

The background of the entire page is a soft-focus photograph of several birds, likely terns, flying over a body of water. The birds are captured in various stages of flight, with their wings spread wide. The water below is a pale, shimmering blue, and the overall scene is bright and airy. The text is overlaid on this background in a dark blue, serif font.

Alzheimer's Disease:

Care and Support at the End of Life

*Resources and Information
for the Caregiver*

Prepared by Laurel Coleman, M.D.

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Alzheimer's Disease: - Care and Support at the End of Life

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Dealing with Advancing Alzheimer's Disease

Introduction

You probably would rather not be reading this. You are helping to care for someone with dementia, a job you didn't choose. Consider this brochure "continuing education," because facing the advanced stage of Alzheimer's disease will take new skills and approaches.

My friend Coach Frank Broyles of the University of Arkansas cared for his wife who had Alzheimer's disease for many years. He taught me a lot. I wanted to adopt his "game plan" approach to this challenging disease.

Researching Your Opponent

While you may rightly believe Alzheimer's disease to be your opponent, you must realize that you will never beat this enemy. If you place your hopes in preventing its progression, you will be disappointed. Someday, we will have treatments and even a cure for Alzheimer's, but for now you must fight this opponent by preventing it from doing unnecessary physical and emotional damage.



It is important for you to appreciate that many of the medical therapies and technologies we take for granted in today's healthcare system are not very effective for people with a terminal illness. For example, when a person with advanced dementia refuses most food, or becomes unable to swallow, well-meaning healthcare workers often will suggest a feeding tube to provide nutrition. While a feeding tube can be very helpful in providing nutrition in a person who is recovering from an illness, it does not prolong the life or improve the quality of life in a person with severe dementia.

As a caregiver, you will have to weigh many common medical therapies and decide if they will help to comfort or improve the life of the person you are caring for.

So how do you fight a battle against a disease that will ultimately cause the death of a person you care about?

You can prevent Alzheimer's from causing isolation, pain, loss of dignity, and many other avoidable problems. By learning more about what you are facing, you CAN make a big difference in the last chapter of someone's life.

Building Your Team

You need a team. This disease will cause more devastation and likely affect your health too, if you face it alone. Your support network of family, friends, and neighbors are important members of your team.

If you have “managed” mostly alone up until now, please wait no longer to ask others for help. They may provide companionship, respite care, and help with something around the house, a meal, or just a needed hug.

A caring physician, who understands the challenges of Alzheimer’s disease, is a valued member of your team. But not everyone is working with this kind of physician, so it is best to consider the issue now, so if a change is desired you can work on options right away. Often a community has one or two physicians who are skilled in end of life care or hospice.

In the advanced stage of Alzheimer’s or other dementias, healthcare workers who know how to treat common symptoms at the end of life are the most helpful.

Getting more information about what services are available in your community is a good idea. A local Area Agency on Aging will have information on resources like respite care, home nursing services, and volunteer help. The local chapter of the Alzheimer’s Association also has many resources to offer, such as support groups, care management, educational materials, and referral services to healthcare agencies.

Hospice care may be helpful as well. Every Medicare enrollee and many people with private insurance have the option to ask for the hospice benefit. Unfortunately, many people with Alzheimer’s do not use hospice care. There are many reasons for

this, but the difficulty predicting how long someone will live with advanced Alzheimer's is the most common barrier.

Hospice care is targeted to the last 6-9 months of life because the specialized care and treatments are the best suited for this time period.

Alzheimer's disease is a terminal illness. It often takes a long time, but eventually the nervous system is damaged so that in the advanced stage a person exhibits many of the symptoms below:

- Difficulty speaking or inability to talk
- Abnormal swallowing, occasional coughing/choking with difficulty chewing appropriately
- Inability to walk alone — or bed bound
- Unstable posture — cannot sit up straight
- Incontinence
- Increased number of infections
- Weight loss
- Severe tremors — Seizures

If your loved one has many of these features and if you “wouldn't be surprised” if they died in the next year, then discussing the possibility and availability of hospice care would be a good idea. Remember, you are never obligated to enroll in a hospice program. You should, however, meet with them and discuss their program to see if what they offer would help you and the person you care for.

Developing Your Game Plan

To meet this “challenge,” it will take advance planning in order to “finish strong.” You need to form a strategy that considers how you will respond to various challenges that might lie ahead. Consider these issues to form your own “game plan.”

- **Legal Issues:** Do you have legal authority to make healthcare and financial decisions for the person you care for? Consulting a lawyer may be helpful to make sure you have a durable power of attorney for healthcare, a durable financial power of attorney, or other legal authority that allows you to make decisions..

- **Difficult Decisions:** It is important to get as much medical information as possible about the person you are caring for and their wishes, so that you can thoughtfully prepare for likely healthcare decisions.

