

PATCH program
Home palliative care
Dementia—advance medical planning and decision-making

While it is best in any progressive condition to have conversations about prognosis, expectations and medical plans in advance, the burden is especially high in patients with dementia. If these conversations are held early in the course of the disease, the patients are often able to contribute meaningful information about their wishes for end of life care. However, it is not infrequent that these conversations are not held at the point where the patient is able to contribute in deeply meaningful ways. In that case, this module helps the care provider understand how to address advance medical planning in the patient with advanced dementia

LEARNING OBJECTIVES:

At the end of this module, the student should be able to:

1. Discuss the importance of advance medical planning for patients with dementia,
2. Understand how to consider benefits and burdens in each individual when making each decision about diagnostics and therapeutics in the patient with dementia.
3. Educate family about possible future events for the patient
4. Enroll end stage patients appropriately to hospice
5. Help families make informed decisions about nutrition in the patient with end stage dementia.

WHAT YOU NEED TO COMPLETE THIS MODULE:

1. Read Synopsis
2. Read case presentation and review questions
3. Answer questions

Be prepared to discuss your answers

SYNOPSIS:

1. Advance planning for Patients with dementia
 - a. Prognostication
 - i. Progressive, incurable disease
 - ii. Difficult to determine 6 month life expectancy but guidelines for stages.
 - iii. Look at trajectory (eg, recent rapid decline? Major change over the last 6 months?)
 - b. Consider benefits/burdens of diagnostics and treatments
 - i. Tests or treatments may cause more harm (especially in a patient who is unable to understand what is happening) or pain than any potential benefit.
 - ii. Re-hospitalization? If so, under what circumstances?
 - c. Educate family about disease,
 - i. Past Advance Directive documentation or discussions?
 - ii. Discuss realistic end of life events, eg—infection which might be a comfortable way to die and the options of therapies such as hospitalization and antibiotics.
 - iii. Tube feeding conversation/stats—See below.
 - d. Hospice
 - i. Criteria for enrollment of hospice patients
 1. Dementia severity--past FAST stage 7c
 - a. Lost all ADLs
 - b. Incontinent
 - c. Can not ambulate independently or carry on conversation,
 2. Medical complications
 - a. aspiration pneumonia,
 - b. UTI,
 - c. weight loss 10% 6 months,
 - d. worsening multiple pressure sores (stage 3-4),
 - e. or recurrent fever after antibiotics
 - ii. Since it is difficult to predict six month life expectancy in dementia, if the patient appears terminal especially with co-morbidities, can be admitted to hospice with clear documentation of evidence of rapid functional decline. They may be discharged if they stabilize.
2. Nutrition
 - a. Hand feeding associated with pleasure of eating including experiencing taste and texture and having someone touch and attend.
 - b. Weight loss is usual.
 - c. Several studies fail to show decrease in aspiration or weight loss or increase in survival with tube feeding in terminal dementia.

BIBLIOGRAPHY

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2. Gillick M. Rethinking The Role Of Tube Feeding In Patients With Advanced Dementia. N Engl J Med. 2000 Jan 20;342:206-10.
3. Shuster J. Palliative Care For Advanced Dementia. Clin Geriatr Med. 2000 May;16(2):373-6.

CASE

Your 88 year old patient with severe dementia had been choking with meals and has just been discharged from the hospital where she had been treated for aspiration pneumonia. Swallowing study during hospitalization was equivocal.

On exam, she is alert and talking non-sensically, sitting up straight in a chair. No other remarkable exam findings. Her daughter wants to know about her prognosis—

What are the usual markers that might help you and her about prognosis in the patient with dementia?

The family asks about the appropriate time for hospice—what would you tell them?

Her daughter asks about g-tube feedings. What might you tell her to help her decide?

On your next visit with the patient, she now has a g-tube placed per the daughter's request. However, the daughter had to wrap an ACE bandage around her abdomen to keep Mrs. G from pulling the tube out. And, the teenaged granddaughter reported positive experiences with feeding grandma soft food—grandma seemed to be swallowing fine and they both enjoyed the experience.