

# The Power of Words



## The Importance of Defining and Documenting Goals in Patient-Centered Care

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# The Power of Words

## The Importance of Defining and Documenting Goals in Patient-Centered Care

by Anne Front, LMFT, and Kendra Deja, LCSW, MSN, ACHPN

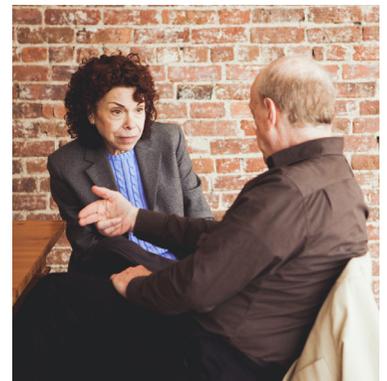
People with a complex or life-limiting illness have a lot to consider in terms of what is important, what defines their own quality of life, and what goals they have for their medical care. The importance of talking about and clarifying goals with patients and families seems inherently obvious, but as palliative care professionals, are we doing this in our daily practice? If we are, how are we sharing that information with the rest of the health care team? If we are not routinely assessing and documenting our patients' goals and preferences, what knowledge do we need to make this part of our routine practice?

This eBook will guide you in how to discuss and document patients' treatment preferences and goals of care. It will lay out the importance of communicating those goals to the rest of the health care team to ensure that everyone is working cohesively to support the patients' wishes. Most of all, this eBook will empower you to help patients have a powerful and defining voice in their own care during the most vulnerable time in their lives.

### CRITICAL CONVERSATIONS

Palliative care is patient-centered care. Palliative care professionals are committed to relieving pain and suffering and supporting quality of life for patients and families. Palliative care clinicians communicate with patients and families to explore their goals and values, and then clearly document these treatment preferences so that the patients' wishes are honored along every step of their serious illness trajectory. Clarifying and documenting preferences and goals allows for greater patient and family autonomy, more personalized care, higher levels of patient engagement, and better symptom management.

As caring and skilled clinicians, patient-centered care is part of our ethical fiber. Knowing what matters to patients, and what their goals are, is not just good professional practice, it is good humanistic palliative care. Even though palliative care clinicians are equipped for these challenging discussions, it is important to ask ourselves:



- *Are we always truly providing patient-centered care?*
- *Are we taking the time to have open-ended conversations with patients and families about what is important as their illness progresses?*
- *Are we giving patients the opportunity to talk to us about their values?*
- *Have we truly tried to learn about our patients, or have we assumed we know what a patient wants, and then checked the necessary boxes to get the assessment done?*

In the fast-paced and complex healthcare world, there are real barriers that inhibit the delivery of optimal patient-centered care. Helping patients articulate their wishes takes skill and time. Time constraints, staff shortages, and high patient census often mean the push is not toward providing the best care, it is for getting the job done quickly and efficiently.

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Sometimes it feels like if we ask patients and families about their goals, it could set up an expectation that we can deliver everything they ask for. There are times that a patient’s goals are outside the realm of possibility given their physical, functional, and financial constraints.

Although these barriers are real and challenging, we need to think creatively about how to overcome them so they do not impede the important work of talking with patients and families to elicit their care preferences.

Social workers, counselors, nurses and anyone on the care team can develop communication and time management skills that allow them to take the time to talk to patients and families about their goals, and by doing so, show them that they are important and that their life has meaning.

## DISCUSSING GOALS AND PREFERENCES

In 1995, when palliative care was beginning to emerge as a medical subspecialty, a group of hospitals and medical centers from around the United States teamed up to learn about patient experiences in end-of-life care and examine opportunities for higher quality of care.

Their research, called SUPPORT (Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatment), identified disturbing gaps between patient/family treatment preferences and provider communication about prognosis and end-of-life discussions.

SUPPORT researchers noted patients were subject to medical treatments that were inconsistent with their goals, and their symptoms were not well controlled because clear communication was not happening between patients, families, and health care providers.

Now, more than 20 years later, the lessons from SUPPORT still resonate, as palliative care professionals strive to practice excellent communication and create thoughtful treatment plans that honor patient and families’ preferences.



In 2013, the National Coalition for Hospice and Palliative Care’s National Consensus Project published The Clinical Guidelines for Quality Palliative Care in order to standardize and optimize the delivery of palliative care across all practice settings.

The National Consensus Project’s Clinical Guidelines recommend an interdisciplinary approach to discussing patient’s health care goals and preferences, and collaborative treatment planning. The Guidelines recommend that all members of the interdisciplinary palliative care team – physicians, nurses, social workers, and chaplains – should be involved with the assessment and documentation of patients’ goals and preferences.



