

Promoting Effective Communication & Advance Care Planning for Patients with Cancer

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Serious Illness Care in Public Consciousness

- "Being Mortal" – Atul Gawande, MD, bestseller list 70+ weeks
- "When Breath Becomes Air" – Paul Kalanithi, MD, bestseller list 50+ weeks, Pulitzer finalist
- TED talk 2015 – BJ Miller, MD – 14,284,311 total views (as of 11.09.2021)
- "Everything Happens for a Reason" – Kate Bowler, PhD, bestseller list
- "The Bright Hour" – Nina Riggs, MFA, bestseller list



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Premise

- Few (? any) clinicians born with bedside manner
- Communication – learned skill & procedure
- Identify best practices, evaluate
- Improve with supervision, practice, reflection
- Words matter
 - Patient & family satisfaction
 - Decision-making
 - Care quality
- We are all learners

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**Patient-Clinician Communication
ASCO Consensus Guideline**

(Gilligan T et al. J Clin Oncol 2017)

- Question: What communication skills and tasks can clinicians use to optimize the patient-clinician relationship, patient and clinician well-being, and family well-being?
- Systematic review – 47 publications from 2006-2016
- 30 recommendations
 - Core communication skills
 - Discussing GOC and prognosis
 - Discussing treatment options and clinical trials
 - Discussing end of life care
- Communication skills training improves quality
 - Program duration 7-40 hours
 - Opportunities to practice skills, including role play

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Imitation is the Sincerest Form of Flattery

-- Oscar Wilde

- Vitaltalk.org
 - Communication skills resources include:
 - Videos – including serious news disclosure, addressing GOC and conducting a family conference
 - One-page handouts
 - Blog
 - Iphone app
- Ariadnelabs.org
 - Serious illness care community
 - Access to serious illness communication guide
 - Video examples

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Objectives

- Identify and implement general strategies to improve communication with patients living with cancer
- Define the components of advance care planning
- Describe a framework to engage in advance care planning with patients living with cancer

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Communication Premise #1

- Clinicians (physicians) talk too much compared with patients/families
- **Risks:** decreased understanding of patient/family agenda, health literacy, trust level
- **Study: 51 audiotaped ICU family meetings in Seattle** (McDonagh JR et al. Crit Care Med 2004)
 - Mean conference time = 32 minutes (range 7-74)
 - Family members spoke 29% of time
 - Increased percentage of family speech associated with – increased satisfaction and decreased conflict ratings with physicians

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Communication Principle: Ask-Tell-Ask

- Builds relationships
- Willingness to listen & negotiate agenda
- **ASK** current understanding, questions about condition
 - Account for knowledge level, emotional state, degree of education, priorities
- **TELL** using straightforward language
 - Short, digestible chunks
 - Eliminate jargon
- **ASK** for understanding of what was told, or move to another topic
 - Restate in patient's or family member's own words
 - Determine where to go next with discussion
- Iterative process

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Communication Principle: Tell Me More

- Use this strategy when stuck, off track, seek clarification
- Avoids jumping to assumptions (e.g., "do everything", "don't want to be a vegetable")
- 3 levels in conversation for patients
 - **First:** What is happening? Apprehend & understanding information
 - **Second:** How do I feel about this? Figure out emotions
 - **Third:** What does this mean to me? Patient's sense of self, quality of life

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Communication Premise #2

- Emotions drive decision-making challenges & conflicts – NOT lack of information
- Emotions as data – don't have to "fix" patients
- Assessing and handling emotions are empathic opportunities
 - Build connections with patients & families
 - Address mistrust

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NURSE

- **N**aming
- **U**nderstanding
- **R**especting
- **S**upporting
- **E**xploring

Back A, Arnold R, Tulskey J. Mastering communication with seriously ill patients: balancing honesty with empathy and hope. Cambridge University Press; 2009

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**Communication Principle:
Name the Emotion(s)**

- Name emotion for yourself (self-awareness)
- Name emotion to patient/family
 - Suggestive, not declarative –float a hypothesis
 - It sounds like..., I wonder if..., I'm sensing that..., Some people in this situation would be...
 - Conveys empathy even if patient disagrees
 - Lowers emotional intensity of encounter
 - Patient/family feels heard



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Understanding

- Explain how you can see it from their perspective
 - Not I understand how you feel
- Sensitive appreciation of context
- Avoid giving premature reassurance
- Validate emotions
- *I recognize that...*

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Respecting

- Message that emotions are not only allowed but important
- Match intensity of acknowledgment to patient’s expression of emotion
- Admire what you genuinely feel good about
- Praise coping, caregiving skills
 - It’s clear how well you’ve cared for your...
 - I’m impressed with how you’re...

