

# The PATH Guide to Medical Decision Making

## Why follow the PATH?

As people age, they generally become frail, which means they may not recover from illness or injury as well as they would have in the past. If existing health problems get worse or new ones come along, you must carefully consider whether or not to accept the treatments offered. Working through your options can be difficult and stressful. You may feel you are being asked to make “life or death” choices without all the information you need.

This guide, which is based on the PATH model, provides an overview of how to approach healthcare decisions as frailty progresses. Although some people may be able to make decisions on their own behalf, when health changes suddenly, most people need the support of a trusted family member or friend to weigh the options. This guide is directed towards those who have been called upon to make decisions on behalf of another person.

### To make the best medical decisions, you need to learn about:

- the person’s “big picture” health status
- existing illnesses and how they are likely to affect the length and quality of life in the future
- the potential benefits and risks of the proposed treatment
- whether an individual is likely to respond well to the treatment or if it could possibly make them worse
- the questions to ask healthcare providers so that you will have adequate information to make appropriate decisions

### Care versus cure

Our society and healthcare system are oriented towards “fighting disease” and “finding a cure.” As a result, we have made great advances in saving and extending people’s lives. There are times however—such as when a person is frail and nearing the end of his or her life—when treatments meant to lengthen life can actually reduce the quality of life. At such times, it is appropriate to think about the best way to care for the person rather than seeking to cure them.



### Consider this real-life situation:

#### The story of John McPhee

At 83, John McPhee had moderate-stage Alzheimer’s disease, kidney disease and heart failure. These illnesses were stable and Mr. McPhee was living happily in his home with help from his family and home care. Everything changed suddenly when Mr. McPhee developed pneumonia. The pneumonia was easily treated with antibiotics, but the chest x-ray revealed a mass in Mr. McPhee’s lung. Further tests confirmed cancer, at a stage early enough to be cured with surgery. John McPhee and his family opted for surgery, in hopes of preserving his good quality of life.

This decision looks reasonable at face value: it seemed that surgery could extend Mr. McPhee’s life. But, in his case, frailty was an issue that needed to be considered. Frail people with dementia and other illnesses appear fit, but they are fragile and do not always recover from interventional treatments. As often happens when people with dementia become ill, Mr. McPhee became more confused and agitated (delirious) after surgery. Medications calmed the agitation, but Mr. McPhee never fully recovered from the delirium and had to move from hospital into a nursing home.

In hindsight, surgery may not have been the right choice. Mr. McPhee’s life expectancy was already limited by dementia, heart failure and kidney disease. Removing the cancer did not likely extend his life, as people can live for several years with some types of lung cancer even without treatment. But the surgery did hamper Mr. McPhee’s quality of life. If he and his family had been involved with the PATH clinic, they would have known what questions to ask to make the best decision. They may have chosen to forego surgery and treat the symptoms of cancer and other illnesses as they progressed. Avoiding surgery would have spared Mr. McPhee enormous physical pain and emotional trauma and preserved his quality of life for a longer period of time.

## Understanding health

### What you need to know about current health status

By choosing the PATH, you have taken a very important step. You've chosen to learn about your own or your relative's health so that you can make informed and appropriate medical decisions. The first step is to understand health issues and frailty status.



### Understanding frailty

Many people think their age has the biggest impact on how much longer they can expect to live, which is not true. Life expectancy has more to do with frailty than age.

#### What is frailty?

As people age, they accumulate health problems. When those health conditions negatively affect a person's walking (mobility), thinking (cognition) or ability to handle daily tasks (function), we call this "frailty". Frailty describes the total burden of disease a person carries and how much it affects their ability to manage their life.

#### Why is frailty important?

Frailty is a state of vulnerability. When a person is frail, they are not able to recover as well or as quickly from an injury or illness as they would have earlier in their life when they were healthier. Thus, a person's level of frailty has a major impact on how well they do with medical and surgical treatments.

Frailty is a continuum—some people are more frail than others, even when they have similar health conditions.

Frailty is generally progressive, which means health gets worse from one year to the next. When people are frail, they may not fully recover from a new illness, surgery, or time in hospital. Thus, when making medical decisions, you need to consider frailty first. If not, a treatment or procedure can make things worse. It's important to learn how frailty will progress over time so that future health can be considered when making medical decisions. It's also important to consider how you and your family will cope with the increasing care needs and loss of independence that come with advancing frailty.

