Chapter 16
Looking Ahead: The Later Stages

> *Worry does not take away tomorrow's troubles. It takes away today's peace.*

This chapter addresses the end-of-life decisions that families face for a loved one with advanced dementia. For patients with advanced dementia, we look for a compelling reason to justify additional assessments or interventions. It sounds logical in theory, but can be challenging in practice. The general rule of thumb is not to test for a condition that you're not going to treat. Here is a formula we suggest that you follow in determining whether to proceed with any medical intervention. First, think ahead to what treatment you would reasonably allow. Then, work backwards to decide if any type of assessment, work-up, or diagnostic test is warranted.

Unfortunately, medical care often continues at the same intensity level for a patient with advanced dementia without much thought as to whether this is appropriate. Physicians may be uncomfortable deviating from routine medical care. A patient's relatives may passively follow physician recommendations without realizing that tests, procedures, and other interventions can be declined. And even with awareness of the option to refuse, a family member may have a hard time saying no to further interventions.

Common sense rule: Don't do the test if the result won't change the plan of care.

A.M. Lipton and C.D. Marshall, *The Common Sense Guide to Dementia for Clinicians and Caregivers*, DOI 10.1007/978-1-4614-4163-2_16,

Medical Care in Advanced Dementia

Comfort Care

This should be the principle guiding medical care in advanced dementia. We aim to preserve a patient's quality of life, with an emphasis on relieving, avoiding, or at least minimizing pain and avoiding unnecessary and futile medical tests and treatment. Even transport to a clinic or noninvasive tests may be difficult for such patients.

What do we mean by advanced dementia? In this stage of dementia, patients depend on others for most or all of their basic ADLs, such as dressing, bathing, eating, brushing teeth, etc. Such patients typically have very poor memory and may not remember key information, such as date of birth, where they live, or some family members (particularly those known to the patient for the shortest amount of time, such as grandchildren or new in-laws). They cannot understand or participate in complex decision-making, such as that required for medical, legal, and financial issues. Many will have behavioral problems, such as agitation. At this stage of dementia, patients may be candidates for Hospice Care (discussed in the last chapter and in further detail below), which emphasizes comfort care only.

However, even a patient not eligible for Hospice or whose family (or other medical decision maker) chooses to decline Hospice care may still have comfort care or even comfort care only. The following sections provide some practical approaches for medical care in advanced dementia and may apply to other stages of dementia as well, depending on individual circumstances.

Common sense rule: Comfort care works with or without Hospice care.

Medical Procedures

Let us say your loved one with dementia has an abdominal aortic aneurysm that is being monitored for an increase in size. Such an aneurysm is an abnormal swelling in the aorta, which is the largest blood vessel in the body. Typically, if an aneurysm is found, tests are done to monitor its size for surgical correction if it becomes large enough. The question is whether to keep doing the tests in a patient with advanced dementia. Thinking ahead, if you are the medical decision maker for such an individual and would not consent for your loved one to undergo a major surgery even if the aneurysm is increasing in size, there is no reason for continued monitoring.

Likewise, let us say a patient with advanced dementia has a history of breast cancer and undergoes routine mammograms to look for cancer recurrence. Thinking ahead, if you are the medical decision maker for this patient and would not choose to expose your loved one to chemotherapy, radiation, or surgery, mammograms may be discontinued.

Many families continue to schedule their loved ones with dementia for screening tests out of habit. Take a moment to think through the physical and psychological consequences of such evaluations, which may include mammograms and colonoscopies, blood draws (e.g., for cholesterol checks), and prostate and gynecological exams. These tests may distress anyone, but particularly a patient who does not understand the rationale.

An annual Pap smear is important in screening for cervical cancer, but it requires that a woman disrobe, put her legs in stirrups, and undergo an invasive exam in an intimate area. It makes no sense to subject a woman with advanced dementia to such an evaluation if her family (or other medical decision maker) would not pursue treatment for any cancer found. This logic applies to other screening procedures (e.g., colonoscopies) as well. For patients with advanced dementia who may become agitated and uncooperative with the exam, these tests might even become painful or dangerous.

