

**Talking about hospice - excerpted from GeriPal.org by Alex Smith, MD
(7/6/12)**

My general explanation about hospice starts out with the experiences and perceptions of patients and family. I usually ask something like: "Have you heard of hospice? Tell me more about what you've heard." I try and respond to that, addressing experiences and misperceptions, and somehow work toward a statement like the following:

"Hospice is both a concept of care and a benefit. Let's talk about the concept first.

Hospice is for people with serious illness like yourself who want to focus on quality of life. The primary focus of hospice is on helping people to live each day as good as it can be.

People in hospice have generally made a choice to focus on living at home, whether that be in the community, a nursing home, or a residential hospice home. While people on hospice are occasionally admitted to the hospital, the general preference of patients on hospice is for receiving all care in their home. Hospice is also a benefit. Medicare pays for hospice services to you for free. Hospice services are delivered by an interdisciplinary team of doctors, nurses, social workers, chaplains, and volunteers. Hospice provides outstanding and expert care for persons with serious illness like your self. They are the experts in treating pain and other symptoms, and in helping address your financial and spiritual concerns.

It's important to recognize what hospice can do for you, and what they can't do. They will generally send a nurse to see you in your home for an hour or so two or three times a week. A social worker and chaplain will visit with you to provide support. Someone may come to sit with you so that your wife can take a break. Hospice is available by phone 24 hours a day, but is not able to provide 24 hour care for days at a time."

That's an approximate version of how I explain hospice, and how I teach trainees to explain hospice. I think it's helpful for them to hold on to the general structure of hospice being both a concept, or philosophy of care, as well as a defined benefit.

I think it's also important to convey a sense of what hospice can and cannot provide for patients. For example, I have many patients and family members (and trainees in July) who believe hospice will provide 24/7 nursing care.

Note also that I avoid some of the language about "hospice is for people who have gone through every curative treatment imaginable and are finally exhausted and ready to die."

In part due to such perceptions about hospice, the word hospice can feel like a "loaded term." One of my mentors during fellowship used to reverse everything I just did in an attempt to avoid the baggage people sometimes associate with hospice. Before mentioning hospice, he'd say something like:

"There is a service that focuses on keeping you as comfortable as possible after you leave the hospital. They provide home nursing services that provide expert pain and symptom relief. They have social workers and chaplains that can visit with you. They are available by phone 24 hours a day 7 days a week.

Does that sound like something you're interested in?

Yes? Great, that service is called hospice."

Sometimes this technique backfires, and the patients and family feel they have been tricked into agreeing to something they've heard about and view very differently from the way it's described (Gotcha!). I have to say, however, that the way this mentor did it was seamless, and accomplished the objective of matching treatment to patient goals first, then dealt with the misperceptions later.

Functional Assessment Scale (FAST)

1	No difficulty either subjectively or objectively.
2	Complains of forgetting location of objects. Subjective work difficulties.
3	Decreased job functioning evident to co-workers. Difficulty in traveling to new locations. Decreased organizational capacity. *
4	Decreased ability to perform complex task, (e.g., planning dinner for guests, handling personal finances, such as forgetting to pay bills, etc.)
5	Requires assistance in choosing proper clothing to wear for the day, season or occasion, (e.g. pt may wear the same clothing repeatedly, unless supervised.*
6	Occasionally or more frequently over the past weeks. * for the following A) Improperly putting on clothes without assistance or cueing . B) Unable to bathe properly (not able to choose proper water temp) C) Inability to handle mechanics of toileting (e.g., forget to flush the toilet, does not wipe properly or properly dispose of toilet tissue) D) Urinary incontinence E) Fecal incontinence
7	A) Ability to speak limited to approximately ≤ 6 intelligible different words in the course of an average day or in the course of an intensive interview. B) Speech ability is limited to the use of a single intelligible word in an average day or in the course of an intensive interview C) Ambulatory ability is lost (cannot walk without personal assistance.) D) Cannot sit up without assistance (e.g., the individual will fall over if there are not lateral rests [arms] on the chair.) E) Loss of ability to smile. F) Loss of ability to hold up head independently.
*Scored primarily on information obtained from a knowledgeable informant. Psychopharmacology Bulletin, 1988 24:653-659.	

