"How best to treat the patient..."

Recognizing the pateint's illness, unique personalized circumstances and wishes.

By Elizabeth J. Latimer, MD, CCFP, FCFP

"To treat or not to treat?" is a commonly asked question when caring for people with advanced illness. We must acknowledge that, as doctors, we *always* treat our patients. Therefore, perhaps a more useful question is "How can I best treat the patient given his/her stage of illness, unique personhood, circumstances and wishes?"

The process of establishing goals of care with patient and family, discussing these with the health care team and documenting them in the patient's chart, is the foundation of person-centered care.

Dr. Latimer is consultant physician in palliative care and pain management, Hamilton Health Sciences, and professor, department of family medicine, McMaster University, Hamilton, Ontario.

Mrs. J and Mr. M

Both Mrs. J and Mr. M, in their mid-50s, have advanced cancer of the esophagus and are no longer able to take sufficient nourishment or fluids. The question of percutaneous endoscopic gastrostomy (PEG) feeding tubes has arisen for both of them. How can you decide? What is the best treatment?

Mr. T and Mrs. W

Mr. T and Mrs. W, both in their late 60s, have advanced chronic obstructive pulmonary disease (COPD). They are admitted for treatment of pneumonia and exacerbation of COPD. How does one set goals of care with them?

Goals of care

Goals of care can include wishes for treatment, place of care, efforts to prolong life and personal goals a patient or family may have. For example, a patient may wish to try to remain at home until he/she dies, or may wish to be admitted for in-patient care as death draws near. Patients may have a spectrum of wishes about treatment; some may wish to have no treatments that would prolong life; others choose NO CPR but want treatment of physical problems that might be reversible, such as infection, low hemoglobin or dehydration. Some patients, although knowing that their illness is advancing, may wish to pursue an aggressive, cure-oriented approach to treatment right until the end of their life.

Personal goals may include such matters as wishing to attend a family wedding, living to see a grandchild born or reconciling with an estranged family member. One person may wish to go to the cottage for one more visit and another may hope to live until a special anniversary or birthday. All patients hope to be free of pain and other symptoms and to have a peaceful death when that time arrives for them.

Why establish goals of care?

Knowing the goals of care is helpful in that it:

* Ensures the care provided is in keeping with the patient's wishes and best interests;
* Ensures a mutual understanding of the nature of the patient's illness and expectations for the future;
* Affirms a united team approach to care. The physician and health care team work with patient and family;
* Facilitates a sense of security and reduced anxiety for the patient and family.
* Helps in developing a plan of care and identifying the team members and resources required to put the plan in place;
* Facilitates making decisions about which treatments may be beneficial to the patient and compatible with his/her goals of care;
* Enhances the certainty of the physician and the interdisciplinary health care team as they care for the patient;
* Helps the patient and family have a sense of focus and satisfaction as they work toward goals of care;
* Enhances the quality of life for the patient and family;
* Facilitates the patient and family in realizing some hopes and dreams through the process of identifying these as goals; and
* Results in more professional satisfaction for the team caring for the patient and family.

A framework for setting goals of care

When to establish goals of care

This is an on-going process which unfolds over the course of the illness, with goals of care changing according to the patient's situation and needs. There are certain times when this needs to be done in a more formal way with patient and family. These include:

* At the time of diagnosis and initial treatment plan;
* On any hospital admission;
* At any time of significant change in the patient's condition, which may be towards deterioration, stabilization or improvement; and
* When decisions about treatment need to be made.

There are four components to be harmonized:

1. **The illness:** Consider its nature and status, medical treatment options, rate of progression and the imminence of death. In many ways, the illness defines the limits of possibility for treatment.
2. **The patient as a unique person:** Consider his/her wishes for treatment, as well as goals, plans, hopes and dreams for the present and future.
3. **The patient's experience of the illness:** Consider the nature, degree and perception of symptoms and suffering as well as perception of quality of life. What can and must be done to relieve suffering and pain?
4. **The degree to which prolonging life is a goal:** Is prolongation possible and is it what the patient wants?

