



CHRONIC ILLNESS: THE LONG JOURNEY

Whether you are receiving care for a chronic illness or are acting on behalf of another person as a health care agent or a family member, there will be times when you will need to communicate with the health care team. As an illness progresses the patient's condition often declines and the changes should prompt a conversation about the course of the illness and the goals of care.

What is the **major goal** for care? To maximize comfort? To maintain function? To prolong life?

If you or your family member notices the following changes in mental or physical conditions, have a discussion with your health care providers about the next phase of care.

Dementia or Alzheimer's disease:

- weight loss, forgetting how to eat, difficulty with swallowing or chewing
- pneumonia and/or bladder infections that occur frequently
- increased resistance and distress with personal care
- withdrawal from family, environment and previous activities

End stage cardiac disease:

- decreased energy and shortness of breath combined with increased anxiety and restlessness
- inability to rest at night unless sitting upright or in a recliner
- increased leg swelling
- chest pain that is frequent and not relieved with nitroglycerin

Long-standing renal disease/dialysis:

- isolation at mealtime due to restrictive diet and fluids
- fatigue that interferes with enjoying each day
- benefit of treatment outweighed by the burden of the dialysis schedule and continued shunt revisions

A chronic disease or condition in an advanced stage:

- complications from a stroke causing decreased mobility, inability to swallow, and increased frustration with the inability to communicate
- ALS (Lou Gehrig's disease) with increasing muscle weakness causing difficulty in swallowing and speaking, and frequent infection
- pulmonary disease causing increasing fatigue, a profound feeling of breathlessness and decreasing ability to carry out daily activities
- long-standing diabetes leading to related complications such as neuropathy, infections, amputations, blindness, or renal disease
- visits to the emergency room that are becoming more frequent
- falls occurring frequently, or a hip fracture that has occurred

If you have named a health care proxy agent and signed a personal wishes statement, your health care team will be better able to converse with you or your agent and choose among the options for care. You as the patient, or as a family member along with the health care agent, may request a care plan meeting to discuss these or any other issues that are of concern. These conversations with your health care team will help to chart the course for the journey.