allow the patient time to reflect on what has been said and ask questions or make comments.
- Be an active listener. Summarize or paraphrase the patient’s talk prior to moving to another topic.

- Minimize the use of medical jargon. If a medical term is used, follow with a lay-person description. Then ask the patient if he/she understands (e.g., "Does that make sense?")
- Be in the moment. It is important to show the patient that this conversation with him/her is your priority at this time.
- If the patient goes off topic, allow him/her to complete his/her thought, then acknowledge the contribution before gently redirecting the conversation.

Key points regarding ACP/GCD conversations:

- Say the terms 'advance care planning' and 'goals of care' several times during your conversation. These terms are often unfamiliar and repetition will help patients become more familiar with the terminology.
- Find ways to incorporate information given by the patient into your talk about the ways in which the ACP process can help him/her to achieve his/her personal goals for care.
- Focus more on what can be done to meet their goals for care and to make their life worth living than on what you cannot do for them.
- Take time to (a) reassure them that you are there to support them and their family, (b) tell them that they are important to you, and (c) work to create a sense of community of care in which the patient is at the core (e.g., you will follow up with other involved HCPs to ensure plans for care have been communicated).
- Praise them for the steps they have taken toward completing components of the ACP process.
- If appropriate, find moments to share something personal with the patient (e.g., how doing the ACP process was for you or a family member).
- Let the patient know that the ACP process is about working to help him/her to achieve his/her goals for care.
- Ensure that patients have enough information to make informed choices for their care, but try to avoid

overburdening them with too much information (e.g., information that is not compatible with their personal goals for care).

- Acknowledge and support patients’ hopes whenever possible. Try to avoid dismissing hopes. Although you may not always be able to promise certain outcomes, you can promise that the community of HCPs caring for them will always be there to help and support them. This translates into a reassurance that they will not be abandoned in a time of need.
- Try to find appropriate places in your conversation to share laughter. Laughter helps develop rapport and an atmosphere of normalization. It may also help relieve tension.

Tips for asking questions

Question design can significantly impact the functionality of talk.[1] The conversation will flow well with fewer derailments from the topic when questions are designed to achieve a goal.[2] Below are explanations and examples of how to design your questions to meet a specific goal.

WH-Questions

Specifying questions that request specific details[3, 4]

“What time is your appointment?”	“10 am”
“When did the pain start?”	“Last Thursday”
“Who did your surgery?”	“Dr. Smith”
“Which hospital were you in?”	“The General”
“Where is the pain now?”	“My lower back”
“How many times did you vomit?”	“Six times”

Telling questions that request a story[3, 4]

“What is important to you in your life right now?”
“What was it like for you the last time you were in hospital?”
“How have you been feeling since the last time we met?”
“How does your family feel about you not wanting surgery?”
“Please tell me about your family.”
“Please tell me more about how that made your feel.”

- It is best to avoid using ‘why’ questions as they usually come across as accusatory.[5] With some thought, all ‘why’ questions can be reframed as ‘how’ or ‘what’ questions.

Yes/No Interrogative Questions

- The words ‘*any*,’ ‘*ever*,’ ‘*at all*,’ “*no*,” “*never*,” and “*not*” are called *negative polarity items*; they will usually encourage someone to answer ‘no’ and not elaborate on the answer even if he/she has something to add. [6]
- The word ‘*some*’ is a *positive polarity item*; it will usually encourage someone to answer ‘yes’ and provide elaboration.
- Use of ‘*any*’ in questions is habitual in the English language. It takes a great deal of awareness to notice how often it is used and then to make an intentional effort to remove it or replace it with ‘*some*.’
- The use of ‘*any*’ and ‘*some*’ should be intentional.[6] If you are seeking more information about a patient’s experience, try excluding ‘*any*’ (and other negative polarity items) from your questions or replace ‘*any*’ with ‘*some*.’

Yes/No interrogative questions that encourage talk[7, 8]

“Do you have something else to add to what we’ve talked about?”
“Has a doctor or nurse told you about advance care planning?”
“Would you like to learn more about advance care planning?”
“Have you chosen an agent?”
“Does what I said make sense?”
“Do you have some questions?” or “Do you have questions?”
“Have you talked with your family about what care you want?”
“Are you willing to be treated in the intensive care unit?”

- Negatively polarized questions are not ‘bad’ questions. They can serve a purpose when used intentionally.
  - If you are attempting to learn specific facts about a situation or it is necessary to wrap up a conversation, including negative polarity items in your questions can fast track the talk.[9]
- However, if a patient is compelled to tell you something, he/she can answer ‘yes’ and give an explanation for an opposing answer from what was expected.[9]

Yes/No Declarative Questions

- ‘Yes/no’ declarative questions discourage patients from elaborating on their answers, whether or not they contain a negative polarity item.[10] This is because declarative questions are designed to simply request confirmation or disconfirmation of assumed information.

Yes/No declarative questions seeking (dis)confirmation[10]

“Your doctor explained your illness to you?”	“Yes”
“That medicine helped your pain?”	“Yes”
“Your family knows your healthcare wishes?”	“Yes”
“No questions for me now?”	“No”
“You haven’t completed a personal directive yet?”	“No”
“You’ve never been admitted to the ICU?”	“No”
“You don’t have any pain right now?”	“No”

Intonation

- The intonation used when asking questions is very important as it has implications for meaning and direction.[11]

Rising intonation[11]

When your voice goes higher at the end of a question you are indicating to a patient that you would like him/her to provide you with an answer.

All questions should end with rising intonation.

Falling intonation[11]

When your voice drops at the end of a question you are indicating to a patient that an answer may not be necessary – that your question may be rhetorical. It can be confusing to patients if the content of the question indicates that an answer is wanted but the intonation does not.

Use falling intonation at the end of statements or assessments.

Functional ACP/GCD Questioning Approaches

- Empirical evidence indicates that some questioning approaches are more functional than others when having ACP/GCD conversations.

Functional approaches

Ask questions that empower the patient, that encourage the patient to share his/her thoughts, feelings and beliefs

When explaining about the ACP process, pause after every couple of statements for a count of four to yourself

After explaining a component of the process, ask the patient if he/she has questions or if what you said makes sense

Ask one question at a time, with a pause after each question to allow the patient to answer

Approaches it is best to avoid

Avoid asking questions that 'test' the patient's knowledge such as "What do you know about CPR?"

Avoid asking questions for which you have a predetermined answer in mind – rather, keep an open mind for a response

Avoid talking quickly and merging a question into the previous talk

Avoid asking the same question more than once unless the patient asks you to repeat the question – if the patient's answer was not sufficient, ask the question in a different way

Personal Notes

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