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Communication Principle: Wish Statements

(TE Quill, Ann Intern Med 2001)

- Instead of stating “I’m sorry”
 - Confused with pity or an apology
 - Short cuts deeper understanding
- Empathic statements
 - Aligns clinician with patient & family
 - Acknowledges emotional impact of loss
 - Builds solidarity (not sympathy)
- Desired outcome unlikely to occur
- Doesn’t specify what can be done
- *I wish the treatment had been effective.*
- *I wish I had better news to share*



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Communication Doesn't Harm Patients

- Prospective study: 332 patients with advanced cancer & caregivers
- Baseline: 37% reported having end-of-life discussion with physician
- No association with depressed, sad, terrified, worried feelings
- Positive association:
 - Accept illness was terminal
 - Prefer symptom-focused vs life-extending treatments
 - DNR order
 - Fewer aggressive medical interventions near death
- Caregivers: aggressive care – higher risk of depression, regret, feeling unprepared

Wright AA et al. JAMA 2008

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Communication Pitfalls – Words to Avoid

- You have failed treatment
 - *Treatment hasn't been effective despite all you have done.*
- Withdraw care
 - *Discontinue treatments that aren't helping anymore.*
- Comfort care only
 - *Exclusive comfort care, intensive comfort care*
- Nothing more I can do
 - *There's a lot we can do to promote your comfort and dignity.*
- Sending you to hospice
 - *Hospice will help each day be the best day possible for you & your family*
- Should we restart your heart?
 - *I would recommend that we allow you to have a natural death when you're so sick that your heart stops – I don't think that treatments then would help.*

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Take to the Bedside, Clinic

- Leave agendas at the door
- "Ask-Tell-Ask" and "Tell me more.." can help deepen and direct conversation
- Balance information with emotional support
 - Conflict driven by emotions, not information deficits
- Communication is a process
- Document communication content, ideally in an advance care planning note

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Advance Care Planning Definition

Advance care planning is a process that supports adults at any age or stage of health in understanding and sharing their personal values, life goals, and preferences regarding future medical care.

The goal of advance care planning is to help ensure that people receive medical care that is consistent with their values, goals and preferences during serious illness and chronic illness. For many people, this process may include choosing and preparing another trusted person or persons to make medical decisions in the event the person can no longer make his or her own decisions.

Sudore RL et al. J Pain Symptom Manage 2017

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Advance Directives

- Health Care Decision Maker
 - Proxy
- Living Will
 - NC-specific (www.sosnc.gov)
 - Prepare for Your Care
 - 5 Wishes
 - Other

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Advance Directives ➡ Advance Care Planning

- Communication process
- Prepare patients and surrogates for “in-the-moment” decision making
(Sudore RL, Fried TR. Ann Intern Med 2010)
- Emphasize clinical (vs legal) documentation
- Respect diversity of approaches
- Patients/families wait for clinicians
- Making sure that patients’ potential care aligns with their goals is an expression of the value of a patient’s life. (Rosenberg AR et al. J Clin Oncol 2020)

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ACP Framework

- Ask permission to discuss ACP
- Identify and involve a healthcare proxy
- Consider whether the patient wants the patient to have “leeway” in decision-making
- Clarify patient and surrogate understanding of the patient’s health status and prognosis
- Explore patient’s goals and values in the context of illness
- Promote care plan consistent with the patient’s goals and priorities

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Table 1. Assessing and Addressing Lack of Readiness to Prepare for In-the-Moment End-of-Life Decision Making

Assessing readiness
 “If you were to get very sick, is there anyone you trust to make medical decisions for you, and have you talked with this person about what is important to you? Can we talk about this today?”

Educating and motivating
 “Because of illness or an accident, most patients will be unable to make their own decisions at some time in their life.”
 “Because making decisions for someone is very stressful, you could help to take the burden off of your family/friends by starting to think about what would be important to you if you became very sick.”
 “When patients talk with me and their loved ones about what would be important to them if they were to become very sick, it helps them to keep a sense of control about their medical care and to have peace of mind.”

