

Coleman Supportive Oncology Initiative

Palliative Training Module

Topic: **Goals of Care**

Presenters: Megan McMahon, PhD, Lauren Wiebe, MD,
and Betty Roggenkamp, BA

Version: 08072017

Learning Objectives

By the end of this module you should be able to:

- 1. Define goals of care**
- 2. Adapt conversations and recommendations for a goals of care plan to a patient's individual wishes and preferences, even when barriers exist**
- 3. Explain how and when to broach the subject of hospice care within a goals of care discussion**

Goals of Care Defined

- **Can include cure, maintaining function/quality of life, symptom management, prolongation of life, a personal goals, remaining home and achieving a good death**
- **Are determined by a patient's priorities, values, hopes and fears**
- **Often change over time and should be revisited regularly**
- **Clinical skills are needed to help patients and families navigate decision-making along the cancer journey**
- **Can be described in plain language without reference to procedures or medical interventions**
- **Consider summary documentation with advance care planning in a defined area in the electronic health record (EHR)**

“How To” Communicate

- **Assess preferences for communication**
 - When
 - With whom present
- **Ask-tell-ask: “What do you know about....?”**
 - “OK. Here is what the tests are showing us...”
 - “Does that make sense? Do you have questions about that?”
 - You can ask them to explain it back to you to check for understanding.
- **Tell me more: “*Tell me more about...*”**
 - Use this when you are not entirely sure what someone is talking about, rather than making an assumption
 - You can also use this if you’re just not sure what to say next
- **Use “I wish...”**
 - Enables you to ally with the patient while acknowledging the reality of the situation
 - Expresses empathy inherently

Common Barriers to Communication of Serious News

- **Feeling responsible for maintaining the patient's or family's hope**
- **Patients' incapacity to make goals of care decisions**
- **Disagreement among family members about goals**
- **Patients' or family members' difficulty understanding the limitations and complications of life-sustaining treatments**

Common Barriers to Communication of Serious News

- **Assuming:**
 - Cure is the goal of all patients
 - What information the patient/family knows or does not know
 - What information the patient/family wants to know or does not want to know
 - What is important to the patient and/or family
- **Talking too much/listening too little**
- **Ignoring your own feelings or those of the patient and/or family**
- **Not understanding cultural differences**

Conversations and Recommendations: REMAP Mnemonic for Goals of Care Discussion

- **Review** cancer stage and prognosis

Review for initial goals of care discussion

OR

- **Reframe** why the status quo is not working and redefine goals of care as needed

Reframe if the patient is physically deteriorating or there has been a progression as well as when the goals of care may need revisiting

- **Expect** emotion and empathize
- **Map** the future
- **Align** with the patient's values
- **Plan** medical treatments that match these values

Remember, conversations should flow naturally.

This mnemonic is not meant to be followed letter by letter in a specific order, but to be used as guidance on what to include in a goals of care conversation. The conversation should remain fluid, meeting the needs of all participants.

REMAP – “R”

Review cancer stage and prognosis.

Have a conversation with the patient about their disease and stage, taking into consideration what the patient knows and wants to know. Keep in mind, some patients may not want to know everything.

- “Can you tell me what you know about your cancer?”
- “What are your expectations about your treatment/care?”
- “What are your personal goals?”

REMAP – “R”

Reframe why the status quo is not working.

Examples of how to start a discussion about bad news such as an unfavorable scan, progression of disease, or change in prognosis:

- “We’re in a different place now.”
- “Things aren’t going as I would have hoped.”
- “Given this news, it seems like a good time to talk about what is next.”

REMAP – “E”

Expect emotion & empathize.

How to address an emotional response with empathy:

- “This must be pretty hard to hear/accept.”
- “Tell me what you are most worried about.”
- “I can see you are really concerned about _____.”
- “Is it OK for us to talk about what this means?”

REMAP – “M”

Map the future.

How to start a discussion about the future:

- “Given this information, what is most important for you?”
- “When you think about the future, what are the things you want to do?”
- “As you think of the future, what concerns you?”

REMAP – “A”

Align with the patient’s values.

How to acknowledge and address the patient’s values:

- “As I listen to you, it sounds like the most important things are {X,Y}. Does that sound right?”
- “Let’s look at the best way to plan your care to meet those goals.”

REMAP – “P”

Plan medical treatments that match the patient’s values.

