



A Roadmap to Serious News

SHELLY LO, MD

HEMATOLOGY/ONCOLOGY

PALLIATIVE CARE

ASSOC MEDICAL DIRECTOR: LOYOLA HOSPICE



Receiving Serious News



- Unprepared?
- Scared?
- Information overload?
- Limited understanding of medical/physical processes?
- Embarrassed by own lack of knowledge?

Giving Serious News



- Stressed?
 - Anticipatory stress and stress during encounter
- Anxious about dealing with a patient's emotion?
- Nervous about how I will deal with my own emotion?
- Sad, feel guilty or to blame for the bad news?

Goal: A Roadmap to Giving Serious News



Communicating Serious News

- Skill
- The skills involved can be observed, learned and taught

Three Fundamental Principles For Better Communication

- 1) Ask – Tell – Ask
- 2) Tell me more...
- 3) Respond to patient emotions
 - Wish Statements
 - NURSE

Fundamental Principle #1

- **Ask-Tell-Ask**

- **Ask** patient to describe her current understanding of the issue
- **Tell** patient what you need to communicate
- **Ask** if the patient understood what was just said, “What’s your understanding now?” “Sometimes I don’t explain things well, can you tell me what you heard?”

Fundamental Principle #2

- “Tell me more”
- Use when you are not sure what someone is talking about/getting at
- Invitation to explore at a deeper level
- Nonjudgemental



Fundamental Principle #3

- **Respond to patient emotion**
- Accepting response rather than offer immediate reassurance, rebuttal, or agreement
- Learn to use:
 - empathic statement
 - wish statement



Accepting Patient Emotions: Wish Statements

- “I wish...”
- Aligns you with the patient while acknowledging that bad things can happen



Accepting Patient emotions: **NURSE**

- Using Empathic Statements



- Name the Emotion
- Understanding
- Respecting
- Supporting
- Exploring

Empathic Statements

- NAME: “People in similar situations are commonly angry.”
- UNDERSTANDING: “I can see this is tough.”
- RESPECT: “I’ m impressed how you are handling this situation.”
- SUPPORT: “We’ ll go through this together.”
- EXPLORE: “I sense how disappointed you are feeling about the results of the CT scan. Tell me more.”
 - Fundamental Principal #2

Empathic Responses

- **Patient (feels) says:**
- (Defeated) “I don’ t know how much I can take...”
- (Sad) “I was expecting a better result...”
- (Stunned) “ You mean I need more surgery?”
- **You can say:**
- “It sounds like it’ s been pretty tough...”
- “So was I. I know this comes as a shock.”
- “ I know you weren’ t expecting to hear this...”

Empathic Responses

- **Patient (feels) says:**
- (Angry) “ no one told me that it would take so long to recover...”
- (Discouraged) “It’ s so difficult taking care of the kids, my mother...”
- **You can say:**
- “It’ s been very frustrating for you...”
- “I can see you have been doing a great job caring for your mother during her long illness.”



ROADMAP FOR GIVING SERIOUS NEWS

Roadmap for Giving Serious News: **GUIDE**

- **Get Ready**
- **Understand**
 - Ask-Tell-Ask (Fundamental Principal #1)
- **Inform**
- **Deepen**
 - Empathic Statements, NURSE (Fundamental #3)
- **Equip**

GUIDE: Get Ready

- **Physical:** Find quiet room, kleenex, know everyone in room
- **Cognitive:** Get the information you will need, what it means.
- **Emotional:** Prepare self, acknowledge your own emotions

GUIDE: Understand

- **Ask before you tell (Fundamental Principle #1)**
 - Find out what patient knows
 - Use patient's knowledge as starting point for telling bad news
 - “What have the other doctor's told you about...I'll pick up from there”

GUIDE: Inform

- Give information as clearly as possible
“headline”
- Use straightforward language
- Give information in small pieces
- “The biopsy showed cancer.” Not “There are multiple enhancing hypodensities in the hepatic parenchyma”
- Pause

GUIDE: Deepen your connection by responding to emotions

- Patient emotion is frequent and normal when receiving bad news
- Emotion can block patient comprehension
- Try an empathic statement (NURSE)
- Try a “wish statement”
- (Fundamental Principal #3)
- Use silence

