



# Planning Now for Life Ahead

**A Guide for Alzheimer's  
and Dementia Caregivers**

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# INTRODUCTION

**L**iving with dementia – either as patient or caregiver – need not be a sorrowful journey. Even as memory recedes, patients can take pleasure in the here and now, and in the memories they retain. Caregivers can find deep satisfaction in helping loved ones navigate difficult challenges affecting how they live with dementia, and how they are cared for at the end of their lives.

But much depends on how well patients and family members prepare. Just as it is important not to ignore escalating symptoms in the hope that they will go away, it is vital to become informed about what lies ahead and to make plans that will ensure the best quality of life at all stages of the journey.

This planning guide will help you identify and work through some of the important choices you will face. It provides information that will help all concerned contribute to sound, practical decisions that will enable life to be lived to its fullest. Although most of the information and advice in these pages is intended for caregivers, if you have been recently diagnosed with Alzheimer's disease or dementia, you will find this guide helpful, too.

Simply put, the decisions you make – or fail to make – will have a profound effect on your quality of life. This planning guide can help you with:

- Conversations you will need to have with family, friends, medical professionals, lawyers and financial planners;
- Decisions that need to be made about medical and other care;
- Celebrating life along the way;
- Practical, hands-on, real-world advice about caring for patients and for caregivers;
- Medical information about dementia, how it progresses and what to expect; and
- Finding meaning in life, even as dementia progresses.

This booklet is not an exhaustive guide to the details of living day-to-day with dementia. Several excellent resources providing such information are available, and many are listed in the Resources Section in Appendix One of this guide. This guidebook does something different. It encourages you to step back, identify, make and live with the decisions that need to be made, so that the journey ahead can begin and end with as much dignity, love and meaning as possible.

Family members will find practical caregiving advice for later in the journey, advice that will make it possible to follow through on your loved one's expressed wishes for care, and help find the support you need in that effort. You might also want to share it with your family and close friends, even if they

are not principal caregivers. They may find it helpful to know what you, your loved one and other caregivers are experiencing.

By planning ahead while you can, you will find that you have much more control than you might expect over the type and quality of care that your loved one will receive, and that you will be able to do a lot to keep important, cherished memories alive.

As you read, and as you travel the path ahead, remember that *you are not alone*. Many others have faced and are facing similar issues, and you can put their experience to work to help you.

In the Appendices you will also find a checklist of questions you need to answer, decisions you need to make and things you need to do.

### **The Gift of Planning Ahead**

By planning ahead, patients with dementia and their caregivers have an opportunity to give each other and their family a long-lasting and meaningful gift.

That planning should include:

- Taking the time to learn about what may lie ahead;
- Designating in advance who should manage affairs when the time comes;
- Defining and talking with your loved one about priorities; and
- Getting financial and legal affairs in order sooner rather than later.

By making these decisions in advance, you can spare both you and your loved ones much anxiety and difficulty later. Doing so is a powerful gift to those you love. If you are caring for someone with dementia, it is important to encourage these activities as early as possible. And if you are the patient, it is important not to put off such decisions.

# Planning Ahead: Conversations You'll Want to Have

**F**or patients and family, the realization that some form of dementia may be at work can be frightening, and the subsequent diagnosis can be even more so. Once the diagnosis is made, everyone involved is likely to feel upset and overwhelmed.

But it is important not to allow that fear to shut down the lines of communication. In fact, it is exactly at that point in the progression of the dementia that communication is most vital. During this early stage of the illness, everyone will benefit from careful discussions about what is happening and what the future may hold. It is important, therefore, to make sure you discuss:

- Seeking help;
- Coming to terms with the diagnosis;
- Coping with ongoing lifestyle changes;
- Planning for the future;
- Making prudent financial and legal arrangements; and
- Developing a philosophy to guide health care decisions.

You should begin these conversations as soon as possible, and involve the person with dementia, family members and key caregivers, doctors and possibly geriatric care managers and other professionals who can help guide your family toward thoughtful and well considered choices.

These will be tough conversations. The subjects are difficult to think about, much less discuss. But not discussing them can be much worse.

Often, the biggest barrier to communication is starting the conversation. The pages that follow describe some conversations you will likely need to have, and offer advice on how to get them started and how to ensure their success.

## Conversations within the Family

It's important that the person with dementia, together with the people he or she thinks of as close family members – a spouse or significant other, perhaps adult children, brothers and sisters, and others – discuss a number of topics openly and honestly.

### Talking about Memory Loss and Diagnosis

Often a person with memory impairment will raise the subject of their memory loss with those who are very close. Typically the patient is aware that something is wrong, and is frightened that it might signal a serious medical issue. Your loved one may say something like,

#### Caregiving Tip

When a loved one raises concerns about memory problems, it's important to convey that you take the problem seriously. An attitude that says, in effect, "Your concerns are important to me and I take them seriously. We can face this together," will be most helpful.