How to acknowledge and address the patient’s values:

- “Here’s what we can do now to help you do those important things:
 - *Detail plan A*
 - *Detail plan B*
 - *Detail plan C*
- What do you think?”

Expect questions about more anti-cancer treatment.

- “My experience tells me that more chemotherapy or surgery would do more harm than good at this point.”

Hospice Referral

- **Hospice care should be mentioned early in goals of care conversations, long before this level of care is needed.**
 - Early discussions can assist more timely hospice enrollment and may improve satisfaction with end-of-life care.

- **When there is reason for a hospice referral:**
 - Discuss the concept fully and robustly before introducing the actual word “hospice”
 - Confirm the patient’s understanding of their disease and prognosis
 - Adding “I wish” can be helpful
 - “I wish there were other curative options, but at this time, there are none”
 - Asking the patient to communicate their worries or concerns
 - Discuss what care may be needed in the near future
 - “We’ve talked about wanting to conserve your energy for important things. One thing that can help us is having a nurse come to your home to adjust your medications so you don’t have to come in to clinic so often.
 - The overall aim is to discuss a patient's goals of care, revising as needed, then present hospice as a means to achieve those goals.

See also Palliative Training Module #7, Reasons to refer to Hospice and Palliative Care

Summary of Points Covered

- **Defining goals of care**
- **Understanding the methods and questions to use when tailoring goals of care conversations and recommendations to a patient's individual wishes and preferences**
- **Broaching the how and when of hospice care within a goals of care discussion**

Next Steps

For more detailed training on this topic, you can go to the following resources:

National Comprehensive Cancer Network® (NCCN®)

- [NCCN Clinical Practice Guidelines in Oncology \(NCCN Guidelines®\) Palliative Care Version 2.2017](http://www.nccn.org/professionals/physician_gls/PDF/palliative.pdf)
http://www.nccn.org/professionals/physician_gls/PDF/palliative.pdf

VITALtalk

- **Vitaltalk: Training oncologists to be better communicators: honest, hopeful, empathic—online and f2f**
 - www.vitaltalk.org
 - www.vitaltalkconversations.com

Education and Training for Health Professionals, EPEC-O

- [EPEC, Education in Palliative and End-of-Life Care](http://www.epec.net/example-EPEC-materials.php)
<http://www.epec.net/example-EPEC-materials.php>
- [EPEC™ -O-Self-Study](http://www.cancer.gov/resources-for/hp/education/epeco)
<http://www.cancer.gov/resources-for/hp/education/epeco>

ONCOTALK®

- [ONCOTALK®](http://depts.washington.edu/oncotalk/)
<http://depts.washington.edu/oncotalk/>

Faculty Bio for Megan McMahon, Ph.D.

Dr. McMahon has a Ph.D. in Clinical Psychology with an emphasis in health and behavioral medicine. Her specialty is working with couples who are coping with chronic illness. In 2003 Dr. McMahon developed the program Partners Empowered™, a six-week structured intervention aimed at facilitating adjustment and softening the impact a cancer diagnosis has on a couple's relationship. In 2011, Dr. McMahon was named the Cancer Wellness Center Clinical Director.

For additional information:

<https://cancerwellness.org/about/our-staff/>

Faculty Bio for Lauren Wiebe, MD

Dr. Lauren Wiebe attended medical school at the Columbia University College of Physicians and Surgeons, then she completed an Internal Medicine residency and fellowship in Medical Oncology, both at the University of Chicago. She completed additional fellowship training in Clinical Medical Ethics at the MacLean Center, and Hospice and Palliative Medicine at Northwestern University.

Dr. Wiebe joined the faculty practice at NorthShore University HealthSystem in January 2017 with dual appointments in Palliative Medicine and Gastrointestinal Medical Oncology. She specializes in the treatment of gastrointestinal cancers with a focus on improving quality of life.

For additional information:

<https://www.northshore.org/apps/findadoctor/physicians/lauren-a.-wiebe?qqs=doctor%3dwiebe>

<https://www.linkedin.com/in/lauren-wiebe-7b5aba2/>

Faculty Bio for Betty Roggenkamp, BA

Ms. Roggenkamp has over 5 years of experience in cancer care improvement, through multiple projects in the Chicagoland area. Betty is a facilitator for the Coleman Supportive Oncology Initiative (CSOI) providing project coordination for the Palliative and Hospice design team. Ms. Roggenkamp has facilitated cancer survivor workshops and group discussions to generate areas of need in cancer care. She is also involved with several care initiation projects and cancer survivorship plan creation. Ms. Roggenkamp has Collaborative Institutional Training Initiative (CITI program) certification in human subjects research.