Palliative Performance Scale (PPS)

%	Ambulation	Activity and Evidence of Disease	Self-Care	Intake	Level of Conscious
100	Full	Normal activity, no evidence of disease	Full	Normal	Full
90	Full	Normal activity, some evidence of disease	Full	Normal	Full
80	Full	Normal activity with effort, some evidence of disease	Full	Normal or reduced	Full
70	Reduced	Unable to do normal work, some evidence of disease	Full	Normal or reduced	Full
60	Reduced	Unable to do hobby or some housework, significant disease	Occasional assist necessary	Normal or reduced	Full or confusion
50	Mainly sit/lie	Unable to do any work, extensive disease	Considerable assistance required	Normal or reduced	Full or confusion
40	Mainly in bed	Unable to do any work, extensive disease	Mainly assistance	Normal or reduced	Full, drowsy, or confusion
30	Totally bed bound	Unable to do any work, extensive disease	Total care	Reduced	Full, drowsy, or confusion
20	Totally bed bound	Unable to do any work, extensive disease	Total care	Minimal sips	Full, drowsy, or confusion
10	Totally bed bound	Unable to do any work, extensive disease	Total care	Mouth care only	Drowsy or coma
0	Death	—	—	—	—

Hospice Card

A hospice is a program designed to care for the dying and their special needs. Among these services all hospice programs should include:

- Control of pain and other symptoms** through medication, environmental adjustment and education.
- Psychosocial support** for both the patient and family, including all phases from diagnosis through bereavement.
- Medical services** commensurate with the needs of the patient.
- Interdisciplinary "team"** approach to patient care, patient/ and family support, and education.
- Integration into existing facilities where possible.
- Specially trained personnel with expertise in care of the dying and their families.

Hospice Eligibility Criteria

GENERAL (NON-SPECIFIC) TERMINAL ILLNESS

- Terminal condition cannot be attributed to a single specific illness. And
- Rapid decline over past 3-6months Evidenced by:
 Progression of disease evidenced by sx, signs & test results
 Decline in PPS to $\leq 50\%$
 Involuntary weight loss $>10\%$ and/or Albumin <2.5 (helpful)

ADULT FAILURE TO THRIVE

Patient meets **ALL** of the following:

- Palliative performance Scale $\leq 40\%$
- BMI <22
- Pt refusing enteral or parenteral nutrition support or has not responded to such nutritional support, despite adequate caloric intake

CANCER

Patient meets **ALL** of the following:

- Clinical findings of malignancy with widespread, aggressive or progressive disease as evidenced by increasing sx, worsening lab values and/or evidence of metastatic disease
- Palliative performance Scale (PPS) $\leq 70\%$
- Refuses further life-prolonging therapy OR continues to decline in spite of definitive therapy

Supporting documentation includes:

Hypercalcemia > 12
 Cachexia or weight loss of 5% in past 3 months
 Recurrent disease after surgery/radiation/chemotherapy
 Signs and sx of advanced disease (e.g. nausea, requirement for transfusions, malignant ascites or pleural effusion, etc.)

DEMENTIA

The patient has **both 1 and 2:**

- Stage 7C or beyond according to the FAST Scale
- AND
- One or more of the following conditions in the 12 months:
 Aspiration pneumonia
 Pyelonephritis
 Septicemia
 Multiple pressure ulcers (stage 3-4)
 Recurrent Fever
 Other significant condition that suggests a limited prognosis
 Inability to maintain sufficient fluid and calorie intake in the past 6months (10% weight loss or albumin < 2.5 gm/dl)

HEART DISEASE

The patient has 1 and either 2 or 3.