It is very appropriate for anyone with severe Alzheimer’s disease to have a healthcare plan that is palliative — that is focused on the person’s comfort and quality of life rather than on the length of their life. This palliative approach is consistent with what most of us would want if we were nearing the end of our lives. A “Do Not Resuscitate” order would be part of this approach, but it is not enough to ensure a constant focus on comfort. You will also need to consider if you will choose to allow medical treatments that might prolong life,

but may cause discomfort. These things might include surgery for a broken bone, medications, intravenous liquids, or even antibiotics.

- **Living situation:** Consider what happens if this phase of life goes on for a few months or a couple of years. What will happen if something prevents you from being a caregiver? Is there a Plan B? Have you considered paid caregivers or long term care facilities? What are your options given your financial resources? It is far better to consider these issues now, rather than in an urgent situation.

- **Caregiver issues:** Too many caregivers exhaust themselves completely in this difficult job and suffer physical and emotional illness in the process. Your game plan must consider yourself. How will you get needed breaks? Do you have options for getting “respite help” with caregiving through your church or temple, social club, friends or family?

The Huddle

A meeting of family, friends, your support network and any healthcare professionals working with you can be a valuable experience. This would be a good time to discuss a caregiving schedule, your “game plan” for unexpected illness or hospitalization, advance directives, and other issues so that all team members are in agreement. If there are differences in

opinion among your team it is better to work to a compromise now, rather than when it is more stressful.

Offense

Many things suggested so far could be considered your offense. Let's review them and add a few more "plays" to your game plan.

- **Make sure you have advance directives completed.** This includes additional wishes about hospitalization, tube feeding, intravenous hydration, and antibiotics.

- **Good communication with all your team members is the best offense.** If your desire to always prioritize comfort and quality of life for the person with advanced dementia is well understood by all those involved, then the chances of inadequate or unwanted care will be less.

- **Consider involving your local hospice agency.** Hospice programs focus on avoiding pain and other damaging symptoms. They are valuable team members.

- **Emergency planning is important.** You should know how you are going to respond to a medical emergency. Talking with the physician now can help you in this area. He or she may agree to prescribe a small amount of sedative or pain medication that you would use in "an emergency" situation to avoid the need for a potential hospitalization. You do not want to be caught in a

situation where you feel unable to provide comfort to the person you are caring for.

It is commendable to try to prevent unwanted hospitalization for a terminally ill person, but you must be prepared to manage common symptoms at home (agitation, pain, shortness of breath, etc.).

Defense

Just as you would protect a child, you may be called upon to “defend” or protect a person with severe Alzheimer’s disease because they can no longer speak up for themselves effectively.

Watch for pain. It can be hard to determine if a person with dementia is having pain because they cannot answer direct questions. Pain may look like agitation, anxiety, restlessness or moaning. Attempts should be made to help make the person more comfortable, and a trial of a pain medicine is a very useful tool.

Treat other symptoms that occur at the end of life. Ask for help with ideas to prevent or treat dry mouth, skin breakdown, agitation, excess secretions (gurgling), or falling. Your physician or hospice agency will help with ideas for these symptoms or others you might encounter.

Defend against isolation and loneliness. This should apply to both the person with dementia and you, the caregiver. Even when Alzheimer’s has robbed a person of most of their intelligence and ability to speak, they

still can appreciate human caring. Try to hold hands, sing, talk, and interact with your loved one — even when you are not sure if they can sense your presence. Your love and caring is a powerful weapon in your battle against Alzheimer’s disease.

Preserve dignity in HOW you provide care. Alzheimer’s cannot rob someone of their inherent dignity. They are still a unique human being that deserves love, care, and respect. If you as a caregiver treat them with compassion, then your actions defend against the loss of dignity.

Special Teams

Once in a while, you may need help from “special teams” — people who are specially trained to help with end of life care or advanced dementia. Feel free to contact the following agencies if you need additional help or advice:

- Area Agencies on Aging
1-877-353-3771
- Maine Alzheimer’s Project
(207) 287-9214
- Maine Alzheimer’s Association
1-800-660-2871
- Maine Hospice Council
1-800-438-5963
- The Maine Office of Elder Services,
Department of Human Services
1-800-262-2232
- Administration on Aging
www.aoa.gov

Post-Game Wrap Up

After the death of the person you are caring for, it is important to realize that you will still need your support team. Grief and bereavement services are available through your local hospice agencies as well. Remember that it is normal and very common to feel a sense of both loss and relief after someone who you cared for dies. These seemingly conflicting emotions are actually very rational and reasonable responses to a long battle with a devastating disease.

Keep thinking, talking, sharing and reaching out to others. You have done something incredibly powerful in your work as a caregiver.

Be proud of your role as you helped with the “long goodbye.”

