

Advance Care Planning Communication Guide: *Overview*

The INTERACT **Advance Care Planning Communication Guide** is designed to assist health professionals who work in home health to initiate and carry out conversations with patients and their families about goals of care and preferences at the time of admission, at regular intervals, and when there has been a decline in health status.

The Guide can be useful for education, including role-playing exercises and simulation training.

Communicating about advance care planning and end-of-life care involves all Home Health staff

- Physicians must communicate with patients and families about advance directives, but all staff need to be able to communicate about goals of care, preferences, and end-of-life care

This Guide should therefore be useful for:

- Nursing staff
- Primary care physicians, nurse practitioners, and physician assistants
- Social workers and social work designees
- Administrators and others who discuss goals of care with patients and family

The Guide may be helpful in discussions on:

- Advance Directives – such as a Durable Power of Attorney for Health Care document, Living Will, and POLST and other similar directives
- Plans for care when a sudden, life-threatening condition is diagnosed – such as a stroke, heart attack, pneumonia, or cancer
- Plans for care when a patient’s health is gradually deteriorating – such as progression of Alzheimer’s disease or other dementia; weight loss without an obvious medical cause; and worsening of congestive heart failure, kidney failure, or chronic lung disease
- Considering a palliative or comfort care plan or enrolling in a hospice program

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Part 1: Tips for Starting & Conducting the Conversation

Set the Stage

1. Get the facts – understand the patient’s conditions and prognosis.
2. Choose a private environment.
3. Determine an agenda for the meeting and who should be present.
4. Allow adequate time – usually these discussions take at least 30 minutes.
5. Turn cell phone or beeper to vibrate to avoid interruptions and demonstrate full attention.
6. If the patient is involved, sit at eye level with her or him.
7. Have tissues available.

Initiate the Discussion

1. Describe the purpose of the meeting.
2. Identify whether the patient wants or already has a spokesperson and who it is.
3. Ask what the patient and/or family understand about advance care planning.
4. Ask about their goals for care
 - Most home health patients and their families are more concerned about comfort than life prolongation. This opens the door to discuss palliative care and comfort care plans.
 - Attempt to understand underlying rationale for the goals (*i.e.* “I’ve lived long enough, now I’m ready to meet God,” or “I want to keep on living until my granddaughter graduates college next spring.”). This provides insight into specific decisions that are made.

Initiate the Discussion

1. Use simple language.
2. Briefly discuss:
 - Cardiopulmonary arrest and CPR*
 - Artificial Hydration/Nutrition (*tube feeding***)
 - Palliative care, comfort care orders*** and hospice if appropriate.

Cardiopulmonary Arrest and CPR*

1. Initiate discussion of Cardiopulmonary Resuscitation (CPR).
 - e.g. “Sometimes when peoples’ hearts stop, doctors and nurses try to delay the dying process... have you considered whether you would want this or not?”
2. Discuss some facts:
 - Cardiopulmonary arrest is the final common pathway for everyone when they die. Not all deaths should involve CPR.
 - The possibility of surviving CPR in a home health is very low, and CPR often results in broken ribs and the need for a respirator (*‘breathing machine’*) in an intensive care unit.
 - A request to not perform CPR (*a Do Not Resuscitate (DNR) Order*) **does not alter care** – it only prevents CPR if the patient is found without a heart beat or not breathing.

* See INTERACT Education on CPR ** See INTERACT Education on Tube Feeding *** See INTERACT Comfort Care Orders

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Artificial Hydration/Nutrition (tubefeeding)**

1. Initiate discussion of feeding tubes:
 - “Many home health patients gradually lose the ability to eat, drink, and swallow. In this situation a tube can be placed in the stomach to provide water and nutrition. Have you considered whether you would want this or not?”
2. Discuss some facts:
 - Feeding tubes have not been shown to prevent pneumonia or prolong life for most Home Health patients.
 - Placement of a tube requires minor surgery, and can have some complications.
 - A request to not place a tube **does not alter care** – patients will be provided oral fluid and nourishment as long as it is comforting for them.
 - People who do not get feeding tubes generally gradually slip into a comfortable coma within a few days and die comfortably.