Addressing barriers
 “Are there things that you worry about when you think about your loved one making decisions for you?”
 “Are there reasons it is difficult to talk about such things with me or your loved ones?”

Sudore RL,
Fried TR,
Ann Intern
Med 2010.

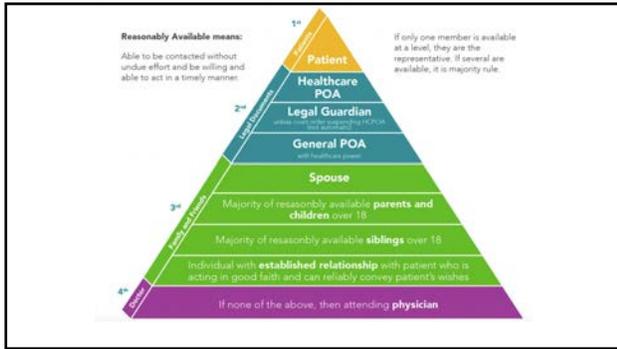
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Table 2. Steps to Prepare Patients for In-the-Moment End-of-Life Decision Making*

Step 1: Choosing an appropriate surrogate decision maker
 Opening: “As your clinician, it would be helpful to know who to contact if you were to become really sick.”
 Choosing a surrogate
 “If you were to become really sick, is there anyone you trust to make medical decisions for you?”
 “Does this person know that you have chosen him/her for this role? It is important to ask him/her if he/she is willing to do it.”

Sudore RL, Fried TR, Ann Intern Med 2010.

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Surrogate Decision-Making Leeway

Sehgal A. JAMA 1992

- 150 patients receiving hemodialysis
- Would you want dialysis stopped or continued if develop advanced Alzheimer's disease?
- How much leeway to override directive if in best interest?
 - No leeway = 39%
 - A little leeway = 19%
 - A lot of leeway = 11%
 - Complete leeway = 31%

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Establishing Leeway

- What if, based on changes in your health, the doctors recommend something different from what you have told your loved one?
- Will you give your loved one(s) permission to work with your doctors to make the best decision they can for you even if it may differ from what you said you wanted in the past?
- Are there certain decisions about your health that you would never want your loved one to change under any circumstance?

Sudore RL. Fried TR. Ann Intern Med 2010.

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6. If I have an Available Health Care Agent

If I have appointed a health care agent by executing a health care power of attorney or similar instrument, and that health care agent is acting and available and gives instructions that differ from this Advance Directive, then I direct that:

<input type="checkbox"/>	Follow Advance Directive: This Advance Directive will override instructions my health care agent gives about prolonging my life.
<input type="checkbox"/>	Follow Health Care Agent: My health care agent has authority to override this Advance Directive.

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Probes to Clarify Goals & Preferences

[Consider the patient's prognostic awareness]

- What is most important to you at this point in your life?
- What hopes do you have as you look towards the future?
- What worries do you have about the future?
- Do you have any strong preferences about your care?
 - If your condition gets worse
 - If you get a lot sicker than you are now
- Have you discussed your...with your family? *[If yes, what have you discussed?]*

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Translating Communication into Actions

- Advance care planning note
- Medical Orders for Scope of Treatment
- Living will and/or Health Care Power of Attorney
 - Prepare for Your Care
 - North Carolina Advance Directive
 - Other: Five Wishes

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ACP Note

- Documentation of ACP discussion content
- Does not require decision-making
- CPT code 99497: ACP including the explanation and discussion of advance directives such as standard forms (with completion of such forms, when performed) by the MD or other qualified health care professional; first 30 min, face-to-face with the patient, family member(s) and/or surrogate
 - 16-30 minutes (1.5 RVUs)
- CPT code 99498: each additional 30 minutes
 - Requires at least 46 minutes (1.4 RVUs)
- No limit to length and # of times ACP codes can be used
- If patient unable to participate, document reason
- Modifier -25 with other E/M codes
- 2.2% of Medicare beneficiaries had a billed ACP note in 2017

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When to Complete an ACP Note

- Content relevant to –
 - Your communication about patient’s condition, prognosis, care options
 - Patient and/or family understanding
 - Decision-making
 - Communication challenges
- ACP note as a baton passed among clinicians or from visit-to-visit with same clinician
- Does not require billable activity (can reference in clinic, hospital progress note)

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Prepare For Your Care (prepareforyourcare.org)