To better understand frailty level and current health status, as a next step, we ask three questions.

### Questions to clarify current health status

- 1 How much frailty is there?
- 2 What illnesses are there? How do these illnesses impact each other? How will they progress over time?
- 3 What is the life expectancy? How might treatments affect length and quality of life?

These questions are so important. Let us explain:

#### 1. How much frailty is there?

To make appropriate healthcare decisions, it is vital to understand frailty stage. Ask your doctor about the degree of frailty that's present based on impairment in memory, function and mobility (walking).

#### 2. What illnesses are there? How do these illnesses impact each other? How will they progress over time?

Each illness has an impact. A single illness may be managed with treatments to prolong life and reduce suffering. However, when there are several ongoing (chronic) conditions, the treatment for one condition can have a negative effect on the other. For example, medications to treat the loss of bladder control can worsen memory; medications to treat high blood pressure can cause falls.

Most chronic illnesses, such as heart failure and dementia, get worse over time. Eventually, they lead to death. It's important to understand each illness and how it will affect the future, especially with dementia, as described on the next page.

#### 3. What is the life expectancy? How might foreseeable treatments affect length and quality of life?

Life expectancy is how long most people with various health conditions can expect to live. Illnesses such as heart failure, kidney disease, emphysema and dementia all shorten life. When they occur together, they shorten life even more. New illnesses or injuries that arise can further reduce life expectancy. Although we cannot always predict how long someone will live, we can acknowledge when an individual is in the final phase of his or her life. Considering this information will help you understand a treatment's value in terms of how much it may or may not extend life and its potential impact on quality of life. For example, if your life expectancy is limited and you are frail, it may be wise to consider whether certain treatments, such as surgery or chemotherapy for cancer, will allow you to enjoy the rest of your life.

## Understanding dementia

### What is dementia?

Dementia is a set of symptoms that includes declining memory, ability to solve problems and capacity to manage tasks of daily life. Alzheimer's disease and vascular disease are the most common causes of dementia. People with dementia often have other medical conditions and frailties that further reduce their life expectancy.

### What are the stages of dementia?

Dementia progresses in stages. While the length of each stage can vary from person to person, overall decline in physical health, memory and thinking is persistent.

**Mild:** At this stage, people have a hard time with complex daily tasks, such as shopping, cooking, managing finances and performing household chores. They may forget appointments, repeat questions and have more difficulty adapting to changes in their routines. Memory loss becomes obvious.

**Moderate:** People start to have major gaps in their ability to process information and remember things. They need help choosing their clothes or reminders to bathe. They are still able to bathe, eat and use the washroom without help. They may become more irritable.

**Severe:** People lose more of their mental and physical abilities. They may not always remember the names of family members or why they know them. They may become agitated or aggressive. At this stage, people make dressing mistakes, putting clothes on backwards or inside out. They eventually become weak and need help with dressing, bathing and personal hygiene. They may also lose control of their bladder and bowel function.

**Very severe:** At this stage, people lose most of their ability to speak and respond to what is around them. Eventually, they can no longer walk, sit without support, hold up their head or feed themselves. Their muscles become stiff and they can no longer swallow. At this point, they will not survive much longer.

**When making medical decisions, it is important to consider how dementia progresses.**



## Facts about dementia and frailty

**FACT:** Dementia leads to physical frailty as well as problems with memory and thinking. It is a terminal illness that plays a direct role in shortening life.

**FACT:** Frail people do not respond to cure-oriented treatments as well as healthier people.

**FACT:** Most clinical trials of cure-oriented drugs and surgery are conducted in relatively young, healthy people. The effects of these treatments on frail older adults are not well studied or understood.

**FACT:** Treatment guidelines for most illnesses are developed for that one illness. They do not take into account the effects of treatment on other illnesses or overall health.

**FACT:** Rather than curing illness or prolonging good quality of life, drugs and surgery can make a frail person's overall health worse.

**FACT:** Increasing frailty signals that a person is entering the final chapter of his or her life.

## Preparing to make decisions

What to consider when health changes for the worse

If a frail older person is injured, develops a new illness, or experiences a sudden worsening of an existing illness, they may require medical attention. We call that event the “health crisis.” At that time it will be important to carefully weigh the risks and benefits of each treatment and how each treatment may impact the remainder of life. This is the time when the family may need to speak on behalf of their parent or spouse and identify an approach that will best preserve quality of life.