### Caregiving Tip

Many patients are relieved to know that it is not their fault that they are having trouble with the way their minds work, that they are not going crazy, and that the problem is the result of a physical condition, a disease of the brain.

*“My brain just isn’t working like it used to.”  
“I seem to be forgetting everything these days.”*

Family members should respond honestly and thoughtfully:

*“I have noticed that, too. Have you been experiencing more stress than usual, or do you think it is something else? Would you like to see a doctor about your memory problems?”*

Those close to the patient should avoid false reassurance, denying that there is a problem, or minimizing its significance. Such responses may suggest to the person with memory problems that they should not have raised the subject. That kind of discouraging signal may cause them to feel isolated and even more depressed about the problem. That’s why, as family members, you need to listen to your loved one’s concerns, and offer support in a matter-of-fact and respectful fashion. That will be much more reassuring.

Sometimes a person with memory loss will resist seeing the doctor, often out of fear of getting bad news. There may also be damage to the area of the brain that controls insight and reasoning. Here, family members should be clear and direct: It is in your loved one’s best interest to have a medical evaluation as early as possible, for several reasons:

- The symptoms could be caused by something treatable and reversible;
- If the diagnosis is, in fact, Alzheimer’s disease or another dementia, medications might be helpful in the earlier stages of the disease; and
- The earlier the diagnosis is made, the more your loved one will be able to participate in the planning necessary to ensure the best care and to arrange for meeting the needs of the family.

If your loved one’s reluctance becomes resistance in seeking medical advice, you might encourage him or her to visit the physician for another reason and then alert the doctor ahead of time that you have concerns about a memory loss problem that might need closer evaluation. This gives the medical team information to work with, and allows the doctor to take the lead in recommending further medical tests that may be necessary.

Once the diagnosis is made, the person with dementia has a moral and legal right to know his or her condition. That’s the only way that your loved one can participate in making vital care decisions, signing legal documents, taking care of personal business and planning for the future in a variety of ways while still able to do so.

Ideally, the doctor will share the diagnosis directly with the person who has dementia. However, it may be necessary for family members to repeat the conversation or to convey the information over time in small amounts so that the patient can absorb it, without being overwhelmed by the news.

When discussing the diagnosis, find a quiet place to talk, and provide information in a way that can be easily understood and at a pace that your loved one can handle. The news may have to be given in bite-size bits over a series of conversations. It is important not to overwhelm your loved one. The prospect of increasing disability that the diagnosis brings is a lot for anyone to handle.

If you are a family member disclosing the diagnosis to a person with dementia, you might begin by saying:



*“I know you have been worried lately about your memory. The doctor has confirmed that you have a brain disease that causes you to have memory loss. This is not your fault. This is a physical disease. I want you to know that throughout this disease we will deal with it together.”*

Of course, because memory loss is a significant aspect of the disease, you may have to reassure your loved one frequently. He or she may have many questions about the disease’s progression. Answer questions honestly and directly, while making sure not to overwhelm him or her with too much detail.

This is a very long road and things may happen that you never expected or planned. So, in breaking the news, never make promises you cannot keep:

- Do not promise that your loved one will remain in his or her own home throughout the course of the disease;
- Do not promise that you will be the sole caregiver; and
- Do not promise that everything will be perfect.

Some important issues for patient and family to talk about at this time include:

- How much and when should information be shared with others about the diagnosis?
- How much information does your loved one want concerning the disease?
- What are your loved one’s initial thoughts and opinions about the future at this time?
- What does your loved one want or need now?
- What are your loved one’s most pressing fears or concerns?

### **Making Decisions about Legal and Financial Issues**

Early on in the course of the disease, it is important to begin a series of conversations about legal and financial matters. These conversations do not have to follow the diagnosis immediately, unless the person with dementia initiates them, but it is important that they happen while the person is still able to make decisions and sign legal documents.

These conversations should touch upon a number of topics, including legal issues covered in a will or estate plan and financial issues. As a caregiving family member you, perhaps with other family members, should learn about and understand the financial resources available that could be used for care, and you should make sure that a will is in place, up-to-date and appropriate for the circumstances.

You might start out by saying:

*“It’s important that we prepare for both of our futures by going over our finances, making sure that our estate plans are up-to-date and filling out any paperwork we need for the people we want to be involved in making decisions for us when we aren’t able to do so . I’m going to set a time for us to meet with an attorney (or sit down together) to go through it all.”*

Or you could begin this way:

### **Caregiving Tip**

In many parts of the country, you will be able to find support groups for people with early dementia. These groups can help the patient cope by interacting with others facing the same condition. You can also find books written by people with Alzheimer’s disease through the local chapter of the Alzheimer’s Association, in local bookstores or online. You may want to have such material available and leave it around the house where your loved one can read it when he or she feels up to it.