The introduction of Advance Directives like the Durable Power of Attorney for Health Care, Living Will, and Physician Order for Life-Sustaining Treatment (POLST) serve as an excellent starting point for advance care planning discussions.

These Advance Directives offer a legally binding place for patients to document specific end-of-life preferences to be shared with all of the health care team in the patient’s chart or electronic medical record.

The completion of these documents is an important part of the patient's plan of care, but Advance Directives sometimes fall short in really exploring and clarifying the personal goals and preferences that individuals have about their lives.

Knowing whether a person consents to CPR if their heart stops beating is very different from knowing where they would like to be when they take their last breath. Knowing who a person has designated as their proxy health care decision-maker is very different from knowing who the patient wants to be surrounded by in their final days and hours.

There are specific tools clinicians can use to draw out such important patient information. One is the **Who I Am and What I Need** guide, recently developed by the CSU Institute for Palliative Care.

This tool goes beyond the information contained in traditional Advance Directive documents to describe what truly matters to patients and families, then helps translate those values and wishes into a more personalized treatment plan.

The entire transdisciplinary team can use the **Who I Am and What I Need** tool to facilitate open, honest, and person-centered discussions with patients and families.

**Who I Am – What I Need – Page 1**

Name \_\_\_\_\_  
Age \_\_\_\_\_ D.O.B. \_\_\_\_\_

**Who I Am** Use the space below to share Who You Are  
*Examples:*  
People I consider 'family' \_\_\_\_\_  
My caregivers \_\_\_\_\_  
Living situation \_\_\_\_\_  
Hobbies/passions \_\_\_\_\_  
Spiritual or Religious preferences \_\_\_\_\_  
Job or profession \_\_\_\_\_  
Pets \_\_\_\_\_  
Defining life experiences or events \_\_\_\_\_  
Key words that describe me \_\_\_\_\_  
(e.g. mother, artist, traveler, reader, spiritual, etc.) \_\_\_\_\_

**What I Need** Use the space below to share What You Need  
*Examples:*  
Key symptom management goals \_\_\_\_\_  
Social interaction or solitude \_\_\_\_\_  
Religious/spiritual practices \_\_\_\_\_  
Things that bring me comfort \_\_\_\_\_  
Things that give my life meaning \_\_\_\_\_  
How I like to communicate \_\_\_\_\_  
(e.g. in person, through someone else?) \_\_\_\_\_  
How I like to learn \_\_\_\_\_  
(Verbal, written, visual?) \_\_\_\_\_

**Summary of Treatment Preferences**  
Name of Medical decision-maker \_\_\_\_\_

	Yes	No
Advance Directive complete	<input type="checkbox"/>	<input type="checkbox"/>
POLST complete	<input type="checkbox"/>	<input type="checkbox"/>
Interventions:		
CPR/Resuscitation	<input type="checkbox"/>	<input type="checkbox"/>
Breathing machine	<input type="checkbox"/>	<input type="checkbox"/>
Tube feeding	<input type="checkbox"/>	<input type="checkbox"/>
Comfort care	<input type="checkbox"/>	<input type="checkbox"/>

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The following case study will introduce this guide in the context of a real patient scenario:

## CASE STUDY

Maryann is a 62-year-old woman diagnosed with stage IV colorectal cancer, metastasized to her liver, lung, and bones. She is divorced with two adult daughters, and is a flutist who enjoys playing her flute in local church and community choirs.



In the past year of her illness, she has become progressively weaker during subsequent rounds of chemotherapy and radiation. She can no longer play her flute due to shortness of breath. It is hard for her to even go to church or social activities.

Because of Maryann's goal to be more awake and interactive, she often forgoes pain medication due to the side effects of lethargy and confusion. She feels that the aggressive treatment she has been doing is affecting her quality of life and considering stopping the treatment.

Her oncologist feels that a new clinical trial would be very good for her, and Maryann feels obligated to continue the treatments to show her daughters that she is "putting up a good fight."

Maryann is admitted to the hospital due to bleeding from a growing rectal mass. The palliative care team meets with Maryann and her family and identifies her treatment preferences: to have her pain and dyspnea well controlled so that she can play her flute, and interact with her family and friends.

Maryann feels that stopping chemotherapy and avoiding the clinical trial would give her more energy to at least go back to church and listen to her friends' music, even if she cannot play in the choir.

The palliative care team assists her in completing her Durable Power of Attorney for Health Care and POLST documents and provides copies for her to take to her oncologist to serve as the starting point for a discussion with the oncologist about how she would like to forgo the clinical trial and focus on her quality of life.

Maryann follows up with her oncologist three days after discharge. In spite of her stated wishes to focus on quality of life, the oncologist urges her to sign up for the clinical trial in an effort to extend her life. At her daughter's urging, Maryann agrees, and signs up to begin a new round of chemotherapy the next week.

