

PREPARING FOR DIFFICULT DECISIONS

QUALITY OF LIFE + COMFORT

Quality of life and comfort are the most important goals for individuals with moderate to severe dementia who are nearing the end of their life. Medical decisions should be made with these goals in mind. Admission to a nursing home for long term care can be overwhelming, not only for the individuals who are experiencing a change in their living environment, but also for family members and caregivers.



THIS IS A TIME IN LIFE WHERE THERE CAN BE MORE QUESTIONS THAN ANSWERS. UNDERSTANDING OPTIONS AND ADVANCE PLANNING ARE IMPORTANT FOR MAKING MEANINGFUL CHOICES AND USUALLY LEAD TO LESS SUFFERING.

Although the medical industry has made amazing advances in recent decades, there is still no cure for dementia, nor are there treatments that can restore function in patients struggling with dementia.

As you navigate the difficult decisions associated with dementia care, here are some terms you should know:

- **Advance Care Planning:** Advance care planning provides direction to health care professionals. This may be in the form of advanced directives such as a living will or a durable power of attorney.
- **MOST form:** Colorado has adopted the MOST form (Medical Orders for Scope of Treatment). This green form and copies record preferences for CPR, medical interventions and artificial nutrition. It is a legally-binding medical order.

DIFFICULT DECISION 1

Hospitalization vs treating at home

Research and decades of experience show that when individuals with dementia are hospitalized, it is likely they will have a permanent loss of up to 20% of their cognitive and physical functioning. They also have an increased risk of serious infections, unnecessary tests, procedures, potentially harmful medications and unnecessary physical and chemical restraints. Residents are often sent to the emergency department alone, so evaluations are very limited and can cause transfer distress. Individuals who are evaluated in the care center where they reside are in a familiar environment with caregivers who know their preferences. There are very few things that hospitals can do that nursing homes cannot do. Outcomes are almost always better for residents who are evaluated and treated in place. For the few things that are clearly better treated at a hospital (such as a hip fracture), we would not hesitate to send the individual out.

DIFFICULT DECISION 2

CPR vs DNR

Here are some facts about CPR. Especially in seniors, CPR is almost never effective. Far less than 1% of patients who have their heart stop in a nursing home survive to discharge from a hospital, and virtually none return to their previous baseline. CPR causes extreme pain and discomfort from chest compressions, fractured ribs, placing intravenous lines and putting a tube down the throat. DNR (Do Not Resuscitate) does not mean "Do not treat!" Every effort is made to prevent illness, keep residents comfortable, and maintain their highest level of function.

DIFFICULT DECISION 3

Artificial nutrition and hydration

Artificial nutrition is not a substitute for eating! For individuals with dementia, it is never viewed as a long-term option when their brain has determined it is time to stop eating. Similarly, while IV fluids may be useful for short periods of time, they have risks and are never a long-term solution. Dementia eventually leads to loss of appetite as a natural progression of the disease and does not cause discomfort.

DIFFICULT DECISION 4

Antibiotic use

Antibiotics may or may not be appropriate in any given situation. There are times when use is appropriate and may decrease suffering and other times when use may be harmful or simply not helpful.

What a Do Not Resuscitate (DNR) Order Means:

What we WILL do

- Provide pain control and management of symptoms
- Offer food and water, but will not force it
- Provide support to loved ones
- Find ways to comfort patients, such as holding their hand, playing music they like, reading to them

What we CAN do

- Draw blood and check labs
- Provide antibiotics when appropriate
- Provide IVs and hydration for a limited period of time

What we WON'T do

- Make attempts to restart a heart that has stopped (i.e., we will not shock the heart or press on their chest with enough force to break ribs)
- Put tubes in their throat to help them artificially breathe
- Call 911 if their heart stops

For additional information on dementia contact the Alzheimer's Association at 800.272.3900 or alz.org/co