*“This seems like a good time to make sure all of your affairs are in order so you can have peace of mind later. Let’s make sure you have a will that’s up-to-date and says what you want it to. Let’s review the finances to make sure that everything is in order so that when needs arise, we understand how to manage them.”*

### **Caregiving Tip**

The patient should designate a “health care agent,” a loved one empowered to make health care decisions once the patient is no longer able to make such decisions. A health care agent named in an advance directive will have more authority over decisions than a family member who becomes a health care agent by virtue of being the next of kin.

Your loved one will be able to make simpler decisions – deciding who should be entrusted with the financial or health care power of attorney, for example – far longer than he or she will be able to make more complicated decisions involving financial transactions, bill-paying, or choosing among medical treatment options. For that reason, even if your loved one is no longer able to manage his or her affairs on a daily basis, he or she may be able to designate the person to do so, and then to execute the needed documents.

The American Bar Association Commission on Law and Aging has published an excellent guide, *Health & Financial Decisions, Legal Tools for Preserving Your Personal Autonomy*, appropriate for many circumstances. The guide is available online at [www.abanet.org/aging/publications/home.html](http://www.abanet.org/aging/publications/home.html). And the Alzheimer’s Association’s useful publication, *Money Matters*, is available at their website, [www.alz.org](http://www.alz.org). It may also be helpful to contact your local government’s agency on aging to find out about available services. Be sure to review the Resources section in Appendix One of this guide for more information on legal and financial topics.

### **Discussing Future Care**

It is very important to discuss who your loved one wants to designate to be his or her “health care agent” – the person empowered to make health care decisions once your loved one is no longer able to make them. This may be a difficult conversation, and it might cause some distress in the family. However, it is far better to have the conversation and know who is responsible for what, than to arrive at important decision points down the road and argue about whom should decide (see Appendix Four for a sample form for designating a health care agent).

Discussing issues surrounding future care will probably require several open and tactful conversations. These conversations might begin with questions such as these:

*We have talked about the fact that as time goes by it will become harder for you to think clearly and remain as independent as you are now. Could we talk about that?*

*When you think about a time when you need more help, what kind of living situation do you think would be best for you?*

*What do you wish for?*

*What would you hope to avoid?*

If you are a caregiver or close family member, it is important to use language that respects the fact that your loved one, despite difficulty with brain function, is still very much a person. He or she may feel embarrassed and depressed, and is likely to be easily hurt. Nevertheless, it should be possible to talk about the future and be candid about the losses that have already occurred and those that

lie ahead, without using words that are discouraging or judgmental. Try to use language that respects your loved one's character and ability to cope with challenges. And, as always, let him or her know that you will continue to give your support and care, and that you will value him or her as a person even as the disease progresses.

### **Developing a Personal Philosophy to Guide Care**

A diagnosis of Alzheimer's disease or dementia-related illness brings other issues into focus. Planning for future health care decisions is more complex than just thinking about the way dementia progresses. Most people with dementia are old enough to have other chronic medical conditions, and to be at risk of other physical problems, especially as time passes.

If you are a caregiver or family member involved in conversations with a loved one who has dementia, you should encourage him or her to address a number of issues that will help clarify your loved one's values and priorities on the subject. Because it is impossible to predict and plan for every medical possibility that might develop in the future, it is best to think in more general terms about the overall goals of care at the outset. The results should be written down in an important legal document called an "advance directive for health care". (See Resources section in Appendix One for more information)

You may find it easier for your loved one to talk about his or her goals of care if you are willing to talk about yours. You might start the conversation with a simple sentence like this:

*I want to do (or update) my advance directive for health care and I want to talk it over with you.*

First, you and your loved one should think about **the aspects of life that matter most**, those things that define the quality of a life worth living. Think and talk about what things your loved one could stand to lose and still feel that life would have meaning. Of course, all of us have difficulty contemplating any such major losses. Few would welcome having to move from our homes to residential facilities, for example. None of us would choose to have declining abilities. But most of us, if we live long enough, may have to face such issues with or without the diagnosis of dementia. If we think carefully about which changes we could accept and the circumstances under which we might be able to accept them, we can begin to discover what our highest priorities really are. Our ideas might change as time goes on and we learn to live with losses we thought we would not be able to tolerate. So, **these issues should be revisited from time to time as long as your loved one is able to do so**. What kinds of things might you think about in this way?

Here are some examples:

- The ability to comprehend conversation or entertainment such as television or a movie;
- Independent mobility;
- The ability to eat and drink without help or artificial means;
- The ability to perform personal tasks without assistance;
- Freedom from pain;

- The ability to interact with others;
- Full function of arms and legs;
- Living separately from family and friends;
- Privacy;
- The ability to recognize friends and family; and
- The ability to communicate.

Your loved one might decide that if a potentially life-threatening condition develops after dementia has reached a certain point, he or she would prefer to be made comfortable rather than receive aggressive treatment aimed at extending life - or perhaps not. Whatever your loved one's view, it is important to discuss, and then write down, the losses that would tip the balance. Doing so will make it far easier for those entrusted to make decisions on the patient's behalf when the time comes, if he or she is no longer able to make them.