GUIDE: Equip

- Equip your patients for the next steps in care
- Summarize conversation and plans
- Provide concrete next steps
- Try a teach-back “Tell me what you’ll say to your spouse after you get home”

ROLE PLAY: **Giving Serious News**

Case review (1)

- 55 year old smoker with progressive shortness of breath, right sided chest pain, dry cough, 10 lb weight loss for the past several months.
- Abnormal lung exam
- Imaging: RUL mass, scattered subcm nodules throughout both lungs, mediastinal and hilar adenopathy, 2.8 cm hepatic lesion.
- CT guided biopsy showed **squamous cell carcinoma**, no actionable mutations found, PDL1 >1%, <50%
- She returns to her doctor's office to discuss test results

Phrases and mnemonics to remember

- **3 Fundamental Principles:**

- Ask-Tell-Ask
- “Tell me more...”
- Respond to emotion
 - “I wish...”
 - **Name**
 - **Understanding**
 - **Respect**
 - **Supporting**
 - **Exploring**

- **GUIDE: Roadmap for giving serious news**

- **Get ready**
- **Understand**
- **Inform**
- **Deepen** (use empathic statements)
- **Equip**

Discussing Advance Directives

Advance Directives

- Written statements that express how you want medical decisions made in the future if you are not be able to make them yourself
- Given to patients upon admission to hospitals, nursing facilities, home health care, hospice
- Do early, do in outpatient setting
- Illinois has 4 types of advance directives:
 - Health care power of attorney (POA)
 - Living will (tells your provider if you want death-delaying procedures used if you have a terminal condition and are unable to state your wishes)
 - Mental health treatment preference declaration
 - Do-Not-Resuscitate (DNR)/Practitioner Orders For Life-Sustaining Treatment (POLST)

DNR/POLST

- 3 components:
 - Decisions about resuscitation in cardiac arrest
 - Decisions about life-sustaining treatments prior to death
 - Decisions about artificial nutrition
 - Creates actionable medical orders ensuring a seriously ill patient's decisions about life sustaining treatments are honored across settings of care
- Patients who should have a POLST discussion:
 - Can be of any age
 - Have a serious illness, such as advanced cancer with limited treatment options, and/or are medically frail
 - A quick assessment can be made by asking yourself:
“Would I be surprised if this patient died in the next year?”

POLST

HIPAA PERMITS DISCLOSURE OF POLST TO HEALTH CARE PROFESSIONALS AS NECESSARY FOR TREATMENT

State of Illinois
Illinois Department of Public Health

IDPH UNIFORM PRACTITIONER ORDER FOR LIFE-SUSTAINING TREATMENT (POLST) FORM

For patients, use of this form is completely voluntary. Follow these orders until changed. These medical orders are based on the patient's medical condition and preferences. Any section not completed does not invalidate the form and implies initiating all treatment for that section. With significant change of condition new orders may need to be written.

Patient Last Name: _____ Patient First Name: _____ MI: _____
 Date of Birth (mm/dd/yy): _____ Gender: M F
 Address (street/city/state/ZIPcode): _____

A **CARDIOPULMONARY RESUSCITATION (CPR)** If patient has no pulse and is not breathing.
 Attempt Resuscitation/CPR Do Not Attempt Resuscitation/DNR
 (Selecting CPR means Full Treatment in Section B is selected)

When not in cardiopulmonary arrest, follow orders B and C.

B **MEDICAL INTERVENTIONS** If patient is found with a pulse and/or is breathing.
 Full Treatment: Primary goal of sustaining life by medically indicated means. In addition to treatment described in Selective Treatment and Comfort-Focused Treatment, use intubation, mechanical ventilation and cardioversion as indicated. Transfer to hospital and/or intensive care unit if indicated.
 Selective Treatment: Primary goal of treating medical conditions with selected medical measures. In addition to treatment described in Comfort-Focused Treatment, use medical treatment, IV fluids and IV medications (may include antibiotics and vasopressors), as medically appropriate and consistent with patient preference. Do Not Intubate. May consider less invasive airway support (e.g. CPAP, BiPAP). Transfer to hospital, if indicated. Generally avoid the intensive care unit.
 Comfort-Focused Treatment: Primary goal of maximizing comfort. Relieve pain and suffering through the use of medication by any route as needed; use oxygen, suctioning and manual treatment of airway obstruction. Do not use treatments listed in Full and Selective Treatment unless consistent with comfort goal. Request transfer to hospital only if comfort needs cannot be met in current location.
 Optional Additional Orders _____