Palliative Care and Comfort Care Orders

1. Review overall goals for care and the importance of comfort and quality of life regardless of advance directives
2. If the goal of care is comfort:
 - Offer to provide and review educational materials on palliative care.
 - Describe examples of comfort care orders.***
 - Discuss limiting hospitalization only for the purpose of improving comfort, not to prolong life.
 - If appropriate, provide information about palliative and/or hospice care.

End the Discussion

1. Ask: “Do you have any questions?”
2. Emphasize that the role of Home Health is to ALWAYS provide comfort no matter what the goals of care.
3. Offer to have a follow-up meeting if indicated.
4. Stand – an effective way to end the conversation.

** See INTERACT Education on Tube Feeding *** See INTERACT Comfort Care Orders

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Part 2: Communication Tips

Tips	Examples
Establish Trust	
Encourage patients and families to talk	<p><i>"Tell me what you understand about your illness."</i></p> <p><i>"Help me get to know you better – tell me about your life before you came to the Home Health."</i></p> <p><i>"How are you coping with your illness?"</i></p>
Recognize patient and family concerns, but do not put down other health care providers	<p><i>"I understand that you didn't feel heard by other doctors/nurses. I'd like to make sure you have a chance to voice all of your concerns."</i></p> <p><i>"It sounds like Dr. X left you very hopeful for a cure. I'm sure he really cares for you, and it would have been wonderful if things would have gone as well as he/she wished."</i></p>
Acknowledge mistakes	<p><i>"You are absolutely right. Four days was too long to wait for that [test or procedure]."</i></p>
Be humble	<p><i>"I really appreciate what you have shared with me about the medication we prescribed. It is clear that it is not right for you."</i></p>
Demonstrate respect	<p><i>"I am so impressed by how involved you have been with your [relative] throughout this illness. I can tell how much you love her/him."</i></p>
Do not force decisions	<p><i>"We've just had a very difficult conversation, and you and your family have a lot to think about. Let's schedule another meeting and see how you feel about things then."</i></p>
Attend to Emotions	
Attend to the emotion	<p><i>"Is talking about these issues difficult for you? Making these decisions is not easy."</i></p>
Identify loss	<p><i>"I bet it's hard to imagine life without your [relative] – I can see how close you are to her/him."</i></p>
Legitimize feelings	<p><i>"It's quite common for someone in your situation to have a hard time making these decisions – it can feel like an enormous responsibility."</i></p> <p><i>"Of course talking about this makes you feel sad – it wouldn't be normal if it didn't."</i></p>
Explore	<p><i>"You've just told me you feel scared. Can you tell me more about what scares you most?"</i></p>
Offer support	<p><i>"No matter what the road holds ahead, I'm going to be there with you."</i></p>
Communicate Hope	
Hope for the best, but prepare for the worst	<p><i>"Have you thought about what might happen if things don't go as you wish? Sometimes having a plan to prepare for the worst makes it easier to focus on what you hope for most."</i></p>
Reframe hope	<p><i>"I know you hope your illness will improve. Are there other goals you want to focus on?"</i></p>
Focus on the positive	<p><i>"Some treatments are really not going to help and may make you feel worse or uncomfortable. But there are a lot of things we can do to help you – let's focus on those."</i></p> <p><i>"What sorts of things are left undone for you? Let's talk about how we might be able to make these happen."</i></p>

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Part 3: Helpful Language for Discussing End-of-Life Care