Betty consulted prior to 2010 as an architectural project coordinator for 10 years including planning, design and construction coordination. She also co-lead a team consisting of community, staff, elected officials and Chicago Public School (CPS) executives in an academic turn around of a CPS School that included an addition of a new building, doubled enrollment, increased test scores and improved community relations.

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Coleman Supportive Oncology Initiative

Palliative Training Module

Topic: Advance Care Planning Over Time

Presenters: Amy Scheu, MSH CHPCA and Catherine Deamant, MD

Version: 08072017

Learning Objectives

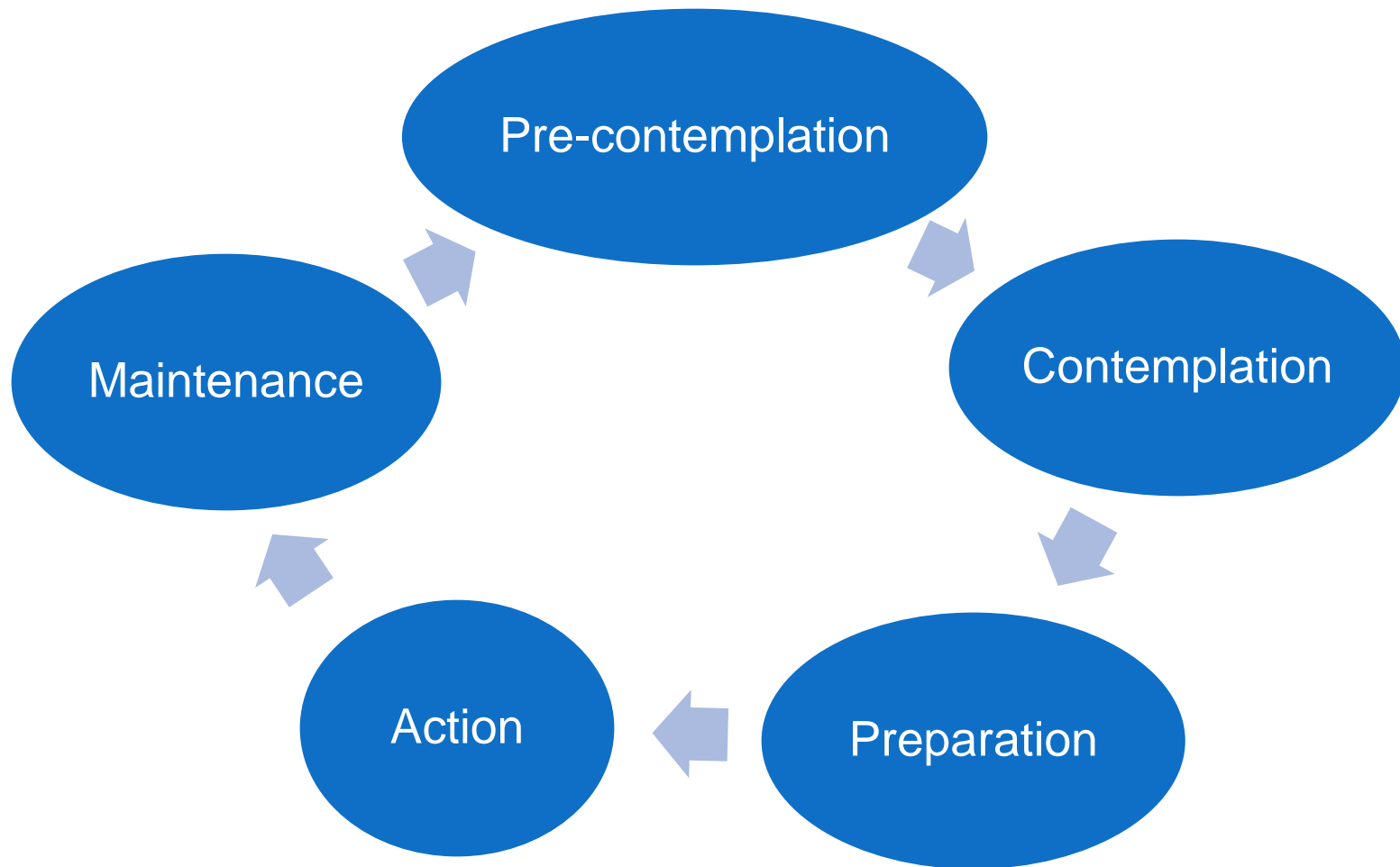
By the end of this module you should be able to:

- 1. Explain the components of an advance care planning discussion tailored to stages of health**
- 2. Describe the elements of an advance care plan based on a model of stages of change for health behaviors**

Paradigm Shift: Advance Care Planning

- **Paradigm shifts from a legal process to a communication process.**
- **Discussion should be tailored to patient readiness and stage of health.**
 - Content and specifics should be targeted based on the patient's clinical condition.
- **Advance care planning is a process over time, not a form.**

Model: Stages of Change for Health Care Behaviors



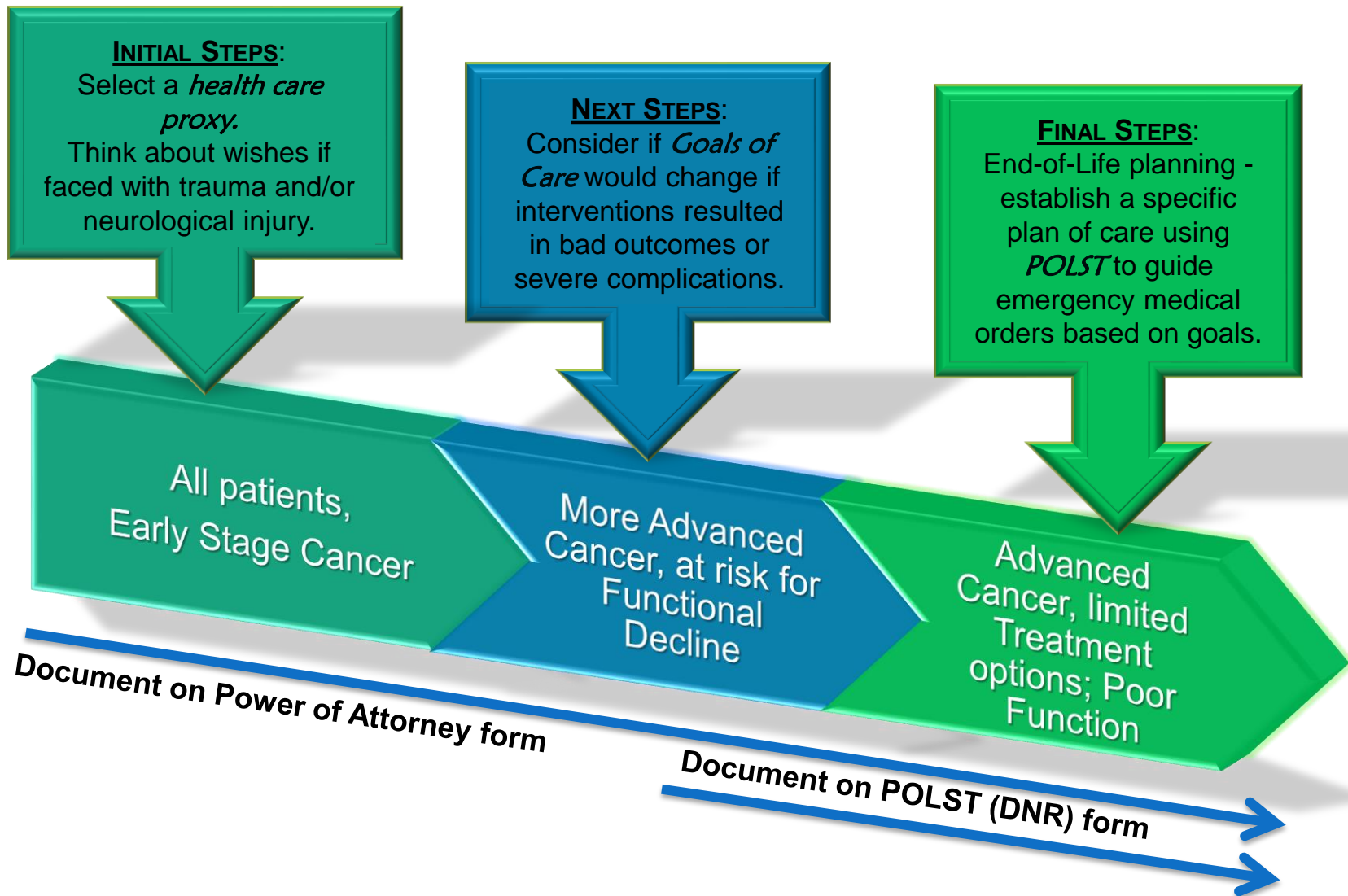
Advance Care Planning: Based on Model of Behavior Change