Sometimes patients with advanced dementia have particular symptoms, including pain, justifying certain procedures, but, even then, the options should be clearly weighed. For example, can the patient's pain or other symptoms be addressed without invasive testing? Is the patient a candidate for Hospice?

Most patients with advanced dementia lose weight, but, in most cases, this may be attributed to late stages of dementia and does not indicate a need for a colonoscopy to look for a cause. Again, if colon cancer were found, would any treatment but pain relief be desired? And, if comfort care is the priority for a given patient, why subject him or her to an invasive test? The bottom line is that the risks of medical screening in patients with advanced dementia may confer no benefit and pose significant risks.

For some patients with advanced dementia, the risks of any disruption to their environment (such as leaving a residence for a clinic) outweigh the potential benefits of any procedure done in which transport is required.

Routine laboratory blood tests (e.g., for cholesterol levels) should generally be avoided in patients with advanced dementia. For those who become agitated, an attempt to insert a needle could injure the patient, the phlebotomist (person drawing blood), or others. If such a patient takes any medications that require blood checks, it may be worth stopping this drug or switching to another that does not necessitate such tests.

Common sense rule: Stop routine medical screening in advanced dementia.

Dental Care

Along the same lines, routine dental cleaning may be discontinued for patients with advanced dementia who may become fearful and overwhelmed by the exam. In case of a compelling reason to intervene, such as a painful tooth abscess, the dentist may recommend anesthesia or other sedation both for patient comfort and staff safety due to risk of biting. In such cases, if the dental procedure is necessary, then such sedation may also be justifiable.

Common sense rule: Discontinue routine dental care in advanced dementia.

Medications

As we discuss elsewhere, regular review of medications benefits patients with dementia. As the disease advances, medical personnel, families, and other caregivers should consider stopping or minimizing medication that may no longer offer more benefit than risk. In addition, families may not want to pursue any treatment that could prolong life. Some may prefer to apply any cost savings to other aspects of a patient's care. Others may just have a "less is more" philosophy.

Terminating a drug (or any medical intervention) is usually psychologically difficult, however, not just for family members, but also for doctors and other medical personnel. It may, nonetheless, be the preferable, or even necessary, option. Therefore, don't start medications without good justification and consider adjustments as a patient's condition changes. This should always be done with medical advice and supervision, particularly from a prescribing physician, and especially because some medicines may need to be withdrawn slowly.

For each medication, ask the questions: (1) What is the reason for taking this drug? and (2) What are the risks and benefits? Discuss these issues with the prescribing doctor to determine whether to (1) continue, (2) stop, or (3) reduce the dosage of medicine.

If a patient's doctor doesn't raise these questions, family caregivers (or other patient decision makers) most definitely should. This especially applies to cases in which a patient has dysphagia (difficulty swallowing) or trouble taking medication regularly for any other reason. A discussion amongst doctors and families can help allay fears and concerns, lead to a careful and considered decision, and bring peace of mind for all.

Routine Medications Unrelated to Dementia

Let's say your loved one with advanced dementia takes a cholesterol-lowering drug. Your family member may have had a prior heart attack, done well on this medication, and you and the patient's physician decide to continue it. However, as dementia progresses, cholesterol, appetite, and/or weight often lessen and may justify stopping this medication. Maybe your family member can no longer cooperate with having blood drawn (or you have decided that he or she should no longer be subjected to such tests). Perhaps the aim of reduced risk of heart attacks and strokes no longer justifies its use due to stage of disease, cost, and/or other factors.

Neuropsychiatric Medications

These treat dementia, anxiety, depression, and other mood and behavioral symptoms.

Dementia medications do not appear to prolong life in Alzheimer's disease [1], and little evidence exists to support such a role in other types of dementia. However, behavioral symptoms may emerge when medicines specifically designed to treat dementia are stopped, even in patients who have no history of behavioral problems or who have not had any in some time [2]. Therefore, these medications may be justified in advanced dementia for reasons of preventing or treating behavioral symptoms, such as agitation.