C **MEDICALLY ADMINISTERED NUTRITION** (if medically indicated) Offer food by mouth, if feasible and as desired.
 Long-term medically administered nutrition, including feeding tubes. Additional Instructions (e.g., length of trial period) _____
 Trial period of medically administered nutrition, including feeding tubes. _____
 No medically administered means of nutrition, including feeding tubes. _____

D **DOCUMENTATION OF DISCUSSION** (Check all appropriate boxes below)
 Patient Agent under health care power of attorney
 Parent of minor Health care surrogate decision maker (See Page 2 for priority list)

Signature of Patient or Legal Representative
 Signature (required) _____ Name (print) _____ Date _____

Signature of Witness to Consent (Witness required for a valid form)
 I am 18 years of age or older and acknowledge the above person has had an opportunity to read this form and have witnessed the giving of consent by the above person or the above person has acknowledged his/her signature or mark on this form in my presence.
 Signature (required) _____ Name (print) _____ Date _____

E **Signature of Authorized Practitioner** (physician, licensed resident (second year or higher), advanced practice nurse or physician assistant)
 My signature below indicates to the best of my knowledge and belief that these orders are consistent with the patient's medical condition and preferences.
 Print Authorized Practitioner Name (required) _____ Phone _____
 _____ () _____ - _____
 Authorized Practitioner Signature (required) _____ Date (required) _____

Form Revision Date - April 2016 (Prior form versions are also valid.)

SEND A COPY OF FORM WITH PATIENT WHENEVER TRANSFERRED OR DISCHARGED • COPY ON ANY COLOR OF PAPER IS ACCEPTABLE • 2016

HIPAA PERMITS DISCLOSURE OF POLST TO HEALTH CARE PROFESSIONALS AS NECESSARY FOR TREATMENT

****THIS SIDE FOR INFORMATIONAL PURPOSES ONLY****

Patient Last Name: _____ Patient First Name: _____ MI: _____

Use of the Illinois Department of Public Health (IDPH) Practitioner Orders for Life-Sustaining Treatment (POLST) Form is always voluntary. This order records your wishes for medical treatment in your current state of health. Once initial medical treatment is begun and the risks and benefits of further therapy are clear, your treatment wishes may change. Your medical care and this form can be changed to reflect your new wishes at any time. However, no form can address all the medical treatment decisions that may need to be made. The Power of Attorney for Health Care Advance Directive (POAHC) is recommended for all capable adults, regardless of their health status. A POAHC allows you to document, in detail, your future health care instructions and name a Legal Representative to speak for you if you are unable to speak for yourself.

Advance Directive Information
 I also have the following advance directives (OPTIONAL)
 Health Care Power of Attorney Living Will Declaration Mental Health Treatment Preference Declaration

Contact Person Name: _____ Contact Phone Number: _____

Health Care Professional Information
 Preparer Name: _____ Phone Number: _____
 Preparer Title: _____ Date Prepared: _____

Completing the IDPH POLST Form

- The completion of a POLST form is always voluntary, cannot be mandated and may be changed at any time.
- A POLST should reflect current preferences of persons completing the POLST Form; encourage completion of a POAHC.
- Verbal/phone orders are acceptable with follow-up signature by authorized practitioner in accordance with facility/community policy.
- Use of original form is encouraged. Photocopies and faxes on any color of paper also are legal and valid forms.

Reviewing a POLST Form
 This POLST form should be reviewed periodically and if:

- The patient is transferred from one care setting or care level to another, or
- or there is a substantial change in the patient's health status, or
- or the patient's treatment preferences change, or
- or the patient's primary care professional changes.