Another useful thing to think about is the **setting and circumstances your loved one would like to have in place during his or her last days**. What would a "good death" look like? That may not be easy to think or talk about, but doing so may be very helpful in making decisions about care later on. Some people might want to avoid aggressive and potentially life-prolonging care even before they reach a quality of life they feel is unacceptable. Some might want to wait until they reach that point before choosing comfort care over aggressive care. And some will choose aggressive care no matter what the quality of life is like during this time. Or, your loved one might prefer to remain at home in the presence of familiar people and things, instead of taking a chance on aggressive treatment in a hospital, surrounded by unfamiliar people in a setting that might stir up confusion and fear. This would be particularly true if the quality of life at that time was below what he or she had already decided was acceptable. Please note that these are important conversations for everyone to have with loved ones, even individuals in perfect health.

You may want to refer to a later section in this book: *When the Time Comes: Facing Tough Decisions about Medical Care*, on page 33.

It is important to talk now and consider the advantages of letting go and allowing a natural death when the time comes. As dementia advances, the opportunity to have these conversations will diminish. Please don't wait if you have the chance to talk about it now.

It is also helpful to consider **the way your loved one would like to be remembered after his or her death**. What does your loved one want family and friends to think of when they remember him or her? This may be a hard thing to think about, but you and your loved one may find it matters a great deal to you both.

Finally, it may be helpful to talk about the **cost of care**, the financial resources available and the needs of the family members who will survive the person with dementia. No one likes to think they will pose a financial burden on those they love, but in most families, resources are limited. All of us make decisions every day about what we can afford and what we cannot. Long-term care and day-to-day medical care, even with Medicare, Medicaid or other insurance, can be very costly. Half of personal bankruptcies are due to health care costs. So, awkward though it may seem, a frank conversation about how costs should be considered

in making decisions about care in the unknowable future can be a tremendous help to you and others who may be faced with some difficult choices down the road. It can be very hard to make decisions to limit aggressive care even if it is the wish of the person with dementia, and even if such costly care would seriously jeopardize the well-being of other family members. But if there has been open discussion in advance and the person with dementia has made it clear that he or she would not want to undergo aggressive care that poses a financial burden on the family, such decisions can be made more easily when the time comes. This is true for anyone, not only a person facing terminal disease.

The discussions about all of these issues will help you determine your loved one's **personal philosophy to guide care**. From there, you can move ahead to create an advance directive that reflects your loved one's views. Of course, it may be necessary to use simple language and limit the scope of the directive; perhaps just to the selection of a health care agent (sometimes called a health care proxy or medical power of attorney). Even if your loved one with dementia does not still have enough mental ability to formulate a philosophy of care, he or she may be able to:

- Choose a health care agent;
- Express simple preferences; or
- Choose among options that are presented to him or her.

The Coda Alliance, a California organization dedicated to optimizing end-of-life care, has developed a helpful tool for this, described in the Resources section in Appendix One of this guide.

The advance directive itself may require simple language and it may be most appropriate to limit it to the selection of a health care agent. Please understand that the conversations within the family that will guide the health care agent in making decisions are very important. They should take place as soon as possible. If you and other family members can agree on the overall goals of care for your loved one, it will help avoid family conflict and hurt feelings in the future. It may be helpful to write the goals down and add them to the advance directive in the form of a "statement of values." If the advance directive form you are using does not allow space for such a statement, you can add a page at the end and refer to it in the actual directive.

If you're not sure how to proceed, consult the Resources section in Appendix One of this guide for more information about tools to help you carry on the conversations you should have, and for advance directive forms. It is not necessary to use a lawyer to create an advance directive. You can use one of many available forms that you can find here, as long as it is appropriate for your state. There are some forms that are recognized in many states. Because some states require their own forms, however, or have specific requirements, you should make sure that the one you use is appropriate for the state(s) in which you live and receive care. If you need help, you may find resources within the legal community through the senior services or legal help organizations listed in Appendix One. Your doctor may also be able to help.

### **If It's Too Late For Your Loved One to Join the Discussion**

Depending on the progression of the dementia and the timing of the conversations, it may not be possible for your loved one to play a large role in these

conversations. In that case, it will also be impossible for your loved one to execute an advance directive for health care. How then can you, as caregiving family members, make such decisions?

First, keep in mind that even after a person develops dementia, the ability to think about and discuss things will vary from one day to the next. Your loved one may be able to participate to some extent, even if not fully, in these conversations. Try to involve your loved one as much as possible, being careful always to avoid speaking as if he or she weren't there. Doing so only plays into your loved one's fears about losing control. Be sensitive to his or her feelings.

That said, if your loved one cannot address these issues now because of the dementia, you should take the time to reconstruct to the extent possible any past conversations you or others may have had with your loved one that might reveal his or her thoughts and attitudes. You may find it helpful to consult with other family members or close friends to pool your memories of relevant past conversations. This will also allow you to develop a consensus among those who care most about the person with dementia about how to make care decisions as the condition progresses.