Issue	Helpful Language
Identify other decision makers	<i>"Is there anyone you rely on to make important decisions?"</i>
Define goals for care	<i>"What do you hope for most over the next few months?" "Is there anything that you are afraid of?"</i>
Reframe goals	<i>"I wish we could guarantee you will be alive for your [event], but unfortunately we can't. Perhaps we can work on a letter to read on that day, so people will know you are there in spirit in case you cannot be there."</i>
Identify needs for care?	<i>"What types of treatments do you think will help you the most?"</i>
Summarize and link goals with care needs	<i>"I think I understand that your main goals are to be comfortable and alert enough to spend time with your family. We have several ways we can help you."</i>
Introduce palliative or comfort care and/or hospice	<i>"One of the best ways to meet your needs would be a comfort care plan." "One of the best ways to give you help is a program called hospice. The hospice program can provide extra support and the hospice has a lot of experience in caring for seriously ill people."</i>
Acknowledge response	<i>"You seem surprised to learn how sick you are." "I can see it is not easy for you to talk about end-of-life care."</i>
Empathize	<i>"I can imagine how hard this is for all of you to talk about – you care about each other so much."</i>
Explore concerns	<i>"Tell me what is upsetting you the most."</i>
Explain comfort care or hospice goals	<i>"Comfort or hospice care does not help people die sooner – it helps people die naturally." "Comfort and hospice care helps people live as well as they can for as long as they can."</i>
Reassure	<i>"The goal of comfort and hospice care is to improve your quality of life as much as possible for whatever time you have left." "Comfort and hospice care can help you and your family make the most of the time you have left."</i>
Reinforce commitment to care	<i>"Why don't you think this over? I think comfort or hospice care is the best choice for you right now, but the decision is yours. You know we will continue to care for you whatever you decide."</i>

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Part 4: The Patient or Family Who Want Everything Done

Patient/Family Concern	How They Say It	How You Can Respond
Abandonment	<i>"Don't give up on me."</i>	<i>"What worries you the most?"</i>
Fear	<i>"Keep trying for me."</i>	<i>"What are you most afraid of?"</i>
Anxiety	<i>"I don't want to leave my family."</i>	<i>"What does your doctor say about your condition?"</i>
Depression	<i>"I'm scared of dying."</i>	<i>"What is the most frightening to you?"</i>
Incomplete Understanding	<i>"I do not really understand how sick I am."</i>	<i>"What are your most important goals?"</i>
Wanting reassurance that best medical care has been given	<i>"Do everything you think is worthwhile."</i>	<i>"What is your understanding of your condition?"</i>
Wanting reassurance that all possible life-prolonging treatment is given	<i>"Don't leave any stone unturned." "I really want every possible treatment that has a chance of helping me live longer." "I will go through anything, regardless of how hard it is."</i>	<i>"What have others told you about what is going on with your illness?" "What have they said the impact of these treatments would be?" "Tell me more of what you mean by 'everything'?"</i>
Vitalism	<i>"I value every moment in life, regardless of the pain and suffering (which has important meaning for me)."</i>	<i>"Does your religion (faith) provide any guidance in these matters?"</i>
Faith in God's Will	<i>"I will leave my fate in God's hands; I am hoping for a miracle; only He can decide when it is time to stop."</i>	<i>"How might we know when God thinks it is your time?"</i>
Differing perceptions	<i>"I cannot bear the thought of leaving my children (wife/husband)."</i>	<i>"How is your family handling this?"</i>
Children or dependents	<i>"My family is only after my money." "I don't want to bother my children with all of this."</i>	<i>"Have you made plans for your children (other dependents)?" "Have you discussed who will make decisions for you if you cannot?" "Have you completed a will?"</i>

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Sources of Information



References

This guide contains information adapted from the following sources:

1. "The Palliative Response – Sharing the Bad News," the Birmingham/Atlanta VA Geriatric Research, Education and Clinical Center
2. Tulsky, JA. Beyond Advance Directives – Importance of Communication Skills at the End of Life. JAMA 2005; 294:359-365.
3. Casarett, DJ and Quill, TE. "I'm Not Ready for Hospice": Strategies for Timely and Effective Hospice Discussions. Ann Intern Med 2007; 146:443-449.
4. Quill, TE, Arnold, R, and Back, AL. Discussing Treatment Preferences with Patients Who Want "Everything." Ann Intern Med 2009; 151:345-349.

Additional Resources for Staff and Families (*available free on the internet*)

1. American Association for Retired Persons
2. The Coalition for Compassionate Care
3. The Conversation Project
4. Closure.org
5. Caring Connections of the National Hospice and Palliative Care Organization