Critical decisions are often made in the middle of the night with healthcare providers you have never met before. These are the key questions you will need to ask healthcare providers when health status takes a turn for the worse.

### Questions when making decisions

- 1 How will frailty make treatment risky?
- 2 How can symptoms be safely and effectively managed?
- 3 Will the proposed treatment require time in hospital? If yes, how long?
- 4 Will the proposed treatment improve or worsen function or memory?
- 5 Will the treatment allow more good quality years, especially at home?
- 6 If the decline in overall health cannot be reversed, what can we do to promote comfort and dignity in the time left?
- 7 Should we now be thinking about how to plan a peaceful and meaningful death experience?

You may be wondering why these questions for the future are so important.

Let us explain:

1. **How will frailty make treatment risky?**  
Frailty increases the risk of any treatment. You need to know how a proposed treatment will affect overall health and quality of life. The next few questions will help you learn more about the nature of these risks.
2. **How can symptoms be safely and effectively managed?**  
Symptoms are the noticeable ways that disease affects us. As illness progresses, there may be new symptoms that cause pain or discomfort. While symptoms sometimes improve with treatment, it is important to know how much improvement to expect and if new treatments will have a negative effect on pre-existing conditions and symptoms. This is the only way you can weigh the benefits against the risks.

Symptoms of acute illness, like pneumonia, will often improve with treatment. But symptoms of chronic disease need to be constantly monitored and managed and may never completely resolve. PATH works with patients to relieve symptoms and minimize side effects, but there may be a trade-off. For example, treating pain can cause confusion or falls. Whether the risk of side effects is acceptable depends on the degree of suffering.

3. **Will the proposed treatment require time in hospital? If yes, how long?**  
Spending time in hospital can have lasting negative effects on frail people. Hospitalization can lead to infection, loss of strength, difficulty walking, functional decline and changes in memory. The longer the stay, the worse the impact may be. Look for ways to make the hospital experience easier, or consider foregoing hospital-based treatments in favor of controlling symptoms at home.
4. **Will the proposed treatment improve or worsen function or memory?**  
Memory and function can both be seriously and permanently affected by surgery, time in hospital and certain drugs, especially if the person has dementia. Often, losses are never regained.



**Memory:** People with dementia commonly develop delirium in the hospital, which makes their memory worse. New research shows that the memory changes that occur with delirium may not go away. Such memory changes can be dramatic and worsen quality of life, as was the case for Mr. McPhee.

Dementia and delirium make the hospital experience more challenging. Due to confusion, it is difficult for people with dementia and delirium to speak for themselves. They may be in pain, but not know how to call for a nurse or ask for help.

**Function and mobility:** Frail people who spend time in a hospital bed lose muscle strength almost immediately. This can make it hard for them to walk and perform the tasks of daily living. Here too, the changes that occur are not always reversible.

5. Will treatment allow more good quality years, especially at home?

New health problems can have a major impact on life expectancy and quality of life. Make sure your healthcare providers understand current illnesses and what life expectancy was before the new problem emerged. This will help them tell you how the proposed treatment could affect the length and quality of your or your family member's life.

It is important for you, your family and your healthcare providers to reflect on the overall goals of medical investigations, treatments and surgery. Prolonging good quality of life is an important goal.

You need to not only consider the risks of the treatment itself, but the risks of time in hospital. Deterioration in function, mobility and memory may make it difficult to return home. Following hospitalization, many older adults with multiple medical problems need to move into a nursing home. Or they return home but require more help from a caregiver. Take these possibilities into account as you consider the proposed treatment.

In addition to risk, one needs to consider that life-prolonging treatment may allow a person to live longer in order to progress through further stages of frailty and dementia. To contemplate this issue, familiarize yourself with the stages of dementia, as described in this pamphlet.

**If the proposed treatment will not result in more good quality years, you may not want to accept it.**

6. If the decline in overall health cannot be reversed, what can we do to promote comfort and dignity in the time left?

It is up to you to let the medical team know your family's wishes. These may include requesting that comfort and dignity become the top priority. At this point, it is important to find non-invasive ways to manage the most troublesome symptoms to minimize pain and discomfort. You may want to discuss ways to stay out of hospital.

7. Should we now be thinking about how to plan a peaceful and meaningful death experience?

**When death is imminent or frailty burden is high, it is time for peace.**

If this is your situation, you, your family and care providers should be planning how to achieve a peaceful and meaningful death experience. The PATH information sheet on Ways of Dying describes practical tips on ways to achieve this.