Based on these conversations, try to identify your loved one's values and priorities, and commit them to writing, developing a personal philosophy to guide care that reflects your loved one's values. This will make it easier to be confident about hard choices about care when the time comes, particularly in the absence of an advance directive.

### Conversations with Extended Family and Friends

When and how to tell extended family members and friends about the diagnosis is an important issue to discuss in advance. Close members of the family should be careful to respect the wishes of the person with dementia unless there is an important reason to override them (with great care, of course). The issue may come up when the family gathers during the holiday or vacation season. At that time, family or friends who have not seen your loved one in a while may notice significant changes in behavior. You might even consider sending a letter in advance to help explain the illness. If you do so, the best way to compose the letter would be with the input and approval of your loved one.

It is normal for a person who is in the early stage of dementia to feel self-conscious and sensitive about telling people about the illness. That is why it must be done with great tact. Remember that even though a person has been diagnosed with dementia, he or she still has many mental faculties and emotions, and is likely to be sensitive about being labeled or treated differently by family and friends. It is vital that you treat your loved one with respect and dignity now, and throughout the course of the illness.

### Asking for Help

Once you've let family members and close friends know about your loved one's illness, you should also tell them what they can do to help, and ask for their support in what is and will continue to be, a challenging role. You will want to educate them about dementia. A range of literature on the topic is available from such sources as the Alzheimer's Association, the Alzheimer's Foundation of America, the National Institute on Aging and the Family Caregiver

#### Caregiving Tip

Some key points to make in discussing the disease with friends and family:

- Dementia is a progressive brain disease that is not the person's fault,
- The patient will need a lot of support and attention but is also sensitive, and
- The patient should be encouraged to continue to do as much as he or she can manage unassisted.

Alliance, as well as others listed in the Resource section at the end of this guide. Several of these organizations also provide free educational programs for families, in addition to support groups for caregivers.

At the same time, it would be helpful for the immediate family to determine *who* will be responsible for *which* aspects of the caregiving. Usually there is one primary caregiver, but other family members can be very helpful in providing care and assistance. For example:

- A brother or sister who lives far away and is good at managing money can take over bill-paying;
- Another family member can handle finding and managing home health care, calling about free or low cost help available through the local area agency on aging or researching local residential facilities; and
- A family member with some free time during the day might drive the loved one to medical appointments and pick up medication.

Some families share the burden of caregiving by moving a parent to a different family home every three or four months for care. That approach is not recommended. While it can provide a break to family members providing care, it is not good for the diagnosed person. Moving around can make your loved one more confused, agitated and anxious.

Occasionally, family members have a hard time accepting the diagnosis. They may reject it, or blame the condition on others. There may also be disagreements about medical treatment and care. Each person handles difficult news in their own way and on their own timeline. News of this sort about a parent or spouse is difficult to hear and accept. In cases of significant disagreement among family members, it may be helpful to call in a third person. Your local agency on aging may have social workers who can help, or a geriatric care manager or other consultant could be hired to work with the family, make care recommendations and provide education on what to expect as the disease progresses. Please call IONA Senior Services for more information on how we can help and see the Resources section in Appendix One.

Alzheimer's disease and related dementias can take a severe toll on caregivers. When others are able to help, they not only give the primary caregiver a much needed break, they come to understand and appreciate the enormous load of caregiving. Often, friends and family want to help but have no idea what to do. You can make a list of tasks to suggest to those who ask how they can help. Some caregivers even hold meetings to talk about how everyone can help and to teach family and friends how best to talk to and be with their loved one.

The conversation at such a meeting might include:

*"I am so appreciative that you are willing to lend your support in this long journey with my father's dementia. Many of you have asked how you can help. In the past, I could handle this on my own, but it has now become clear that I do need your help. Thank you so much for offering. I have a list of things that would help me tremendously in caring for Dad. I would also like to use this time to help you better understand how to communicate and interact effectively with Dad:*

*"When you speak with him, be sure to make eye contact first.*

*“Talk slowly and clearly so that he fully understands and can participate in the conversation.*

*When you are out with Dad, he might feel more secure if you hold his arm and guide him.*

*Dad really enjoys ice cream, and loves to go for a drive in the car. As you well know, he has been a woodworker all his life, and enjoys talking about his handiwork.”*

The list of ways to help might include:

- A walk with Dad every Tuesday;
- Preparing a meal once a week;
- An outing for a cup of coffee with Dad every other Wednesday;
- Help with the grocery shopping;
- Sitting with Dad on Friday afternoons while I go to my book club;
- Driving Dad to the adult day health center once a week;
- Taking Dad golfing once a month;
- Helping with repairs around the house;
- Cutting the grass;
- Helping with upkeep of the car; and
- Attending Dad’s medical appointments with me or staying with Dad while I go to my appointments.