1. CHF with NYHA Class IV* sx and both :
Significant sx at rest
Inability to carry out even minimal physical activity without dyspnea or angina



2. Patient is optimally treated
(ie diuretics, vasodilators, ACEI, or hydralazine and nitrates)
3. The patient has angina pectoris at rest, resistant to standard nitrate therapy, and is either not a candidate for/ or has declined invasive procedures.

Supporting documentation includes:

EF \leq 20%, Treatment resistant symptomatic dysrhythmias
h/o cardiac related syncope, CVA 2/2 cardiac embolism
H/o cardiac resuscitation, concomitant HIV disease

HIV/AIDS

The patient has either 1A or 1B and 2 and 3.

- 1A. CD4+ < 25 cells/mcL OR 1B. Viral load > 100,000

AND

2. At least one (1) : CNS lymphoma, untreated or refractory wasting (loss of > 33% lean body mass), (MAC) bacteremia,

Progressive multifocal leukoencephalopathy
Systemic lymphoma, visceral KS, Renal failure no HD,
Cryptosporidium infection, Refractory toxoplasmosis

AND

3. PPS* of < 50%

LIVER DISEASE

The patient has both 1 and 2.

1. End stage liver disease as demonstrated by A or B, & C:
A. PT > 5 sec OR B. INR > 1.5

AND

- C. Serum albumin < 2.5 gm / dl

AND

2. One or more of the following conditions:

Refractory Ascites, h/o spontaneous bacterial peritonitis, Hepatorenal syndrome, refractory hepatic encephalopathy, h/o recurrent variceal bleeding

Supporting Documents includes:

Progressive malnutrition, Muscle wasting with dec. strength. Ongoing alcoholism (> 80 gm ethanol/day), Hepatocellular CA HBsAg positive, Hep. C refractory to treatment



PULMONARY DISEASE

Severe chronic lung disease as documented by 1, 2, and 3.

1. The patient has all of the following:

Disabling dyspnea at rest
Little of no response to bronchodilators
Decreased functional capacity (e.g. bed to chair existence, fatigue and cough)



AND

2. Progression of disease as evidenced by a recent h/o increasing office, home, or ED visits and/or hospitalizations for pulmonary infection and/or respiratory failure.

AND

3. Documentation within the past 3 months \geq 1:

Hypoxemia at rest on room air (pO₂ < 55 mmHg by ABG) or oxygen saturation < 88%

Hypercapnia evidenced by pCO₂ > 50 mmHg

Supporting documentation includes: Cor pulmonale and right heart failure Unintentional progressive weight loss

NEUROLOGIC DISEASE (chronic degenerative conditions such as ALS, Parkinson's, Muscular Dystrophy, Myasthenia Gravis or Multiple Sclerosis)

The patient must meet at least one of the following criteria (1 or 2A or 2B):

1. Critically impaired breathing capacity, with all:

Dyspnea at rest, Vital capacity < 30%, Need O₂ at rest, patient refuses artificial ventilation

OR

2. Rapid disease progression with either A or B below:

Progression from :

independent ambulation to wheelchair or bed-bound status

normal to barely intelligible or unintelligible speech

normal to pureed diet

independence in most ADLs to needing major assistance in all ADLs

AND

A. Critical nutritional impairment demonstrated by all of the following in the preceding 12 months:

Oral intake of nutrients and fluids insufficient to sustain life

Continuing weight loss

Dehydration or hypovolemia

Absence of artificial feeding methods

OR

B. Life-threatening complications in the past 12 months as demonstrated by \geq 1:

Recurrent aspiration pneumonia, Pyelonephritis, Sepsis,

Recurrent fever, Stage 3 or 4 pressure ulcer(s)

RENAL FAILURE

The patient has 1, 2, and 3.