Non-pharmacologic treatment should be tried for mood and behavioral symptoms which occur despite treatment with dementia drugs. Other neuropsychiatric agents may pose significant risks and should be used judiciously. Chemical and physical restraint of patients should be avoided. For example, medications should be adjusted for a patient who appears overly sedated.

Unless specific new issues arise, we almost always recommend that our patients with advanced dementia stay on the regimen that has worked for them previously. However, it is important to regularly check that the benefits of each medication continue to outweigh the risks.

Stopping one or more of these medicines may be a consideration due to cost or other issues. Dosage reduction may be indicated due to sedation, poor appetite, or other symptoms. If a decision is made to attempt withdrawal or reduction, we highly recommend following the measures discussed in the chapter on medications. Namely, only one medicine should be adjusted at a time, and this should be done slowly, cautiously, and with medical supervision. Any problems arising may then be addressed by restarting the drug or resuming the prior dosage of the drug.

Appetite Stimulants

We do not recommend medications solely prescribed to stimulate appetite in our patients with advanced dementia. Overall, studies of appetite stimulants in dementia show some benefit for weight gain, but not for prolonging life, improving function, or otherwise enhancing quality of life [3]. We therefore look to what medications might be stopped, reduced, or switched in order to maintain health. For example, cholesterol-lowering medication could be discontinued for a patient who is no longer eating much. If a patient has previously done well on an oral form of a cholinesterase inhibitor, but is now experiencing poor appetite and weight loss, this type of anti-dementia medication might be switched to a patch form to minimize these symptoms. For a patient needing a sleep aid, we might try mirtazapine in low doses to stimulate appetite and weight gain. (Note that mirtazapine may also be used to treat mood and behavioral symptoms besides insomnia.)

Common sense rule: Streamline medications.

Consolidated Care

While one or more specialists may benefit a patient in initial stages of dementia, advanced dementia may be the time to consolidate care. Consider conducting all of a patient's care via one physician. First, identify the doctor who will adopt this role and make sure that he or she is comfortable with this plan.

This might be the primary doctor (such as an internist, family practitioner, or geriatrician) who has cared for your loved one for years. If it is difficult to transport your family member to the primary doctor's office, you might ask for a recommendation for a physician house calls service.

A physician affiliated with the long-term-care facility in which your loved one resides could also serve in this role. This doctor visits patients on-site, thus eliminating the need to take your loved one out of the facility for such evaluation. This approach has pros and cons. It may benefit a patient and enhance care by allowing the doctor to examine the individual in a familiar place, easily access the medical chart and medications, and facilitate discussion with nursing and other staff who regularly interact with the patient. Families love the convenience, particularly when it is a struggle to get a loved one out and about. Medical issues and families' concerns can be addressed promptly when they arise. On the negative side, sometimes families don't have as much interaction with the doctor as with a family physician. They may worry that the visiting physician is unaware of pertinent health history, including current issues, particularly when the patient is no longer able to contribute relevant information during an exam.

When considering a doctor affiliated with a facility or who makes house calls, ask if the visiting physician works alone or as part of a team of nurse practitioners or physician assistants, who may see your loved one more frequently than the doctor supervising the care. The latter is the typical arrangement and often works well. If your loved one is enrolled in Hospice, the medical team operates similarly and is yet another option for point-of-care.

In any event, if your loved one currently follows with a primary care physician, have him or her weigh in on the decision. He or she will likely have invaluable insight into the particulars of your loved one's situation (and yours).

Speak with specialists to see if their medications and care can and should be transitioned to the primary care physician and, if so, how best to do this. If a patient has significant psychiatric or behavioral issues, it may also make sense to continue care with a dementia specialist, such as a psychiatrist or a neurologist.

Common sense rule: Consolidate medical care in advanced dementia.