### **Dealing with Concerns about Privacy**

In some cases, people with this diagnosis feel so upset and self-conscious that they do not want anyone to know about it. Or they may simply reject the diagnosis entirely, which might also be due to impaired judgment caused by the dementia. While it is not the ideal situation, the individual cannot be required to admit or talk about his illness. In such cases, as much privacy should be maintained as possible. The person should be treated with dignity and respect, and encouraged to feel accepted and valued. Eventually, of course, others will have to be told of the diagnosis. Close family (children, siblings) and colleagues will wonder about changes they have seen. Neighbors may notice unusual behavior and come to their own conclusions. Do not be reluctant to plan for care, even if your loved one does not see a need to do so. It is important that the spouse or an adult child not carry the enormous load of caregiving entirely alone.

### **Conversations with the Doctor**

When visiting the doctor, it is important to allow your loved one to express any concerns and ask any questions that he or she may have. However, you or another close family member should also be there to share information about your loved one’s behavior, to describe any medical issues with the doctor, to support your loved one and to hear, understand and remember what the doctor says.

### **Preparing in Advance**

For a variety of reasons, it can be difficult to get your doctor to spend as much time as you’d like on your medical visits. That may be one of several criteria you



consider when choosing a doctor, of course. But you should also make the most efficient use of whatever time your doctor gives you. That requires preparation before your appointments. Here are some tips:

- Working with your loved one, make a list of questions and concerns that need to be discussed.
- Make a complete list of all medications, including nonprescription drugs and supplements that your loved one is taking. Take the list and the medicine bottles themselves with you to each visit with the doctor to make certain there is no confusion about them.

Doing this for each visit will give you an opportunity to regularly review all medications, make certain that the doses and the way they are being taken match your physician's latest instructions. Write down any questions or observations you may have about them. Regularly reviewing the purpose and side effects of each medication will also serve as a reminder during your visit to discuss any questions about which ones remain appropriate as the dementia progresses and the goals of treatment evolve.

You should be realistic about how much time the doctor has to meet with you. Prioritize your full list of concerns and questions so that you can be sure to cover the most important at each visit. Bring them all up at the beginning of the session and come to an agreement with the doctor on an agenda for that visit, and on topics that may have to be postponed until another time.

As time goes on, you and the doctor(s) will need to work together to develop approaches to care that maximize quality of life. For instance, early on, patient and family may decide that quality of life in the present is more important than the possibility of prolonging life in the future. In such circumstances, careful attention to the goals of treatment may lead a patient or, on the patient's behalf, the health care agent to discontinue certain medications and tests because their quality-of-life side effects and risks outweigh the potential benefits. That is one of many reasons why it is important to have honest and clear discussions with your loved one in advance, and to decide on and write down the goals and priorities that will guide future decisions.

If there is information that the doctor needs but that might be embarrassing to relay in front of your loved one, put it in writing and make sure the doctor has the information before the appointment. Being placed in an embarrassing position could damage the trust your loved one has in the doctor, making him or her feel unsafe and reluctant to return to the doctor's office.

### **Creating a Partnership**

It is important to have a doctor with whom you can develop a working partnership. So, in choosing a doctor, ask these questions:

- Is the doctor willing to listen carefully?
- Is the doctor open to the opinions and preferences of patient and family?
- Does the doctor share information fully and honestly?
  
- Is the doctor willing to honor the goals for care and the priorities of patient and family?
- Does the doctor take a thoughtful approach to problem-solving?

### Caregiving Tip

Keep a notebook or diary of your physician visits, questions and answers and medications that you bring on your visits.

A good doctor will recognize the expertise and experience of the patient and the family, and realize that the way a patient appears in the doctor's office is merely one snapshot from an ongoing story – a story that is much more familiar to you and your family than to the doctor. The doctor should therefore affirmatively seek your input as well as your loved one's, and attempt to make all decisions with you and your loved one as part of a team, and in a way that is consistent with your and your loved one's wishes.

Remember that while doctors have expertise and experience in their respective fields of study, you and your loved one are the experts about the day-to-day realities of dementia and how it affects your lives. However, when a situation develops that requires giving up an activity or making a major lifestyle change, it may be helpful to enlist the doctor as the ultimate medical authority. For example, while there are no laws specifically requiring a person with dementia to discontinue driving, it is necessary to do so when it becomes a safety issue. That transition is often very difficult for all concerned, and it can be hard on the family to persuade their loved one with dementia of its necessity. In such cases, the doctor can insist that driving is no longer possible. It may be helpful for the doctor to write a prescription stating that driving is forbidden. The authority of the family doctor may also be helpful when referral to a specialist, or a move to residential care, is necessary.