Voiding or revoking a POLST Form

- A patient with capacity can void or revoke the form, and/or request alternative treatment.
- Changing, modifying or revising a POLST form requires completion of a new POLST form.
- Draw line through sections A through E and write "VOID" across page if any POLST form is replaced or becomes invalid. Beneath the written "VOID" write in the date of change and re-sign.
- If included in an electronic medical record, follow all voiding procedures of facility.

Illinois Health Care Surrogate Act (755 ILCS 40/25) Priority Order

1. Patient's guardian of person
2. Patient's spouse or partner of a registered civil union
3. Adult child
4. Parent
5. Adult sibling
6. Adult grandchild
7. A close friend of the patient
8. The patient's guardian of the estate

For more information, visit the IDPH Statement of Illinois law at
<http://dph.illinois.gov/topics-services/health-care-regulation/nursing-homes/advance-directives>

HIPAA (HEALTH INSURANCE PORTABILITY AND ACCOUNTABILITY ACT OF 1996) PERMITS DISCLOSURE TO HEALTH CARE PROFESSIONALS AS NECESSARY FOR TREATMENT

IOCI 18-425

SEND A COPY OF FORM WITH PATIENT WHENEVER TRANSFERRED OR DISCHARGED • COPY ON ANY COLOR OF PAPER IS ACCEPTABLE • 2016

Roadmap for Discussing Advance Directives: **SPEEED**

- **S**etting
- **P**ower of Attorney/Surrogate
- **E**liciting Goals
- **E**xpect Emotions
- **E**stablish Plan
- **DNR?**

SPEED

- **Setting the scene**
 - “I’d like to talk with you about possible health care decisions in the future.”
 - “Have you talked with anyone about a living will or advance directive?”
 - “Have you been with family or friends when end-of-life decisions were made? What went well and what could have been better?”

SPEED

- **Power of Attorney/Surrogate**
 - “Who would be the best person to help make medical decisions on your behalf if you couldn’t do it yourself?”

SPEED: Eliciting Goals

– Early:

- “If the illness were to get very serious and might take your life, what would be most important?”
- “Could we talk about an extreme situation that is very different from now?”

• Late:

- “We’re in a different place.”
- “When your time comes, would you prefer to be at home, in a hospital, or in a nursing home?”
- “When your time comes, what is most important – quality of life or length of life?”
- “What kind of medical care would you want if you were near the end of life?”

SPEED

- **Expect emotion**
 - “Tell me more”
 - “I wish...”
 - “NURSE”

SPEED

- Establish plan that match your patient's values
 - Use insight into patients' expectations/ goals to guide conversation
 - “I'm hearing that what's important is...”
 - “You said that time at home is important. Let's help you do more of that”

SPEED

- **DNR?**
 - “We won’t use CPR because it won’t help us get towards your goals, I will enter a DNR order into the chart.”

Discussing Advance Directives

- Outpatient and early discussion is best
- It's a Process

ROLE PLAY: Discussing Advance Directives

Back to the case (2):

- Pt undergoes first line chemotherapy.
 - Initially feels well!
- Over next months, she slowly declines, notes increased weakness, shortness of breath, poor appetite.
- She is seen in the **palliative care clinic.**

Basic Structure for Discussing Advance Directives

- Setting
- Power of Attorney/Surrogate
- Eliciting Goals
- Emotions
- Establish plan that match your patient's values
- DNR?

Back to the case (3)

- She starts on 2nd line immunotherapy with nivolumab (Opdivo).
- Scans performed after 3 months of immunotherapy show progression of metastatic disease. She reviews the results with the oncologist.
- **Hospice recommended**

Points to Remember

- Giving serious news and advance directive discussions can be difficult
- Recognize the feelings that you and your patients may have
- Conversations are best when done early and in the outpatient setting
- Advance care planning is a process
- Patients and families may not remember the exact words used, but they will remember your respectfulness, attention, and empathy

- **Special thanks to:**
- **Loyola's Palliative Care Team**
 - Theresa Kristopaitis, MD
 - Donna Quinones, Director of the Simulation Center
- **For more information about communication skills:**
- <http://www.vitaltalk.org/>
- **VITALtalk from app store**
- <https://education.nccn.org/supportive-oncology-care>
 - Goals of Care and Advanced Care Planning over Time
 - POLST