Emergency Room Visits and Hospitalizations

Families often do not realize that they have a say in whether their loved one goes to the emergency room (ER). If a patient with advanced dementia lives at home, family can agree not to call emergency services or send a loved one to the emergency room.

We recommend discussing this with all relevant and concerned family members and doctors and putting instructions in writing to avoid confusion and miscommunication. If a loved one with dementia lives at a facility, you will need to speak with the facility's administrator. The facility may require written documentation of a family's wishes as they may have internal procedures where ER visits are automatically triggered by certain events, such as a fall, fainting, or chest pain. Such visits are usually avoided for patients in Hospice Care, but may be called for in some circumstances. Family members should discuss this with the Hospice medical team. However, even if a patient with advanced dementia is not in Hospice Care, transport to an emergency room doesn't need to occur if the patient's medical decision maker decides against it. Ideally, this decision should be arrived at, documented, and communicated to a patient's doctors and family members well in advance and not in the midst of an emergency situation. And, Hospice Care should be seriously considered for such a patient.

Common sense rule: It is possible to avoid hospitalization in advanced dementia.

Resuscitation Status

If a patient does not have directives in place, family members will most likely need to determine resuscitation status. If resuscitation is not desired, it is best to document this decision in advance of any emergency, since withdrawing care tends to be much more difficult psychologically and emotionally than simply avoiding an unwanted procedure in the first place.

Survival rates of elderly patients after resuscitation are under 10 % [4–6]. Therefore, it is usually difficult to justify subjecting a person with advanced dementia to the rigors of a resuscitation effort.

What Does DNR Mean?

DNR stands for "Do Not Resuscitate." Therefore, Cardiopulmonary Resuscitation (CPR) will not be administered by anyone present or emergency medical services (EMS) will not be called to administer CPR if a patient's heart or breathing stops. All noninvasive, non-painful efforts to make a patient comfortable still can and should be made.

In reality, sometimes EMS are still called in a nonhospital setting (e.g., home, assisted living, rehabilitation or long-term-care facility). This may be due to uncertainty about a patient's medical condition, a facility's policies, etc. If EMS are called, they could be called again and told that they are not needed (however, once en route, they often must proceed regardless). If EMS does arrive, the patient's DNR directive should be produced and shown immediately to them so that they can avoid administering unwanted and unnecessary resuscitation efforts.

DNR forms and regulations vary from state to state. Blank DNR forms may be found online or requested from medical institutions and clinics, including hospitals, doctors' offices, home health agencies, and long-term-care facilities. They generally require the approval and signatures of the person with medical decision-making power for the patient and at least one physician.

What Is Resuscitation?

As its name suggests, CPR includes two basic components: trying to restart a heart that has stopped beating normally and providing oxygen to someone who has stopped breathing normally. One physiologic process can go on independently for a short time, but the two often go hand in hand if no intervention is made. That is, if you stop breathing, your heart soon follows and vice versa.

Resuscitation is generally not gentle and may not best serve the interests of a patient with advanced dementia or other terminal, irreversible illness. CPR may include removing clothing from the upper body, chest compressions (repeatedly pushing down on a patient's chest with both hands using the weight of your own body—this can and sometimes does result in broken ribs), precordial thump (hitting the chest to try and restart the heart), and defibrillation (using paddles to deliver electric shocks, which can cause burns). It may also involve mouth-to-mouth resuscitation to deliver breaths to a patient.

Advanced Cardiac Life Saving (ACLS) resuscitation techniques may be performed outside the hospital by EMS (including ambulance personnel such as Emergency Medical Technicians, also called paramedics) or by nurses and doctors in a hospital or a similar setting. ACLS includes CPR and may also involve putting a breathing tube down a patient's throat and airway (windpipe), inserting an intravenous (IV) line via a needle into a vein (or using a preexisting one) to deliver medications, and other procedures.

