

## 5. Appendix

# Sample Materials for a Workshop on Advocacy

Sample story to introduce the workshop

### BETWEEN YES AND NO

by

Sandra McCollum

Used with the permission of the American Academy on Communication in Healthcare (formerly the American Academy on Physician and Patient), published in *Medical Encounter*, Vol. 17, No. 1, pg.13. Available at <http://www.aachonline.org/>.

"No. No more." I was absolutely clear with the ICU ward team. I had decided I would never again allow myself to be maintained on life support. Life as I defined it was slipping away. There had been six hospitalizations in eight months, six episodes in ICU on a ventilator. The progressively worsening lung disease ravaged my body, and the machine that breathed for me was sucking my soul dry. Everything I valued--family and social activities, work, independence, fun- was all being stripped from me. I had one choice left-to say no and end my life before I became completely useless.

The arguments began. They were eager to stop the talking and get to work. A nurse wheeled the ventilator into my room. "But you're so young, we can save you." It was a familiar mantra. Save me for what? I had put my directives in writing weeks earlier, knowing that if I waited until this moment, I would be declared decisionally incompetent. I simply intended to refuse all treatment. I had anticipated everything, everything except the remarkable man who was about to enter my life.

My regular physician was out of town, and a pulmonologist had been called in to consult. I knew exactly what was going on. The team didn't want me to die on their shift, so a high-powered specialist had been summoned to deal with me, the ultimate difficult patient. I was ready. I knew my rights and had rehearsed my speech many times about my legal and ethical right to refuse treatment.

"I can't face it again." He then threw me a curve. Instead of telling me all the reasons why I should consent to treatment, he quietly asked me, "What is it you can't face? Tell me what we could do differently." In that moment I had to decide whether or not I would try to trust this stranger, this person who had been sent to convince me to endure the mechanized torture chamber to salvage my physical existence. "What can't you face?" he repeated. "Is it the pain?"

"That's only part of it," I responded guardedly. I had lived with this disease all my life and had overcome the physical dimensions-I had gone to school, worked, married a man I was madly in love with. It was more than the pain.

"The restraints-I feel like an animal. They tell me I have to be restrained because I'm 'agitated', but I'm trying to get free." He assured me he would not allow me to be restrained. He told me he would stay with me until I was stable and calm. If he had to leave, he would leave explicit orders to call him if I became restless. No one would have permission to restrain me.

"And the morphine-I don't want to be doped up all the time. I need to be able to ask for it when I need it. Sometimes it's more important for me to be alert, so I don't slip away into the rhythm of that machine, breathing in and out, in and out." He showed me the order sheet as he wrote a prn order for morphine.

Our conversation couldn't have taken more than 5 or 6 minutes, but it was a powerful force. I could feel myself slipping into the dreaminess that would end my life if I refused the ventilator. Literally, this man stood between me and death. He took my hands, looked at me and said, "I don't want you to die. In a few minutes you'll be unconscious, but I won't do this if you say no. We can work together on this." Those words conquered my fear--the fear of having no control in my life. He was willing to make my wishes primary; in that moment he returned my humanity to me. I nodded agreement. He did keep his part of the bargain to honor the things I didn't want and made the next few days easier to endure.

This time the ventilator didn't possess me. It was different because I was able to say no:

No to restraints- I could reach the call button

No to scheduled morphine - I could decide if it was more important to have relief from pain or to be more conscious.

No to isolation - I had a pencil and paper and could communicate

I had choices and was able to make decisions about important aspects of my care. This brief dialogue pulled me back from the only decision I thought I had left to make. One human soul reaching out to another made space between two extreme options: either yes, agreeing to everything the doctor ordered, or the final no. I discovered I did want to live when my values were considered. Having the power to say no to some treatment approaches allowed me to say the ultimate yes--yes to life.

Guidance for discussion about priorities, needs, and healthcare and community resources

**PASS-C**  
**Priorities, Activities, Social context, Support/coping—Coordination**  
**Advocating for Patients and Families**

**Priorities:**

What are you most concerned about right now?      What are your biggest concerns?      What is most important to you?  
 What's on your mind?      What are your thoughts about going home, having this procedure, your diagnosis?  
 What might it look like if this turned out the best you can imagine?  
 What could we do to help you live with this change in your circumstances?

