

California HealthCare Foundation
Education materials for patients with advanced cancer

The California HealthCare Foundation (CHCF) commissioned research to explore options around the development of patient education materials to support decision making by patients with advanced cancer regarding whether to end aggressive medical treatment and/or initiate palliative care.

The consultant, Maryann O’Sullivan, interviewed 28 people, including 20 physicians, all of whom have had involvement with patients with advanced cancer and the decisions they face. The remaining eight non-physician interviewees are involved in supporting patient education/shared decision-making with this patient population. The consultant also completed internet research.

The memo is divided into the sections listed below.

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Introduction

The following is a summary of findings from the interviews and internet research.

- Almost everyone interviewed was ***not*** able to identify patient education materials they think are effective for this audience.
- Most interviewees who see patients with advanced cancer are ***not*** using patient education materials to support those patients in decision-making.
- While some interviewees stress the critical importance of the decision-making conversation between the oncologist and the patient, everyone sees a role for patient education materials for this audience.
- While most interviewees feel it would be very challenging to provide materials specific to particular cancers (e.g. lung cancer, breast cancer), many believed that organ-specific and treatment-specific information is important for physicians and patients to have.

- Web research revealed only a modest amount of patient education materials addressing the tough questions facing this patient audience (see Appendix A). Most references to stopping or ending treatment refer to the completion of treatment and are often included in discussions of survivorship. The following are two notable exceptions.
 - The National Cancer Institute provides a thorough 56-page patient education document, "Coping with Advanced Cancer: Support for People with Cancer."
 - The American Society of Clinical Oncology's (ASCO), Cancer.net provides a 24-page patient education document, "Advanced Cancer Care Planning: What Patients and Families Need to Know about Their Choices When Facing Serious Illness."

What the interviewees had to say

The status quo

Interviewees communicated a great deal of concern about overuse by some physicians of chemotherapy in advanced cancer patients, citing generally reduced efficacy/palliation with each additional line of chemotherapy. Some cited oncologists' commitment to offering helpful treatments and preserving hope. Others cited patients' unwillingness to accept the inevitable: that their cancer was not curable and would eventually probably be what kills them. Some physicians saw financial incentives playing a role in overtreatment.

Developing goals of care

Interviewees expressed concern that some physicians and patients may avoid difficult conversations and felt education materials might help foster more truthful conversations. Interviewees believe it very important that physicians be clear with patients about their prognosis: For most patients with advanced cancer, this cancer will cause their death. Providers should be sure patients understand early in the process that, while palliative radiation and/or palliative chemotherapy may prolong life and provide symptom relief, these cannot produce a cure for patients with advanced cancer.

Interviewees believe it is important to assess patient values and define realistic goals of care very early on in the process. It is important that patients understand that those goals may change over time depending on the cancer's response to therapy, the patient's overall health and the evolution of the patient's values, among other things. Providers should be explicit that there can be two goals of chemotherapy in advanced cancer: reducing symptoms and prolonging life. Cure cannot be an option; patients will eventually die of causes related to the disease.

Patients need to be shown a roadmap of what is coming. They need to be told early on that potential benefits may outweigh risks, but, depending on response and symptom management, risks may later outweigh benefits. They need to know how likely it is their cancer will respond, shrink, stay the same or grow and what the rare and common side effects may be. Patients need to know what the average survival is and they also need to understand that half will live longer

and half will live shorter than the average; patients need to consider how they want to live in either case, and what they want their focus of living to be.

Defining terms for the patient

People noted that oftentimes key terms may be used imprecisely by physicians, and may be heard in unrealistic ways by patients. Materials should clearly define key words and phrases including: prognosis, cure, remission, shrinking a tumor, palliative chemotherapy, palliative radiation, progress of the disease, stable disease, etc.

Format suggestions

The "conversation" between the provider and the patient who has advanced cancer is central. Of course, materials would never be seen as a replacement for the conversation but rather as a tool to educate patients to be more fully informed participants in the conversation. Interviewees saw value in materials to support patients in better understanding their options and articulating their values and preferences. Below are suggestions from interviewees.