### Topics for Discussion

Here are 12 questions you might want to ask in your initial visits with the doctor:

1. What is the specific diagnosis? What type of dementia is this?
2. Are any other tests recommended? Should we see a specialist?
3. What should we expect as the disease progresses?
4. How often should we visit the doctor?
5. What are all the available treatment options?
6. What is the expected effect of each medication, in terms of memory, behavior and other symptoms?
7. What are the side effects, dosage, possible drug interactions, and pros and cons of each medication?
8. Do you have any recommendations in terms of diet, vitamins, physical exercise and mental stimulation? Are these things effective in delaying the progression of symptoms?
9. Are there any clinical drug trials that would be appropriate to participate in? What are the risks and benefits?
10. What advice can you provide regarding care?
11. Do you have information about community resources, such as support groups, educational workshops and services for my family?
12. Will you be speaking with my loved one's other doctors?

Be sure to have conversations with the doctor about the goals of care that you have established in family discussions, and be sure that those discussions come well in advance of the need to make specific treatment decisions. If you find that the doctor you are working with is not comfortable with your loved one's

desired goals of care, look for one who is. Doctors are individuals also, and some of them have deeply held personal or religious beliefs that may conflict with their patient's philosophy.

As the dementia and/or other medical conditions progress, it will be easier to address specific decisions about treatment if you have taken the time to write down overall care goals, as described earlier. As the medical situation changes, or when a significant transition of any sort occurs, the overall goals of care and the specific care plans or treatment decisions should be reviewed and discussed anew.

## Navigating Health Care

### Medical Conditions

The medical system can be frustrating, confusing, even enraging. Doctors and other health care professionals have many demands on their time, and are often unable to spend as much time as they would like with each of their patients. As caregiver, you can help navigate the medical system by doing two things: First, learn as much as possible about your loved one's medical conditions. That should include:

- Making yourself familiar with the history of your loved one's dementia and any other conditions that are present;
- Learning about the benefits and side effects of medications, and the limitations of current treatments;
- Learning how to interpret behavioral changes and how to cope with difficult behavior; and
- Learning how to maintain, to the greatest extent possible, the privacy, dignity and integrity of your loved one.

Being knowledgeable will allow you to advocate effectively and make certain that those who provide care are aware of any physical and emotional needs, and how best to interact with your loved one. You can learn about dementia by reading this guide and the many other excellent publications on Alzheimer's disease and dementia. And you can go to educational programs and support groups for caregivers and use the many resources available through organizations such as IONA Senior Services and the Alzheimer's Association.

### Medical Records

The second thing you can do to help get the most value out of medical visits is to keep a well organized notebook or file with your loved one's medical history, current medical information and goals for care that is always made available to doctors and other health care professionals.

Anyone who has experienced health care in recent years realizes that it has become increasingly fragmented. Communication between doctors and patients and even among doctors is often rushed. As doctors' roles become more specialized, a patient who is hospitalized or moves to an assisted living or nursing home facility is likely to have his or her care turned over to doctors unfamiliar with the medical history.

Maintain up to date records, for your own purposes so that you are able to provide complete information to doctors who might be providing care in an

### Caregiving Tip

It will be easier to navigate sometimes confusing and frustrating medical systems if you do two things. First, learn as much as possible about the diagnosed medical conditions.

Second, take responsibility for making certain that the medical history, current medical information and goals for care are always made available to the doctors and other health care professionals caring for your loved one.

emergency room, hospital or residential setting. At the same time, as dementia progresses, your loved one will be decreasingly able to provide information about medical problems and history. Having a complete record may help avoid redundant, costly, and upsetting procedures ordered by doctors who don't know your loved one's medical history.

A complete and well-organized medical history will also free up the doctor's time to discuss current concerns, the overall goals of care, and planning for the future. Take an updated copy with you anytime you meet with a medical professional or your loved one goes to the hospital or a residential facility.

What should the medical record include?

- Details about the dementia and any other ongoing medical problems;
- A section for each problem that includes the onset of symptoms, dates and places for any tests, and conclusions and recommendations from doctors;
- Information about treatments and responses to treatments, as well as information on how your loved one is doing now;
- A complete list of medications (prescription as well as nonprescription and supplements), and allergies or reactions to drugs used in the past;
- A summary of past illnesses, surgeries and hospitalizations;
- Important family medical history, including information on smoking, alcohol or drug use; and
- A paragraph long description of your loved one's occupation, interests, religious practice (if relevant), and family life.

This information will allow health care professionals to better understand what makes your loved one unique, even as the illness progresses, and make it easier to build a strong therapeutic relationship.

If you have access to a computer, you might consider creating a form that you can copy and use before, during and after each trip to the doctor or hospital or you can use copies of the sample form provided in Appendix Three of this guide. The form can serve as a place to write down your questions and review all medications in preparation for the visit. You may also want to keep a daily log of care and behaviors which you can refer to when pulling together information for the doctor.

During the visit, you can use it as a place to record what the doctor says, recommended changes in medications and the reasons for those changes, as well as recommended tests, referrals or instructions and the date of the next appointment. The completed form can then become part of the personal health record. This will help ensure that important information is communicated and that continuity of care is maintained, even when someone other than the primary caregiver accompanies your loved one to a doctor visit. That will allow several family members to rotate this responsibility, sharing the caregiving workload.