Planning a peaceful death is not something many people consider. Although most individuals would prefer to die at home or comfortably in the hospital, frail individuals often go through diverse treatments that limit their opportunity to experience a comfortable death. As such, people who are frail are more likely to die alone and in pain.

**Just as it is possible to live well, it is possible to die well.**

With awareness and foresight, you can increase the chances that you or your family member will die with dignity and minimal suffering in familiar surroundings with loved ones nearby. The medical decisions that are made in the coming months will have a major influence on how well someone is able to die.

Many believe that people die *with* dementia, not *from* dementia. They think dementia affects only the mind. This is not true. Although dementia begins with the failing of the mind, over time this condition causes the body to deteriorate. Dementia cannot be cured and eventually leads to death. It can't be said too many times: When making medical decisions, it is important to understand how dementia progresses.

## Stories from the PATH

### The story of Sandra Parker

At the age of 74, Sandra Parker started showing early signs of Alzheimer’s disease. For example, even though she watched the news and read the newspaper on a regular basis, she could not recall or describe current events. Her disease progressed slowly and steadily to the **severe** stage of the disease.

An intellectual and author with four university degrees, Sandra could no longer read or carry on meaningful conversations. She did not remember her husband, Don’s, name, although she did recognize him. She could no longer cook or do household chores and needed help with bathing and dressing. Don looked after his wife at home.

We first saw Sandra five years ago and have been following her ever since. In consultation with Don, we charted a course for managing Sandra’s current symptoms and conditions, while planning for the future. In addition to Alzheimer’s, Sandra has arthritis, chronic neck pain, an abnormal heart rhythm and high cholesterol levels. To avoid unnecessary medications, we recommended that Sandra stop taking the medication she was using to lower cholesterol, as the drug was unlikely to have benefit given the severity of Sandra’s other medical conditions. At the same time, we felt Sandra should stay on medications for managing pain and her abnormal heart rhythm.

After we helped Don understand how Sandra’s illness would inevitably progress, he chose a comfort care plan for the future. This plan makes it clear that Don does not want his wife to be resuscitated in the event of a heart attack (no chest compressions, defibrillation (paddles), or the use of breathing machines). Nor does he want her to undergo surgery to extend life. In addition, Don does not want his wife to have surgery for comfort, if there are other ways to provide comfort, such as providing pain medications for a hip fracture instead of going through hip repair. Don also decided against complex medical treatments, like chemotherapy, but agreed to simple treatments that his wife could receive at home. Don would like to keep his wife out of hospital until the end of her life is near. At that time, he would like Sandra to receive palliative care in hospice.

Don said, “The physicians helped me look at the options in light of the scenarios that could unfold as Sandra’s disease progressed. They were straightforward and honest, which helped me know what to expect and prepare for the worst. At the same time, the nurses provided me with information and compassionate support to help me in my role as Sandra’s caregiver.”

### The story of George Wilson

Although George Wilson is only in his early 70s, he has advanced, very severe Alzheimer’s and vascular dementia, with dramatic physical effects. Once an athlete, he now needs to be moved in and out of bed with a mechanical lift. With regret, his wife Claire admitted him to a nursing home, where she visits him every day. She instructed the nursing home staff not to send her husband to the emergency department should medical problems arise. However, the nursing home staff sent George to the nearby emergency department twice—once for abdominal pain and a second time for shortness of breath—where George and Claire spent several miserable, stressful nights.

We learned about George after his second admission to the emergency department and contacted Claire. Together with Claire, we decided on a comfort care approach for George in the future. This meant that the goal of any treatment would be to promote comfort and treat pain, not to prolong life.

At the same time, we discussed problems that could arise in the future, such as pain, vomiting, nausea, inability to eat, shortness of breath, hip fracture and agitation. We wrote detailed instructions to the nursing home describing how they could handle each of these problems—in the nursing home, not the hospital—and stating that Claire wanted treatment for symptoms only, and end-of-life medications if symptoms could not be controlled. We also stopped medications that did not promote George’s quality of life, including Aspirin, blood pressure medication, and vitamins.

“I don’t want George to be overmedicated or over treated, because I love him so much,” says Claire. “The physicians in the PATH clinic made it easy for me to make the right decisions for George, by telling me everything and making things very clear. Most of all, they took a leadership role in his care to ensure that my wishes for his wellbeing were honored by the other professionals.”