- Make sure that materials look patient friendly, are in color and include checklists not paragraphs.
- Provide disease-specific information that includes average life expectancy, benefits and side effects of treatment, and life review considerations.
- Provide a list of questions for patients to ask their provider. This could include questions regarding benefits and burdens of treatments and about whether the disease is curable, for instance. Or provide a frequently asked questions document.
- One interviewee suggested developing a very small number of questions to be used repeatedly over time to frame conversations. For example, one question could be: "Do you think we are paying enough attention to the quality of your life as compared with the length of your life?" He suggested the provider could use a thermometer as a visual when asking the question. Another question could be, "And what do you think the emphasis should be in the coming weeks/months?" The patient could be apprised that her responses to these questions may change over time.
- Provide a pamphlet in the waiting room or to be handed to patients during an office visit that would include a link to a website where patients could find in-depth information about key questions in private, possibly along with friends and family, and, when the timing feels right to them.
- Materials might be made specific to cultures and age ranges. A patient with metastasized lung cancer in their early 20s may have very different considerations than a patient in their late 90s.

- Materials might be made specific to the treatment process. A patient might need certain information at the time of initial diagnosis (e.g. a description of the journey, side effects, cost, effect on work and other activities). Different information at the midpoint into treatment (e.g. how long treatment will last, what evidence there is for continuing treatment versus stopping treatment until the disease symptoms return, discussion of cure/remission). Finally different information at the point where the patient is no longer responding to treatment (e.g. what happens when I stop chemo, how long can I live.)
- Materials might be made specific to the disease progression. Materials for patients who have a rapidly progressing disease would be distinct from materials for patients who have less than six months to live. These are distinct from materials for patients who have less than one year to live or for those intended for patients who may live many years.
- A couple of interviewees believe that, even if the doctor did not initiate the conversation, if patients come to an appointment well informed by materials they found on the web, physicians will respond.

Getting physician buy-in

Interviewees agreed that physician buy-in would be essential to widespread use of materials, and proposed a range of ideas.

- Tell physicians they can send patients home with the materials and ask the patient to review the materials and come back next week for a 20-minute appointment / conversation.
- Physicians would be pleased to understand that educational materials could increase patients' understanding, therefore allowing for the highest and best use of the physician's time with the patient. Physicians would be pleased if they thought that prior education might make patients and families feel less anxious
- Physicians might be encouraged if they believed that use of the materials would make it practical for others in the medical practice to have a conversation with the patient, rather than the physician.

Palliative care

When interviewees were asked whether there were any published studies they thought were important on the general topic of decision-making for patients with advanced cancer, one study came up over and over: "Early Palliative Care for Patients with Metastatic Non-Small-Cell Lung Cancer."¹ Interviewees appreciate having the support for early palliative care provided by this randomized, controlled trial, which found that people who received early palliative care had

better quality of life and a median survival of almost three months more than people in the control group.

There seems to be consensus among interviewees that the concept of palliative care should be introduced early and reintroduced over time as circumstances change; likewise, the concept of ending treatment needs to be revisited periodically. Palliative care should not be broached for the first time when treatment seems to be failing. Early introduction of the topic of palliative care creates the opportunity to engage in a fuller conversation that may happen later in time when certain triggers indicate the patient's weakened condition and/or the patient is considering ending aggressive care.

Interviewees identified key messages to communicate to patients regarding the introduction of palliative care:

- Palliative care is not the same as doing nothing;
- Moving to palliative care does not mean giving up/abandoning hope;
- Palliative care may enable higher quality of life and/or longer life;
- We have not been treating your cancer; we are treating you and will continue to do so. At some point we will want to stop the treatment of cancer, but we won't stop treating you;
- Ending chemotherapy does not mean you will be on your own;
- One does not need to be near death to benefit from palliative care;
- Palliative care is not the same as hospice.

Appendix A
Selected Existing Patient Education Materials
for Patients with Advanced Cancer

Through internet research and conversations with interviewees the following patient education supports, which address decisions by advanced care patients to end aggressive medical care and/or beginning palliative care, were identified.

Written materials for patients

- National Cancer Institute, National Institutes of Health *Coping with Advanced Cancer: Support for People with Cancer*, a 56-page patient education document includes options related to ending cancer treatments and initiating palliative care as well as information about advance planning and questions to ask one's doctor.
<http://1.usa.gov/1by99K8>
- National Cancer Institute, National Institutes of Health - *Questions to Ask Your Doctor About Advanced Cancer*, a one-page set of questions for patients to ask their doctors regarding ending cancer treatments, beginning palliative care and entering hospice care.
<http://1.usa.gov/1IzJCv8>
- American Society of Clinical Oncology (ASCO) – *Advanced Cancer Care Planning: What Patients and Families Need to Know about Their Choices When Facing Serious Illness* – a 24-page patient education document that includes options related to ending cancer treatments and initiating palliative care as well as information about advance planning.
<http://bit.ly/1H0CUgA>
- American Society of Clinical Oncology (ASCO) – *Cancer in Older Adults* – a 36 page patient education document that includes a discussion about treatment for patients with advanced cancer.
<http://bit.ly/1E5Iqkl>
- American Society of Clinical Oncology (ASCO) – *Topic # 1: Cancer Directed Treatments at the End of Life* - a webpage that includes options related to ending cancer treatments and initiating palliative care as well as links to information about advance planning.
<http://bit.ly/1ioroiN>
- American Cancer Society – *What Happens if Treatment is No Longer Working?* – a one-page patient education description of options, including ending cancer treatment, beginning palliative care and entering hospice care. (also available with reference to melanoma non-Hodgkin's lymphoma but essentially the same one-page description)
<http://bit.ly/1NjLXuQ>