- **Contemplation/Awareness**
 - Determine patient familiarity with advance care planning
 - Make the patient aware of the need for this plan
- **Preparation**
 - Educate and motivate the patient
 - Reflect on the patient's situation
 - Explore patient values and priorities
- **Taking Action**
 - Discussion with a proxy (family or friends)
 - The provider and the patient talk, plan and document
 - A proxy present for discussion
 - Advanced care planning is completed over time
- **Maintenance**
 - Review and revise with changes in condition

Advance Care Planning: Elements of Conversation

- **Identify an appropriate health care proxy**
- **Elicit the patient's understanding of their illness and assess prognostic awareness**
- **Explore prior experiences with serious illness**
- **Explore understanding of treatment options and impact**
- **Explore what is most important to the patient in the context of their values**
- **Identify priorities and trade-offs**

Advance Care Planning Over Time



Health Status-Early Stage Cancer (1 of 2)

- **Assist in identifying a health care proxy**
 - “If you were too sick to speak with me, is there anyone you trust to make medical decisions for you? Have you talked with this person about what is important?”

- **Explore the patient’s goals and values for medical care**
 - Wishes about care if the patient experienced an unanticipated event, such as traumatic injury or complications, and unlikely to recover

- **Explore specific or personal beliefs that may influence decision-making**

Health Status-Early Stage Cancer (2 of 2)

Action Items:

- May complete Power of Attorney for Health Care form
- Discuss with the identified health care proxy to determine their willingness to serve as agent
- The patient reviews their values with the health care proxy

Health Status-Progression of Cancer: At Risk for Functional Decline (1 of 5)

Explore the patient's understanding of their illness and potential complications

- “What is your understanding of your illness?”
- “How has your illness affected your life?”
- “What have you been told about the possible complications that can occur from your illness or the treatment?”
- “How much information would you like to know about what may transpire/happen during the course of your illness?”

Health Status-Progression of Cancer: At Risk for Functional Decline (2 of 5)

Explore prior experiences:

- “Have you had experiences with yourself or family or friends who became seriously ill and decisions about life-sustaining treatment had to be made?”
- “What did you learn from those experiences?”
- “When you were in the hospital recently, what was that experience like for you?”

Health Status-Progression of Cancer: At Risk for Functional Decline (3 of 5)

Cultivate prognostic awareness

- “What is your sense of what the future holds?”
- “What is your sense of what is happening now?”
- “What has your team told you about your illness and what to expect?”
- “Have you ever had times when you think about what it might be like if you get sicker?”

Health Status-Progression of Cancer: At Risk for Functional Decline (4 of 5)

- **Explore the patient's goals, fears and worries:**
 - “If your health situation worsens, what are your most important goals or desires?”
 - “What are your biggest fears and worries about the future in terms of your health?”

- **Identify the patient's priorities for function and possible trade-offs:**
 - “What abilities are so critical to your life that you can't imagine living without them?”
 - “What side effects are you willing to experience as you undergo treatment?”
 - “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?”
 - Offer to meet with the health care proxy or family

Health Status-Progression of Cancer: At Risk for Functional Decline (5 of 5)

Action Items:

- Identify a health care proxy and complete the Power of Attorney form, if not previously done
- Remember to respect the patient's information preferences, i.e., the way the patient prefers to hear and receive information from a medical team member.
- Schedule a meeting with the health care proxy or family based on the patient's preference for information-sharing

Health Status-Advanced Cancer: Limited treatment Options and Functional Decline (1 of 3)

- **Explore the patient's understanding of their illness and complications**
- **Explore the patient's prior experiences**
- **Advance the patient's prognostic awareness**
 - "How much do you want to know about the likely course of this illness?"
 - Assess patient readiness: "Would it be important for you to have information about how much time you might expect to live?"
 - "What kind of information do you want about the future?" (e.g., average time to live, best/worse case scenario, functional decline)