1. The patient is not seeking dialysis or renal transplant

AND

2. Creatinine clearance* is < 10 cc/min (< 15 for diabetics)

AND

3. Serum creatinine > 8.0 mg/dl (> 6.0 mg/dl for diabetics)

Supporting documentation for chronic renal failure includes:

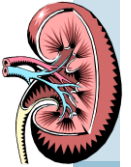
Uremia, Oliguria (urine output < 400 cc in 24 hours), Intractable hyperkalemia (> 7.0), Uremic pericarditis, Hepatorenal syndrome, Intractable fluid overload.

Supporting documentation for acute renal failure includes:

Mechanical ventilation, Malignancy (other organ system)

Chronic lung disease, Advanced cardiac disease,

Advanced liver disease



STROKE OR COMA

The patient has both 1 and 2.

1. Poor functional status PPS* \leq 40% **AND**

2. Poor nutritional status with inability to maintain sufficient fluid and calorie intake with \geq 1 of the following:

\geq 10% weight loss in past 6 months

\geq 7.5% weight loss in past 3 months

Serum albumin < 2.5 gm/dl

Current history of pulmonary aspiration without effective response to speech therapy interventions to improve dysphagia and decrease aspiration events

Supporting documentation includes:

Coma (any etiology) with 3 of the following on the third (3rd) day of coma:

Abnormal brain stem response

Absent verbal responses

Absent withdrawal response to pain

Serum creatinine > 1.5 gm/dl



Palliative care resources
Primary Care Days – April 2013
Jennifer Reidy, MD

For clinicians:

Fast Facts (End-of-life/palliative education resource center, Medical College of Wisconsin): hundreds of concise, peer-reviewed, evidenced-based summaries of palliative care topics; good point-of-care reference.

www.eperc.mcw.edu

EPrognosis: online tool for estimating prognosis in elders. www.eprognosis.org

How to find a hospice in Massachusetts: www.hospicefed.org (Hospice and Palliative Care Federation of Massachusetts)

EPEC (Education in Palliative and End-of-Life Care, sponsored by AMA, Robert Wood Johnson Foundation, National Cancer Institute, NIH, US Department of HHS): a comprehensive CME curriculum in palliative medicine.

Order free of charge at www.cancer.gov/cancertopics/cancerlibrary/epeco

The Lois Green Learning Community: a network for professional development in palliative care, founded by Dr. Suzana Makowski at UMass.

www.loisgreenlearningcommunity.org

For patients and families:

The Conversation Project (Ellen Goodman, Atul Gawande, Donald Berwick & others): how to talk with your loved ones about your wishes.

www.theconversationproject.org

PREPARE: an interactive online tool for advance care planning; includes user-friendly videos. www.prepareforyourcare.org

General information about palliative care & hospice:

www.getpalliativecare.org (Center to Advance Palliative Care)

www.palliativedoctors.org (American Academy of Hospice and Palliative Care)

Your Conversation Starter Kit

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The Conversation Project is dedicated to helping people talk about their wishes for end-of-life care.

We know that no guide and no single conversation can cover all the decisions that you and your family may face. What a conversation can do is provide a shared understanding of what matters most to you and your loved ones. This can make it easier to make decisions when the time comes.

In that spirit, we've created this Starter Kit. It doesn't answer every question, but it will help you get your thoughts together, and then have the conversation with your loved ones.

You can use it whether you are getting ready to tell someone else what you want, or you want to help someone else get ready to share their wishes.

Take your time. This kit is not meant to be completed in one sitting. It's meant to be completed as you need it, throughout many conversations.

Step 1: Get Ready

There are a million reasons to avoid having the conversation. But it's critically important. And you can do it.

Consider the facts.

60% of people say that making sure their family is not burdened by tough decisions is "extremely important"

56% have not communicated their end-of-life wishes

Source: Survey of Californians by the California Health Foundation (2012)

70% of people say they prefer to die at home

70% die in a hospital, nursing home, or long-term-care facility

Source: Centers for Disease Control (2005)

80% of people say that if seriously ill, they would want to talk to their doctor about end-of-life care

7% report having had an end-of-life conversation with their doctor

Source: Survey of Californians by the California Health Foundation (2012)

82% of people say it's important to put their wishes in writing

23% have actually done it

Source: Survey of Californians by the California Health Foundation (2012)

One conversation can make all the difference.