Traditional advance directives do not adequately represent needs of patients from diverse backgrounds, including low health literacy

1. Choose a medical decision maker
2. Decide what matters most in life
3. Choose flexibility for decision maker
4. Tell others about your wishes
5. Ask doctors the right questions

*Website with videos
Easy-to-read advance directive; English and Spanish versions*

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PREPARE RCT (Sudore RL et al. JAMA Intern Med 2018)

- 4 safety-net primary care clinics in SF
- 986 Spanish or English speaking pts, > 55, > 2 chronic illnesses
- PREPARE + AD vs AD alone
- Primary outcome = new ACP at 15 mos
- Mean age 63, 40% limited health literacy, 45% Spanish speaking
- ACP documentation
 - 43% intervention vs 33% control (<.001)

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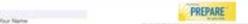
North Carolina Advance Health Care Directive

This form lets you have a say about how you want to be cared for if you cannot speak for yourself.

This form has 3 parts:

- Part 1 Choose a medical decision maker, Page 3**
A medical decision maker is a person who can make health care decisions for you if you are not able to make them yourself. They are also called a health care agent, proxy, or surrogate.
- Part 2 Make your own health care choices, Page 6**
This form lets you choose the kind of health care you want. This way, those who care for you will not have to guess what you want if you are not able to tell them yourself.
- Part 3 Sign the form, Page 11**
The form must be signed before it can be used.

You can fill out Part 1, Part 2, or both. Fill out only the parts you want. Always sign the form in Part 3. 2 witnesses need to sign on Page 12 and a notary on Page 13.



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Part 1 Choose your medical decision maker

Your medical decision maker can make health care decisions for you if you are not able to make them yourself.

A good medical decision maker is a family member or friend who:

- * is 18 years of age or older
- * can talk to you about your wishes
- * can be there for you when you need them
- * you trust to follow your wishes and do what is best for you
- * you trust to know your medical information
- * is not afraid to ask doctors questions and speak up about your wishes



Your decision maker cannot be your doctor or someone who provides care for you at your hospital or clinic.

What will happen if I do not choose a medical decision maker?

If you are not able to make your own decisions, your doctors will turn to family or friends to make decisions for you. This person may not know what you want.

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Part 2 **Make your own health care choices**

What Matters Most in Life: Quality of life differs for each person.

For some people, the main goal is to be kept alive as long as possible even if:

- They have to be kept alive on machines and are suffering
- They are too sick to talk to their family and friends

For other people, the main goal is to focus on quality of life and being comfortable.

- These people would prefer a natural death, and not be kept alive on machines

Other people are somewhere in between. **What is important to you?**

Your goals may differ today in your current health than at the end of life.

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TODAY, IN YOUR CURRENT HEALTH
Put an X along this line to show how you feel today, in your current health.

AT THE END OF LIFE
Put an X along this line to show how you would feel if you were so sick that you may die soon.

Your Name _____

If you want to write down why you feel this way, go to Page 10.

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Strategies to Improve Advance Care Planning

- Equip health care teams to engage in effective care planning conversations
- Engage communities in flexible, culturally competent ACP approaches
- Support surrogate decision-makers to engage in iterative planning
- Make documentation easy to understand while removing barriers
 - NC requires 2 witnesses and notarized signatures
 - Until August 1, video notary and no witnesses permitted
- Ensure ready accessibility of ACP documentation

Wood BS, Winzelberg GS, NC Med J. 2020

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Equip Health Care Teams

- Promote interprofessional clinician communication skills
 - MD
 - APP
 - Nurse
 - Social work
 - Chaplain
 - Lay navigators
- ACP training
 - CAPC, Respecting Choices, Vitaltalk

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Racial Inequities

- Compared with white patients, African-Americans and Latinos are more likely to –
 - Die in the hospital
 - Less like to utilize hospice
- Differences in advance directive completion rates
 - 44% Whites, 29% Latinos, 24% African-Americans
- Prioritize flexibility and cultural humility
- Partnerships with religious and civic groups

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Recommended Approach

- Spirit: know patients (and their families) as people, promote quality of life and care, manage our biases
- Practice:
 - Identify preferred surrogate decision-maker(s)
 - Discuss patient's condition, current and future goals/priorities
 - Complete advance care planning notes/notelets
 - Consider whether document completion serves patient's interests
 - Facilitate communication among patient, family, clinicians
 - Be intentional about timing, frequency of ACP discussions

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