Several days later, Maryann is readmitted to the hospital for an episode of recurrent rectal bleeding and severe acute pain. She is given blood transfusions and started on a PCA pump to control her pain.

The inpatient palliative care team meets with Maryann and her family again during her seven-day hospital stay. The palliative care team assists with a plan to manage her pain at home, while maintaining her alertness and ability to interact with people.

The palliative care social worker also introduces Maryann and her daughters to the **Who I Am and What I Need (Who-What)** form.

This tool supplements the information contained in a traditional Advance Directive. It's not a legal document, but rather something palliative care clinicians can use to expand upon a patient's medical and treatment preferences – to get a true sense of who they are as people and how their wishes reflect the people, places, and activities that bring them meaning.

Palliative care teams can place/scan the **Who-What** tool in a patient's chart or electronic medical record (EMR) so that every clinician who comes in contact with the patient knows what they value as they navigate through various healthcare settings along their serious-illness trajectory.

Alternately, instead of scanning the document into the patient's record, clinicians may choose to incorporate the information into the "standard" assessment that is part of their palliative care practice. The important thing is to consider how they will share the information



The **Who I Am** section can contain personal information about the patient such as their:

- Self-identified family members
- Key friends and caregivers
- Hobbies
- Profession
- Passions
- Religious or spiritual designation
- Pets
- Defining life experiences or events
- A few key words that define them, for example: Maryann is a “musician,” “mother,” and “spiritual”



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The **What I Need** section can contain information such as:

- Key symptom management goals (i.e. “I need to be free from pain so I can enjoy my pets.”)
- Preferences for environment of care (i.e. “I need to be at home so I can look out the window at my garden.”)
- Hobbies to provide fulfillment and distraction
- Key people or pets that provide strength and comfort
- Specific religious or spiritual acts that provide strength and comfort
- Key foods, smells, or sights in their environment
- Touch
- Sexual activity
- Exercise
- What type of communication they prefer (direct, through a family point-person) and how they learn best (verbal, written, visual, quick decision-maker, etc.)



The **Who-What** tool also includes sections for patients to reiterate treatment preferences and long and short-term goals. This gives them a chance to reinforce preferences that are extremely important to them, or that they feel were not adequately covered in their Advance Directives. Below is a sample of the guide related to our patient Maryann:

### **Who I Am**

I am Maryann.

My family is my daughter Sarah (32), son-in-law Kevin, granddaughter Zoe (3) and my daughter Rachel (29).

I am a flutist for St. Mary’s Catholic Church. I have been playing the flute for nearly 40 years.

I love all kinds of music, but my favorite kind of music is classical music.

I am Catholic and my church community is a key part of my life.

I am a mother, grandma, musician, Catholic, believer.

I am tired. I am hopeful. I am not scared.

### **What I Need**

I need to see my family every day to help me keep up my strength.

I need to have music playing in my room.

I need to breathe better and be free from pain.

I need to be at home surrounded by my things.

I need to talk to my oncologist to ask questions about the clinical trial.

I need help at home in order to keep living independently.

I need better symptom control in order to go home.

I need to meet regularly with my priest.

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### **Treatment Preferences:**

1. I do not want to be hooked up to a breathing machine.
2. I do not want to be artificially resuscitated if my heart stops.
3. I would like to be home with hospice at the end of my life.

### **Short Term Goals:**

1. Stabilize symptoms to discharge to home as soon as possible.
2. Talk to my oncologist about the clinical trial.
3. Have my priest visit the hospital.

### **Long Term Goals:**

1. Go to church at least one more time.
2. Enroll in hospice care when I have exhausted all options for chemotherapy and clinical trials.
3. Stay in my own home for the end of my life with hospice support for me and my family.



## **HELP PATIENTS FIND THEIR VOICE**

Many patients will not easily be able to articulate who they are, exactly what they need, and the specific steps that will help them achieve these goals.

Asking directly for what one needs is a difficult task that many people feel uncomfortable doing, particularly in health care. Patients are typically put into a submissive position in a hierarchical system where they are expected to “follow the doctor’s orders” instead of speaking up for themselves. Additionally, patients’ symptoms and existential distress may impede their ability to focus on what they need.

For these reasons, the expertise and experience of a transdisciplinary care team becomes critically important in guiding these discussions.

Various team members can help patients and families navigate their choices based on their experience helping other patients.

Clinicians can draw from their knowledge and experience to help patients and families define what is possible given the specific disease trajectory, symptoms, insurance constraints, and intricacies of the medical system.

The palliative team may need to give patients and families suggestions, or “fill in the blanks” as patients try to articulate their needs. Team members must be careful to avoid coloring the patients’ choices with their own values in a paternalistic manner.