Remember:

- You don't need to talk about it just yet. Just think about it.
- You can start out by writing a letter—to yourself, a loved one, or a friend.
- Think about having a practice conversation with a friend.
- These conversations may reveal that you and your loved ones disagree. **That's okay.** It's important to simply know this, and to continue talking about it now—not during a medical crisis.

What do you need to think about or do before you feel ready to have the conversation?

Step 2: Get Set

Now, think about what you want for end-of-life care.

What matters to me is ____.

Start by thinking about what's most important to you. What do you value most?
What can you not imagine living without?

Now finish this sentence:

What matters to me at the end of life is_____.

Sharing your "What matters to me" statement with your loved ones could be a big help down the road. It could help them communicate to your doctor what abilities are most important to you—what's worth pursuing treatment for, and what isn't.

Where I Stand scales

Use the scales below to figure out how you want your end-of-life care to be.

Circle the number that best represents your feelings on the given scenario.

As a patient...

1

2

3

4

5

I only want to know
the basics

I want to know
as much as I can

1

2

3

4

5

Ignorance
is bliss

I want to know how
long I have to live

1

2

3

4

5

I want my doctors to
do what they think
is best

I want to have a say
in every decision

Look at your answers.

What kind of role do you want to play in the decision-making process?

How long do you want to receive medical care?

1

I want to live as long as possible, no matter what

2

3

4

5

Quality of life is more important to me than quantity

1

I'm worried that I won't get enough care

2

3

4

5

I'm worried that I'll get overly aggressive care

1

I wouldn't mind being cared for in a nursing facility

2

3

4

5

Living independently is a huge priority for me

Look at your answers.

What do you notice about the kind of care you want to receive?

How involved do you want your loved ones to be?

1

I want my loved ones to do exactly what I've said, even if it makes them a little uncomfortable at first

2

3

4

5

I want my loved ones to do what brings them peace, even if it goes against what I've said

1

When the time comes, I want to be alone

2

3

4

5

I want to be surrounded by my loved ones

1

I don't want my loved ones to know everything about my health

2

3

4

5

I am comfortable with those close to me knowing everything about my health

What role do you want your loved ones to play? Do you think that your loved ones know what you want or do you think they have no idea?

What do you feel are the three most important things that you want your friends, family and/or doctors to understand about your wishes for end-of-life care?

1. _____
2. _____
3. _____

Step 3: Go

When you're ready to have the conversation, think about the basics.

Mark all that apply:

Who do you want to talk to? Who do you trust to speak for you?

- | | | |
|---|--|---------------------------------------|
| <input type="checkbox"/> Mom | <input type="checkbox"/> Partner/Spouse | <input type="checkbox"/> Doctor |
| <input type="checkbox"/> Dad | <input type="checkbox"/> Minister/Priest/Rabbi | <input type="checkbox"/> Caregiver |
| <input type="checkbox"/> Child/Children | <input type="checkbox"/> Friend | <input type="checkbox"/> Other: _____ |
-

When would be a good time to talk?

- | | | |
|--|--|---------------------------------------|
| <input type="checkbox"/> The next big holiday | <input type="checkbox"/> Before my next big trip | <input type="checkbox"/> Other: _____ |
| <input type="checkbox"/> At Sunday dinner | <input type="checkbox"/> Before I get sick again | |
| <input type="checkbox"/> Before my kid goes to college | <input type="checkbox"/> Before the baby arrives | |
-

Where would you feel comfortable talking?

- | | | |
|---|--|---------------------------------------|
| <input type="checkbox"/> At the kitchen table | <input type="checkbox"/> On a walk or hike | <input type="checkbox"/> Other: _____ |
| <input type="checkbox"/> At a cozy café or restaurant | <input type="checkbox"/> Sitting in a garden or park | |
| <input type="checkbox"/> On a long drive | <input type="checkbox"/> At my place of worship | |
-

What do you want to be sure to say?