As you can see, resuscitation can be painful and invasive. What you might be surprised to learn is, unlike what you see on TV and in the movies, how often it fails, even for patients for whom it is appropriate. CPR administered by medical professionals is successful only 15 % of the time for hospitalized patients [4–6] and less than 10 % for those outside the hospital [7]. Contrast this to fictional television programs and movies in which CPR is depicted as successful more than two-thirds of the time [8]. Therefore, CPR may not only be a rough procedure for a patient with advanced dementia, but also most often will be in vain.

> I'm moving my husband to a memory facility due to his advanced dementia. They asked me about DNR status, since I am his Medical Power of Attorney and his doctor said that he is no longer capable of making his own decisions regarding such matters. I don't know his specific wishes, but I suspect he wouldn't want his life prolonged. He always talked about not wanting to be a burden. However he's in pretty good health. I'm not sure what to do.

First and foremost, try to make the decision that your husband would if he were able and act in his best interests. If you have considered all of the foregoing and your gut then tells you that he would not want resuscitation given his current condition, then you can complete and sign forms to designate his status as "DNR" (usually with the agreement and signature of at least one of his doctors). Provide a copy to the facility and his physicians. It may help to discuss this decision with other family members and doctors or at least inform them of it. It's certainly important to document.

A DNR directive provides a way to protect patients from having to go through possibly uncomfortable, unnecessary, and futile CPR in the last moments of their lives. Such patients can instead be made comfortable via much kinder and gentler measures.

Common sense rule: Doing everything for a patient may not be best for the patient.

Avoid Feeding Tubes

We strongly discourage the use of feeding tubes in dementia. Based on the preponderance of medical evidence [9] which has shown that:

Feeding tubes in dementia:

- Do NOT prolong survival.
- Do NOT decrease the risk of aspiration pneumonia (pneumonia developing when food or saliva goes down a person's airway or windpipe instead of the esophagus).
- Do NOT improve a patient's functional status.

But, feeding tubes in dementia are associated with:

- Increased infection.
- A substantial number of deaths at the time of or shortly after the procedure for tube insertion.

And, in a recent study [10], family members whose loved ones with advanced dementia died with a feeding tube in place were less likely to report excellent end-of-life care than those whose loved ones did not have a feeding tube.

Common sense rule: Avoid feeding tubes for dementia.

Consider Hospice

Hospice evaluation should be strongly considered for a patient with advanced dementia and eligibility for this was discussed in the last chapter. Our families almost universally endorse positive experiences with hospice. In addition to the medical care they provide, hospice team members offer their extensive experience and unique skills to address the emotional and spiritual issues that arise for patients and their families. Several patient families have reported that the greatest blessing of their time with hospice was not feeling alone.

Letting Go, Gently

There comes a point in any illness that we, as physicians and families, need to follow a loved one's lead and let nature take its course.

> I just don't understand it. Mom is clearly ready to go. She would never want to live this way. But she just hangs on. It's so hard to watch.

Wow. This is tough stuff and hard to watch, let alone for family and other caregivers to live through each. Here we have a situation where Mom's body has outlived her mind. At this point, family members may have made peace with a loved one's passing. They may even see Mom's death as a blessing, believing she will go on to a better place. It is important to look at what we (physicians, family, and other caregivers) are doing and see if we are doing anything to actively block a loved one's efforts to go in peace. If DNR status has been designated, we can then move on to whether we should continue to treat medical symptoms and illness. Our health care system defaults to treating almost anything, whether it should be or not. We want to avoid overwhelming the brain further with repeated and futile medical interventions. Are we sending Mom to the emergency room each time she is somnolent, confused, or falls? Are we testing and treating for all medical problems, including every instance of possible dehydration and infection? Answering these questions in the affirmative is not necessarily a good thing, the right thing, or the best thing for a patient with advanced dementia. We need to talk about why we're continuing to utilize the hospital and treating infections, and, most importantly, if we should stop. From a medical standpoint, we might think of simply letting nature take its course. From a philosophical standpoint, we may wish to try and align ourselves with the course the patient is following. You might think of it as following Mom's lead. A spiritual viewpoint might suggest that by blocking Mom's exit from this world, we're blocking the threshold of heaven.