- Content provided by Mayo Clinic.com – *Stopping Cancer Treatment: Deciding When the Time is Right* – a four page patient education discussion of what to consider when making the decision to end cancer treatment, including reference to palliative care, hospice care and advanced planning. <http://bit.ly/1OFvwMZ>
- The Abramson Cancer Center of the University of Pennsylvania – *Deciding to End the Journey: Stopping or Taking a Break from Therapy* – brief three paragraph description of options. <http://bit.ly/1xiFAGg>
- BreastCancer.org – *When Do You Stop Treatment?* – A two page patient education description of what to consider when making the decision to end treatment. <http://bit.ly/1H0DDhZ>
- Cancer Support Community – *Be Prepared, Making the Most of Your Time with Your Healthcare Team Worksheet* – a two-page worksheet for patients with advanced breast cancer to be completed by a patient prior to a visit; makes mention that a patient may need to "reassess your options at some point." <http://bit.ly/1OB6Mp2>

Written materials for patients specific to palliative care

- National Cancer Institute, National Institutes of Health – *Palliative Care in Cancer*, a description of palliative care and 14 related questions for patients. <http://1.usa.gov/1CRZlp3>
- National Institute of Nursing Research, National Institutes of Health – *Palliative Care: the Relief You Need When You're Experiencing the Symptoms of Serious Illness*, a nine page patient education brochure illness. <http://1.usa.gov/190YA0E>
- The GetPalliativeCare.org website is provided by the Center to Advance Palliative Care (CAPC) – *Palliative Care: What You Should Know*, a one page patient education description of palliative care. <http://bit.ly/190YFBH>
- The GetPalliativeCare.org website is provided by the Center to Advance Palliative Care (CAPC) – *Take the Quiz: is Palliative Care Right for You*, a one-page patient education quiz regarding palliative care. <http://bit.ly/1crUNnc>

Video for patients

- Prepare for Your Care website – *How to Ask Doctors the Right Questions* – a brief video of a cancer patient and his wife having a conversation with his physician about ending care (script is also available). <http://bit.ly/19nLMRU>

Patient support available by phone

- The National Cancer Institute of the National Institutes of Health has phone support available (1-800-4-cancer). Staff would refer to documents and a list of organizations.
- The Cancer Support Community's Open to Options program (1-888-793-9355) offers free consultation to cancer patients to prepare them for decision-making with their physicians. The service has been up for one year. When a patient calls, an appointment is scheduled. Most appointments last for 45 minutes to one hour but some are longer. They go through an interview protocol with patients and later snail mail them a written document reflecting the conversation and including a list of questions to be asked of the physician, as much as possible in the patient's own words. They operate out of seven offices around the country, including in the Bay Area and Los Angeles.
- *CancerCare* (1-800-813-4673) offers free phone consultation to cancer patients. Consultation can be one time by phone or, when a patient chooses to do so, they may sign up for six weekly 30-minute sessions with the same oncology social worker. For patients living near their offices, in-person counseling is available. If the patient with advanced cancer called about making a decision to stop care they would explore issues with the patient including: the patient's current thoughts about quitting or continuing treatment; barriers; influence of family members; what they have talked to their doctor about. They have written materials regarding hospice. There are about 15 social workers in the Manhattan office and also have offices in New Jersey and Connecticut.
<http://www.cancercares.org/>

Written materials for caregivers

- National Cancer Institute, National Institutes of Health - *When Someone You Love Has Advanced Cancer: Support for Caregivers*, a 64 page document for caregivers.
<http://1.usa.gov/1OB8sPr>
- American Cancer Society – *What You Need to Know as a Cancer Caregiver* – includes about two pages related to when treatment stops helping.
<http://bit.ly/1BOAs8b>