Areas to Assess	Resources	
<p><b><u>Activities</u></b>                      ADLs:                      How are you doing with                          Dressing      Eating                          Toileting      Bathing                          Communicating      Writing                          Walking, getting around                      How do you think this (injury, illness, diagnosis, etc.) might affect the things you do every day?</p> <p>IADLs:                      What is a typical day like for you?                      What was a typical day like for you before this happened?                      How do you think this (injury, illness, diagnosis, etc.) might affect the things you do every day?                      How are you doing with (or how will you manage):                          Cooking and shopping                          Transportation                          Your job or education                          Managing finances</p>	<p><b><u>Physical Care/Rehabilitation</u></b>                      Skilled nursing facility                      Rehabilitation Program                      Head Injury Program                      Occupational therapy                      Physical therapy                      Respiratory therapy                      Spinal cord injury program                      Speech/language therapy                      Vocational Rehabilitation</p> <p><b><u>Nursing Services</u></b>                      Community health nursing                      Home health nursing                      Hospice                      Visiting Nurse Association</p>	<p><b><u>Logistical Supports</u></b>                      Disabled American Veterans                      Durable medical goods                      Meals on Wheels                      Nutrition services                      Transportation</p> <p><b><u>Child and Family</u></b>                      Child Find                      Childcare                      EDIS                      Exceptional Family Member Program                      Family-to-Family Support                      Respite Program                      Parent Training and Information Center (PTI)</p>
<p><b><u>Social and family context</u></b>                      Where do you live?                      Who lives with you?                      Tell me about your family.                      Who is a friend or source of support?                      Are you (or your child) going to school right now?                      What do you do as far as working or going to school?</p>	<p style="text-align: center;"><b><u>Communication that builds partnership</u></b></p> <p><b><u>P*E*A*R*L*S</u></b>                      Partnership: "Let's tackle this together."                      Empathy: "You look pretty upset."                      Apology: "I'm sorry this happened."                      Respect: "I appreciate your (courage, decision, action)."                      Legitimization: "Anyone would be confused by this situation."                      Support: "I'll stick with you as long as necessary."</p>	
Areas to Assess	Resources	
<p><b><u>Support and coping</u></b>                      How are you doing with this?                      Who might be able to help you deal with this?</p>	<p><b><u>Psychosocial Services</u></b>                      Adult day care                      Alcohol/Substance abuse services                      Day treatment program                      Patient Representative                      Psychiatry</p>	<p>Psychology                      Psychiatric nurse liaison                      Respite program                      Senior citizen program                      Social work                      Support groups</p>
<p><b><u>Coordination and payment</u></b>                      Who might be able to help you coordinate your (health care, help on a day to day basis, etc.)?                      What resources do you have available to help pay for the care you need?</p>	<p><b><u>Coordination</u></b>                      Care coordinator                      Case manager                      Social worker                      Discharge planner                      Hospital Administrator                      Military disability counselor                      Primary care physician/Medical Home</p>	<p><b><u>Payment/Health Benefits</u></b>                      TRICARE                      Health benefits advisor                      Medicaid                      Medicare                      SSI/SSDI                      Veterans Administration                      Debt assistance officer</p>



Guidance for patient- and family-advisors

**Advocating for Patients and Families**  
*Family Medicine Clerkship*  
*Uniformed Services University of the Health Sciences*

*Information for Patient- and Family-Advisors*

Thank you for your interest in sharing your experience with health challenges with a small group of medical students. Here is a summary of the activities you will do with the students.

**Activity #1:** Discuss what “doing well” would mean to the students if they encountered an unexpected, major medical event in their own lives, such as being in a serious car accident.

**You will pair with a student and share what would be on your mind and what you would be worrying or wondering about, if you awoke unexpectedly in an ICU.**

**Activity #2:** Discuss “doing well” in small groups. What does “doing well” mean to the resource person in each small group, in light of the medical circumstances that he or she has encountered.

**You will discuss with a small group of students what it means to you and/or your child to live well with medical challenges. What are your needs as a person, and how do they affect choices you might make about health care? What are your child’s needs, and how do they affect decisions about health care? Please be prepared to discuss these questions with the students. You may want to share a story about a medical decision that you have made or are making, where the decision is affected by your circumstances or values.**

**Activity #3:** Discuss in small groups, “the context of a patient’s life.”

**The students in your small group will ask you questions like these:**

- **Who are the members of your family?**
- **What sources of support are available and/or important to you and your family?**
- **What concerns you about how your illness (or condition) or your child’s illness (or condition) may affect family life, work life, social life?**
- **Which aspects of life are most important to you [and your child]?**
- **Which daily activities have been affected by your illness or condition [or your child’s]?**

**Activity #4:** Discuss in small groups the resources that you and your family have needed to meet the needs created by a health condition or other special needs.

**The students will ask you to explain the resources you have needed and what roles physicians have played (or could have played) in helping you find those resources. Resources include things like rehabilitation hospitals; physical, occupational or speech therapy; special education; respite care; child life services; home nursing; special equipment; hospice care; assistive technology; parenting classes.**

**You might have a story about a resource or service that has made a significant difference for you. In addition to one particular story, try to think of every resource you have needed, and be ready to talk about them with the students.**

*Thanks so much for teaching this session with us!*