Health Status-Advanced Cancer: Limited treatment Options and Functional Decline (2 of 3)

Provide support and guide communication if making recommendations for comfort care

- “Tell me what you are most worried about.”
- “What are you hoping for?”
- “What is most important to you about how you spend your time?”
- “Who is a support in your life?”
- “How do you define quality of life?”
- Offer hospice as an option of support for patients when their goals are for comfort, or when there are limited treatment options or poor functional capacity

Health Status-Advanced Cancer: Limited treatment Options and Functional Decline (3 of 3)

Action Items:

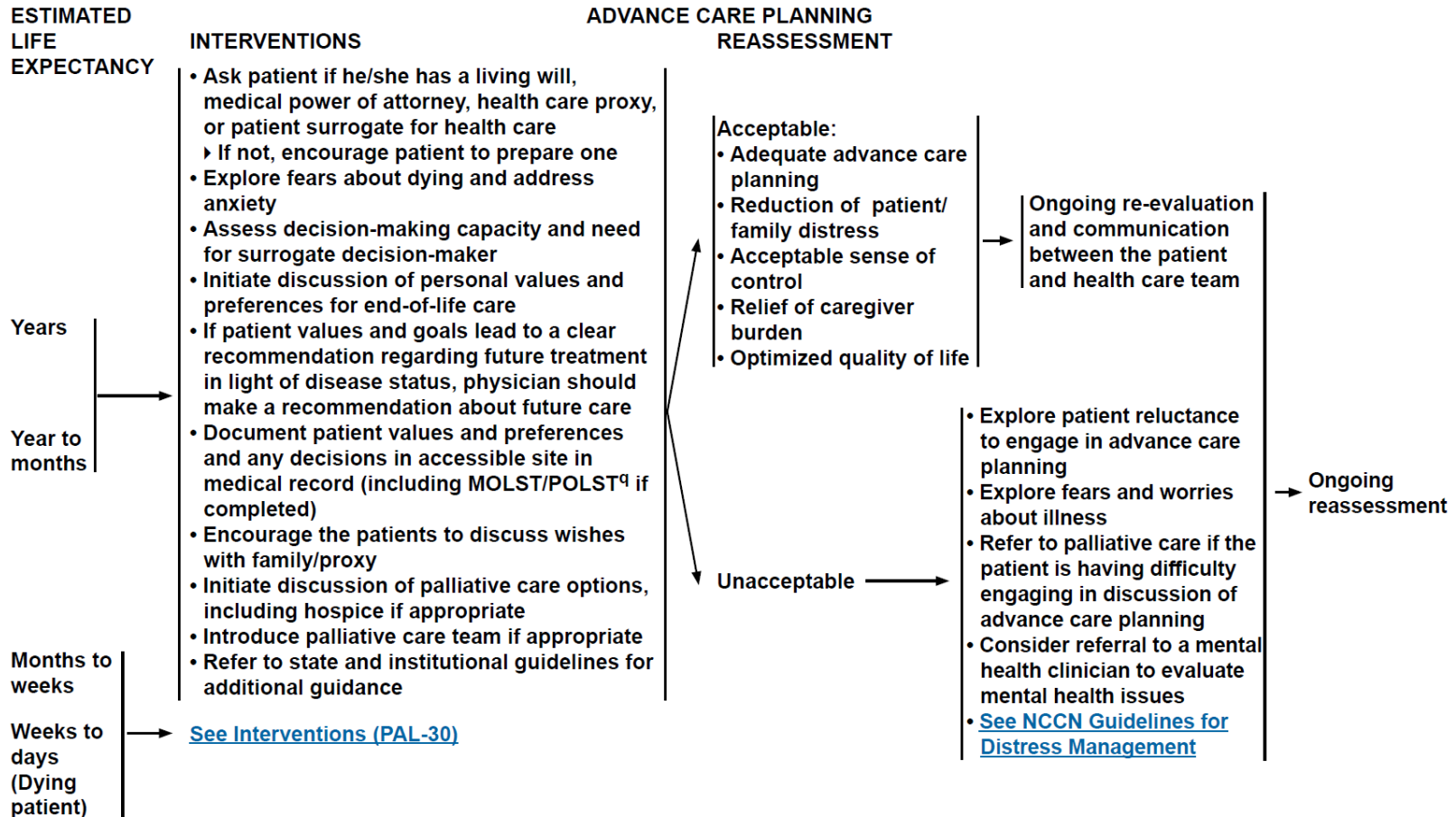
- Identify a health care proxy and complete a Power of Attorney form, if not previously done
- Establish a plan for care and a framework for addressing patient wishes about life-sustaining treatment decisions (e.g., CPR, intubation, selected interventions, comfort care, artificial nutrition)
- Complete the POLST (Physician Orders for Life-Sustaining Treatment) based on patient goals (see training module Palliative #5, POLST)
- Prepare the patient, family and staff for possible course of functional decline