Steps to take in this process:

* Gather all knowledge about the illness (*i.e.,* tests, operative reports, assessments, chart notes, previous treatments and their effects, and consultations with colleagues).
* Establish the patient and family's understanding of the illness and present situation.
* Convey accurate information about the illness and possibilities for treatment. Use a gentle manner.
* Give the patient and family the opportunity to convey general and specific goals of care.
* Outline the possible paths of treatment and care, including the potential benefits and burdens of each.
* Give some guidance as to which path of care is recommended by the physician and health care team.
* Determine which way the patient (or family, if patient cannot speak for him/herself) would like to proceed.
* Establish when the goals may need to be revisited, for example, after 48 to 72 hours if a trial of antibiotics is undertaken.
* Document the goals of care on the chart.
* Provide on-going follow-up care.

Goals of care and treatment approaches for our patients

MRS. J AND MR. M

These two patients have the same diagnosis and problem of not being able to swallow nourishment. As we apply the framework, however, we can see that each patient is quite unique.

Mrs. J's cancer has metastasized to her liver but she is not jaundiced. She is physically comfortable with a transdermal fentanyl patch — a route of analgesia which is particularly suited to patients who cannot take oral medications. Mrs. J is able to be up and about and can go for short trips in the car. She says she is enjoying her quality of life. She understands her illness is no longer treatable. She requested "no CPR" and said, "No life support machines, doctor." She has a personal goal, however:

> *"Some more time, to be with my family and to enjoy what I can. How can I do this if I have no nourishment? I seem to be getting weaker every day. I would like to try the feeding tube to see if it helps me. After awhile, if it isn't helping me to enjoy things and feel stronger, I would like to think about having it removed. Can I do that? Can I try the feeding but stop it if I don't want it any more?"*

Mr. M also has liver metastases. He is significantly jaundiced, however, and is mostly bedridden. He is quite cachectic and frail, although peaceful within himself. He also is physically comfortable with the transdermal fentanyl patch. Mr. M, however, has different wishes than Mrs. J. He has completed the tasks he felt he needed to do with his family.

> *"I am ready to go, doctor. The Lord can take me any time. I just want to be comfortable here at home with my family and let nature take its course. I don't want any tubes."*

We can see how the treatment plan is tailored to the wishes and goals of the patient and the unique way that their illness is unfolding for them. Mrs. J will proceed with a trial of artificial feeding with a PEG tube to determine if it helps her to meet her goals of care. The potential benefit of the feeding, for her, outweighs its burden at this point in time. Mr. M will not receive artificial feeding, as it is contrary to his wishes. Given his own goals of care, and the more advanced state of his illness, he has decided that the burdens of artificial feeding outweigh the benefits for him.

Goals of care and treatment approaches for our patients

MR. T AND MRS. W

Both Mr. T and Mrs. W will undergo treatment for pneumonia with intravenous antibiotics and general medical management. They differ, however, in their goals of care. Mr. T has been ventilated three times for pneumonia superimposed on his COPD. In recent months, he has become much more breathless and physically frail. He has requested no CPR and no ventilation:

> *"I am tired of it all, doctor."*

He has agreed to the antibiotics because he would like to live long enough to enjoy his daughter's arrival from Edmonton, which will take place within the next 48 hours:

> *"She and I can talk about everything then, doctor. Maybe by that time, I will be better or maybe I won't be. If I'm not, maybe then we can just stop everything and let nature take its course. I can go peacefully then."*

Personal goals are very much on Mr. T's mind, from his experiences of being ventilated in the past and his knowledge that he is in failing health.

Mrs. W has never been ventilated. In fact, this is her first episode of pneumonia. She is relatively strong, given her COPD. She has never had heart problems. She consents to have a "breathing machine" if she needs one, and if it might help her get better again:

> *"I am a fighter, doctor, and I would like to have a chance to fight this one. I've still got living to do, you know."*

For Mr. T, the burdens of artificial ventilation outweigh any benefits, given his own goals of care and his failing health. He may possibly feel the same way about the antibiotics, but at present, they are helping him to meet his goal of seeing his daughter one last time. Mrs. W is physically stronger than Mr. T and her goals of care include all methods to help make her better and prolong her life, including artificial ventilation if it is required.

Goals of care for both patients may change as their illnesses unfold, either towards improvement or deterioration. For this reason, goals of care need to be revisited from time to time. D_x