You may consider these and other points of view, but the crux is to find and follow your path alongside your family member. Take comfort in knowing that your loved one doesn't have to go it alone.

Common sense rule: Follow your loved one's lead.

Our parting wish for all who read this book is peace. One of the greatest gifts you can give your loved one is reaching an inner peace about his or her journey, including its end. This is a journey in itself. Discuss it openly with the people who matter to you and your loved one with dementia, including family, friends, and other caregivers. Let go of grudges, guilt, and unresolved issues. Always remember, your loved one will only do as well as you are doing. So, let yourself find and feel at least some serenity. Peace is a gift. Allow yourself to accept it.

Dear Caregiver, we salute you. Thank you for all that you do.

Summary

When evaluating the utility of medical assessments or interventions, use the compelling reason rule: Don't do the test if the result won't change the plan of care. Emphasize comfort and consolidate medical care for patients with advanced dementia. Review and streamline medications. Avoid excessive and futile intervention, such as feeding tubes. Consider palliative care/Hospice care in advanced dementia. Take comfort and find peace and self-worth in your vital role as caregiver and companion to your loved one with dementia.

Common Sense Rules

- Don't do the test if the result won't change the plan of care.
- Doing everything for a patient may not be best for the patient.
- Comfort care works with or without Hospice care.
- Streamline medications.
- Avoid feeding tubes for dementia.
- Follow your loved one's lead.

Common sense rules specific to patients with advanced dementia (but which may be considered in other stages of dementia, depending on individual circumstances):

- Stop routine medical screening.
- Discontinue routine dental care.
- Consolidate medical care.
- It is possible to avoid hospitalization in advanced dementia.
- Consider Hospice.

Websites

Alzheimer's Association: www.alz.org
Caring.com: www.caring.com
Family Caregiver Alliance: www.fca.org
National Hospice and Palliative Care Organization /National Hospice Foundation**:** http://www.nhpco.org

References

1. Rountree S, Chan W, Pavlik V, Darby E, Doody R. Factors that influence survival in Alzheimer's patients. Alzheimers Dement. 2011;7(4 Suppl):S513.
2. Holmes C, Wilkinson D, Dean C, Vethanayagam S, Olivieri S, Langley A, Pandita-Gunawardena ND, Hogg F, Clare C, Damms J. The efficacy of donepezil in the treatment of neuropsychiatric symptoms in Alzheimer disease. Neurology. 2004;63(2):214–9.
3. Hanson LC, Ersek M, Gilliam R, Carey TS. Oral feeding options for people with dementia: a systematic review. J Am Geriatr Soc. 2011;59:463–72.
4. Murphy DJ, Murray AM, Robinson BE, Campion EW. Outcomes of cardiopulmonary resuscitation in the elderly. Ann Intern Med. 1989;111(3):199–205.
5. Varon J, Fromm Jr RE. In-hospital resuscitation among the elderly: substantial survival to hospital discharge. Am J Emerg Med. 1996;14(2):130–2.
6. Taffet GE, Teasdale TA, Luchi RJ. In-hospital cardiopulmonary resuscitation. JAMA. 1988;260(14):2069–73.
7. "CPR statistics." American Heart Association. Retrieved 2011-11-1.
8. Diem SJ, Lantos JD, Tulsky JA. Cardiopulmonary resuscitation on television. Miracles and misinformation. NEJM. 1996;334(24):1578–82.
9. Finucane TE, Christmas C, Travis K. Tube feeding in patients with advanced dementia: a review of the evidence. JAMA. 1999;282(14):1365–70.
10. Teno JM, Mitchell SL, Kuo SK, Gozalo PL, Rhodes RL, Lima JC, Mor V. Decision-making and outcomes of feeding tube insertion: a five-state study. J Am Geriatr Soc. 2011;59(5):881–6.