NCCN Guidelines: Advance Care Planning



NCCN Guidelines Version 2.2017 Palliative Care

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^qPatient's values and preferences and any decisions should be documented in the medical record, including MOLST/POLST (Medical Orders for Life-Sustaining Treatment or Physician Orders for Life-Sustaining Treatment).

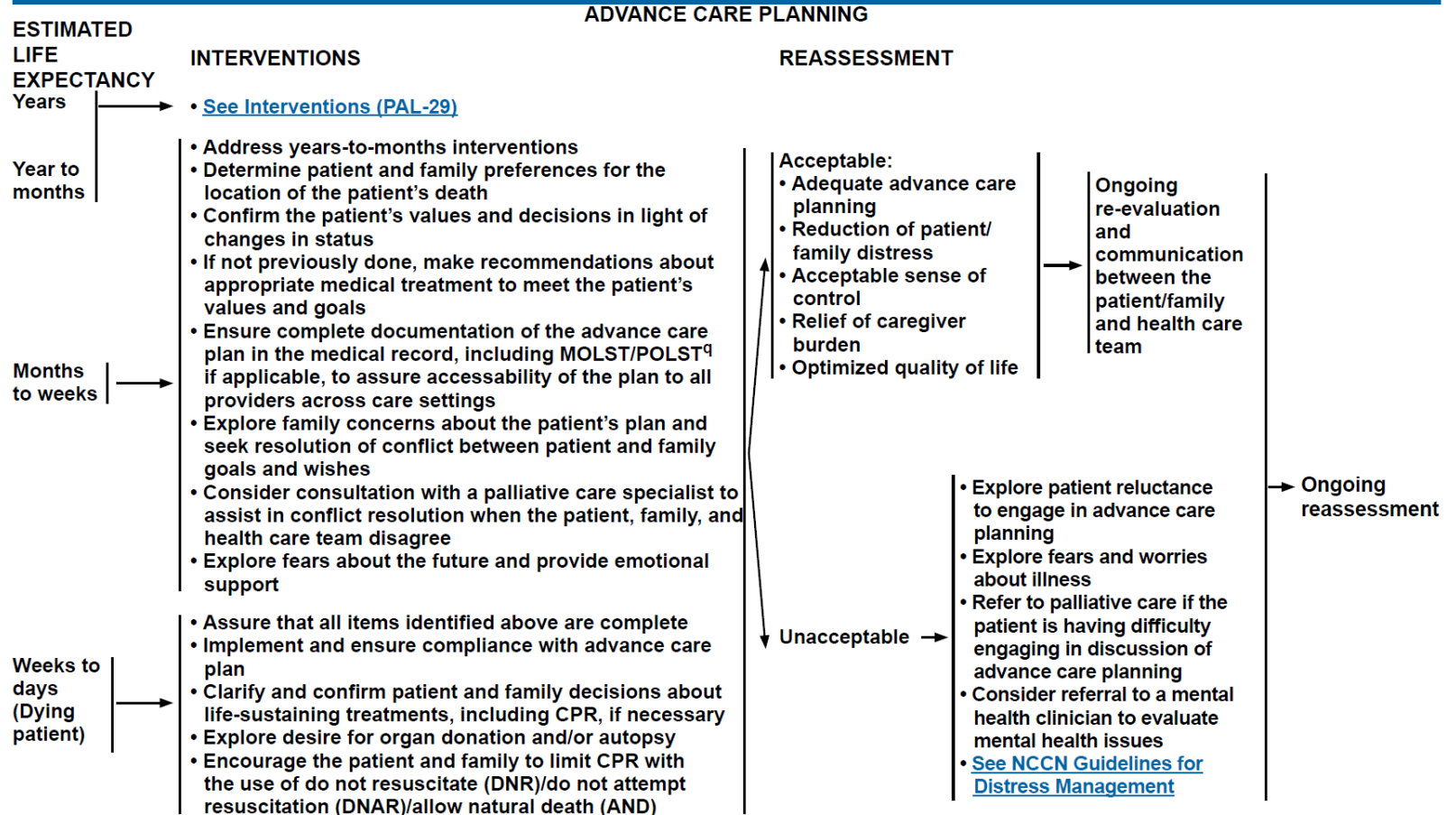
Note: All recommendations are category 2A unless otherwise indicated.
 Clinical Trials: NCCN believes that the best management of any patient with cancer is in a clinical trial. Participation in clinical trials is especially encouraged.