Although it can be hard to articulate, most people know what is important to them and what gives their life meaning, purpose, and joy. Many times, it just takes the guidance and focused attention of palliative care clinicians to help patients voice who they are and what really matters.

## **EMPOWER PEOPLE WITH THEIR OWN GOALS**

Completing the **Who-What** tool helps patients and families anchor their health care choices to what is important to them as individuals.

Establishing goals can empower patients with a sense of control and personal satisfaction during a time when their illness often makes life feel out of control. Setting goals also helps patients maintain their hope and motivation by pushing them forward and keeping themselves at the center of every decision.

As patients move along the disease trajectory and experience physical and functional changes, their goals may also change. Specific treatments or settings of care that they were hoping for might no longer be feasible given

new constraints or challenges. Patients and families may also just abruptly change their mind about their goals if a choice no longer feels consistent with who they are.

Changes in goals are completely acceptable – we can never forget that human beings are at the center of any illness. As long as the patient is keeping themselves at the center of their decisions, it should be celebrated that the patient is a human being who is inherently complex and capable of growth and change.

Just because a person has a serious illness, does not mean that they stop learning and changing. In fact, many times it is the experience of the illness itself that pushes people to grow and evolve into a stronger individual with a truer sense of self and priorities than they were before they got sick.

## CONCLUSION

Discussing and documenting patients' goals of care is one of the most powerful ways that clinicians can empower patients to control the circumstances of their life...and their death.

By using the **Who I Am and What I Need** tool, clinicians can move advance care planning conversations beyond the traditional work of completing Advance Directives, to helping patients define who they are and what goals and values will guide their care.

Focusing on who patients really are, and what they need, reminds us that palliative care is a privilege and a calling...to work with people who are infinitely more than a set of symptoms or a disease.

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## ADDITIONAL RESOURCES

The Joint Commission Standard Measures for Palliative Care Certification, January 2017 [https://www.jointcommission.org/certification/palliative\\_care.aspx](https://www.jointcommission.org/certification/palliative_care.aspx)

Palliative Care Resources <http://www.med.unc.edu/pcare/resources/health-professional-resources>

Paternalism in medical ethics <https://moralmusings21.wordpress.com/2009/10/16/paternalism-in-medical-ethics-a-critique/>

### About the Authors:

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**Kendra Deja, LCSW, MSN, GNP-BC, ACHPN** is a geriatric nurse practitioner who completed her MSN at Marquette University in Milwaukee, Wisconsin. Prior to becoming a nurse practitioner, Kendra received a Master's Degree in Social Work from the University of Wisconsin-Madison and worked as an LCSW in the VA system and for several community hospice programs. Kendra has worked as a nurse case manager for community hospice and as a palliative care nurse practitioner in the VA, long-term care, on an inpatient palliative care consult service, and in an outpatient palliative care clinic embedded in an NCI-Designated Comprehensive Cancer Center. Kendra joined the CSU Institute for Palliative Care as the Manager of Clinical Curriculum and also serves as faculty for the Institute's APRN Palliative Care Certificate course. Kendra is an Advanced Certified Hospice and Palliative Nurse (ACHPN) and is an ELNEC trainer.

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## Who I Am – What I Need – Page 1

Name \_\_\_\_\_

Age \_\_\_\_\_ D.O.B. \_\_\_\_\_

### Who I Am

*Examples:*

People I consider 'family'

My caregivers

Living situation

Hobbies/passions

Spiritual or Religious preferences

Job or profession

Pets

Defining life experiences or events

Key words that describe me

(e.g. mother, artist, traveler,  
reader, spiritual, etc.)

Use the space below to share Who You Are

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### What I Need

*Examples:*

Key symptom management goals

Social interaction or solitude

Religious/spiritual practices

Things that bring me comfort

Things that give my life meaning

How I like to communicate

(e.g. in person, through someone else?)

How I like to learn

(Verbal, written, visual?)

Use the space below to share What You Need

---

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### Summary of Treatment Preferences

Name of Medical decision-maker

---

Advance Directive complete

POLST complete

Interventions:

CPR/Resuscitation

Breathing machine

Tube feeding

Comfort care

Yes

No

<input type="checkbox"/>	<input type="checkbox"/>

## Who I Am – What I Need – Page 2

### My Short-Term Goals:

*Examples:*

Better pain control

---

Relief from symptoms

---

Go home

---

Get more chemotherapy

---

### My Long-Term Goals:

*Examples:*

Achieve remission

---

Attend my daughter's graduation

---

Get hospice care at home

---

Die at home surrounded by family, pets

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Three Things I Want You to Know About Me:

1. 

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2. 

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3. 

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