If you wrote down your three most important things at the end of Step 2, you can use those here.

How to start

Here are some ways you could break the ice:

- "I need your help with something."
- Remember how someone in the family died—was it a "good" death or a "hard" death? How will yours be different?
- "I was thinking about what happened to _____, and it made me realize..."
- "Even though I'm okay right now, I'm worried that _____, and I want to be prepared."
- "I need to think about the future. Will you help me?"
- "I just answered some questions about how I want the end of my life to be. I want you to see my answers. And I'm wondering what your answers would be."







What to talk about

- ☐ When you think about the last phase of your life, what's most important to you? How would you like this phase to be?
- ☐ Do you have any particular concerns about your health? About the last phase of your life?
- ☐ Who do you want (or not want) to be involved in your care? Who would you like to make decisions on your behalf if you're not able to? *(This person is your health care proxy.)*
- ☐ Would you prefer to be actively involved in decisions about your care? Or would you rather have your doctors do what they think is best?
- ☐ Are there any disagreements or family tensions that you're concerned about?
- ☐ Are there circumstances that you would consider worse than death? *(Long-term need of a breathing machine or feeding tube, not being able to recognize your loved ones)*
- ☐ Are there important milestones you'd like to meet if possible? *(The birth of your grandchild, your 80th birthday)*

- ☐ Where do you want (or not want) to receive care? (*Home, nursing facility, hospital*)
 - ☐ What kinds of aggressive treatment would you want (or not want)? (*Resuscitation if your heart stops, breathing machine, feeding tube*)
 - ☐ When would it be okay to shift from a focus on curative care to a focus on comfort care alone?
 - ☐ What affairs do you need to get in order, or talk to your loved ones about? (*Personal finances, property, relationships*)
-

This list doesn't cover everything you may need to think about, but it's a good place to start. Talk to your doctor or nurse if you're looking for more end-of-life care questions.

Remember:

-  Be patient. Some people may need a little more time to think.
-  You don't have to steer the conversation; just let it happen.
-  Don't judge. A "good" death means different things to different people.
-  Nothing is set in stone. You and your loved ones can always change your minds as circumstances shift.
-  Every attempt at the conversation is valuable.
-  This is the first of many conversations—you don't have to cover everyone or everything right now.

Now, just go for it!

Each conversation will empower you and your loved ones. You are getting ready to help each other live and die in a way that you choose.

Step 4: Keep Going

Congratulations!

Now that you have had the conversation, here are some legal and medical documents you should know about. Use them to record your wishes so they can be honored when the time comes.

- **Health Care Planning (ACP):** the process of thinking about your wishes—exactly what you have been working on here.
- **Advance Directive (AD):** a document that describes your wishes.
- **Health Care Proxy (HCP):** identifies your health care agent (often called a “proxy”), the person you trust to act on your behalf if you are unable to make health care decisions or communicate your wishes. In some states, this is called the Durable Power of Attorney for Health Care. This is probably the most important document. Make sure you have many conversations with your proxy.
- **Living Will:** specifies which medical treatments you want or don’t want at the end of your life, or if you are no longer able to make decisions on your own (e.g. in a coma).

You can find more information about these documents from the link in the “Keep Going” section of the website Starter Kit at www.TheConversationProject.org.

Remember, this was the first of many conversations.

You can use the questions below to collect your thoughts about how your first talk went, and then look back to them when you prepare for future conversations.

Is there something you need to clarify that you feel was misunderstood or misinterpreted?

Who do you want to talk to next time? Are there people who should hear things at the same time (like siblings who disagree about everything)?

How did this conversation make you feel? What do you want to remember? What do you want your loved ones to remember?

What do you want to make sure to ask or talk about next time?

We hope you will share this Starter Kit with others. You have helped us get one conversation closer to our goal: that everyone’s end-of-life wishes are expressed and respected.