NCCN Guidelines: Advance Care Planning



NCCN Guidelines Version 2.2017 Palliative Care

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Note: All recommendations are category 2A unless otherwise indicated.
Clinical Trials: NCCN believes that the best management of any patient with cancer is in a clinical trial. Participation in clinical trials is especially encouraged.

Summary of Points Covered

In this training module we addressed:

- **Advance care planning is a process over time.**
- **It should be discussed with all patients and tailored to their health status.**
- **Completion of an advance directive, such as a POA form, is relevant for ALL patients and does not mean the patient is a DNR.**

Next Steps

For more detailed training on this topic, you can go to the following resources:

➤ **[Gundersen Health System®, Respecting Choices® Advance Care Planning](http://www.gundersenhealth.org/respecting-choices)**

<http://www.gundersenhealth.org/respecting-choices>

➤ **[Ariadne Labs, Serious Illness Care](https://www.ariadnelabs.org/programs/serious-illness-care/)**

<https://www.ariadnelabs.org/programs/serious-illness-care/>

➤ **[EPEC®, Education in Palliative and End-of-life Care](http://www.epec.net/)**

<http://www.epec.net/>

➤ **[PREPARE, Patient education website tool](https://www.prepareforyourcare.org/)**

<https://www.prepareforyourcare.org/>

National Comprehensive Cancer Network® (NCCN®)

➤ **[NCCN Clinical Practice Guidelines in Oncology \(NCCN Guidelines®\) Palliative Care](http://www.nccn.org/professionals/physician_gls/PDF/palliative.pdf)**

http://www.nccn.org/professionals/physician_gls/PDF/palliative.pdf

Faculty Bio for Amy Scheu, MSH, CHPCA

Amy Scheu, MSH, CHPCA, joined Advocate at Home, the home care division of Advocate Health Care, in 2007 and currently serves as Administrator of Advocate Hospice and System Palliative Care. In this role, she has led implementation and operations of hospice programs across the Chicago area and central Illinois that serve more than 2,200 patients annually. In 2010, Amy was asked to lead efforts to further assure care across the continuum by designing and implementing a system wide palliative care program for Advocate Health Care. Through her efforts, Advocate has launched successful home- and skilled nursing facility-based programs; established four outpatient clinics serving patients in the south, west and north areas of the city and suburbs; and expanded inpatient palliative care services at several hospitals. Amy has also been instrumental in initiating physician palliative medicine education efforts through Advocate Physician Partners, Advocate Health Care's PHO. She has also worked with Advocate Medical Group to secure funding and implement a palliative care pilot serving Medicare Advantage patients on Chicago's south side.

Amy has been certified as a hospice and palliative care administrator by the National Hospice and Palliative Care Organization. She received her bachelor of arts degree from Marquette University and a master's degree in health services administration from Cardinal Stritch University, Milwaukee. She also has a certificate from Harvard School of Public Health in Healthcare Project Management.

Faculty Bio for Catherine Deamant, MD

Catherine Deamant , MD, graduated from Rush Medical College and completed her internal medicine residency at Michael Reese Hospital in Chicago, IL. From 1990-2014, she worked as a general internist in the Division of General Internal Medicine at Cook County Health and Hospitals System (CCHHS), with a focus on HIV care and homeless healthcare. In 2001, she established the Palliative Care Program for CCHHS.

From 2012-2014, she served as the Program Director for the Hospice and Palliative Medicine Fellowship, in collaboration with Rush University Medical Center and Horizon Hospice. She was an assistant professor at Rush Medical College.

She is board certified in hospice and palliative medicine. Currently, she is an associate hospice medical director for JourneyCare.

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