# Finding Meaning in the Journey: The Spiritual Aspects of Living with Dementia

**M**any people associate spirituality with religion, but the two are not the same thing. *Spirituality* is a broader concept that involves finding an ultimate meaning in life and confronting the mysteries of life and death. Some people find a spiritual home in organized religions – as part of a church, synagogue or mosque community – while others find spirituality at a very private, personal level as a set of beliefs that may or may not draw from one or more religious traditions. For some, spirituality has nothing to do with any religion, but with a sense of awe and reverence when they experience nature, immerse themselves in solitude, are transported by music or other creative arts, or come face to face with the edges of life as they perceive it, by encountering birth or death.

Whatever one's interpretation, spirituality is a very personal matter, and it is fair to say that all of us have a spiritual life of one sort or another, even though we may not think of it as such. Many people view spiritual care as the realm of clergy, pastors and other spiritual leaders. But it is important for you, as a caregiver, to see yourself as a member of the spiritual-care team.

## Seeking Meaning from the Experience

Dementia forces us to deal with important spiritual issues. Some people might think of dementia as a prolonged transition between life and death, with a gradual loss of many things that are central to who we are as individuals. And yet the person with dementia is in some sense still very much present, able to enjoy the moment, to laugh, to look into the eyes of another and to cry. Some days, the person who has traveled deep into dementia will suddenly have several minutes or hours of relative clarity and be *back* as he was some time before, able to remember and recognize friends and family and even make very insightful comments. What part of her was gone? Where did she go? How did she manage to come back? Is the process of traveling from here to there a gift meant to teach us what is really important about living and loving, and what is actually irrelevant?

Your loved one facing dementia may wonder, "If I am not able to find the words to communicate my thoughts or even to gather my thoughts clearly, will I still be the person that I was? And most importantly, what difference does that make? Who are we all along? What is it that really matters?" Your loved one may also wonder, "Why me? Why now? What have I done to deserve this?" And in fact, as a caregiver, you may ask the same thing with regard to yourself.

On a more practical level, everyone involved may well wonder, "How can we look into the face of all this mystery to learn about the answers to these and

many other questions that will arise, and transform ourselves into wiser, more compassionate people as a result? How can we draw upon these spiritual encounters, for that is what they are, to face the situation with compassion, grace and trust? How can we use these gifts to help us as we face further losses and the decisions about health care that may lie ahead?”

It may be helpful to consider the following spiritual lessons that coping with illness may bring:

- Adversity can be an opportunity for growth.
- It is helpful to look for the positive in every life experience.
- There is great value in the wisdom and experience that comes from living in general and coping with losses.
- Healing is not the same as curing. Healing has to do with achieving inner peace and harmonious relationships with one’s family and community.
- There is value in simply being, rather than always striving or achieving. Disability of any sort forces us to slow down, be present and enjoy the moment, enjoying those who are around us.

It is helpful for your loved one with dementia, as he or she grapples with questions of meaning in the early stages of illness, to have you and others listen compassionately to his or her fears, anger and despair. In the later stages of the illness, just being present and providing physical outlets for anxiety and frustration can provide comfort and security. Those who care about both the person with dementia and the caregiver can be very helpful by continuing to visit and participating in shared activities, or even just by being present.

It is also important for you, the caregiver, to be able to find others willing to listen to your feelings of frustration, grief and anger without judgment. Being able to focus on the positive, transcending day-to-day challenges to achieve personal growth, requires that you talk about and work through the negative feelings, just as those who have lost a close relative need to be able to give voice to their feelings to move through the bereavement process.

### Continuing a Life of Meaning

Victor Frankl, a renowned psychiatrist who survived imprisonment in Nazi concentration camps during World War II, drew from his experiences to write what has become a classic book, *Man’s Search for Meaning*. He identifies three ways to create meaning in life:

- To pursue meaningful work;
- To engage in meaningful relationships with others; and
- When all else fails and one is deprived of the opportunity to engage in the first two, to undergo with dignity whatever suffering must be endured.

Frankl observed during his experience in the camps that often those who were best able to maintain their dignity were not those who lived longest, but those who made choices that set them apart from the desperate scrambling and selfishness that was sometimes necessary for physical survival. It is helpful to keep these things in mind when living with or alongside dementia.

As a caregiver, it is important that you be aware of the life story of your loved one with dementia and take time to think about what the sources of meaning in

life have been for him or her. With that in mind:

Try to plan activities that tap into your loved one's life-long sources of satisfaction and identity.

Remember that even in the advanced stages of the disease, certain symbols associated with sources of meaning will continue to strike a familiar chord, such as a dress shirt and tie or a purse.

When dealing with difficult behavior, think about what may be happening at the time that conflicts with something of meaning to your loved one.

Try to accomplish necessary tasks in ways that accommodate your loved one's preferences and sense of self worth.

Help your loved one maintain a positive outlook by focusing on what he or she can still do, rather than on what is now beyond his or her reach.

Remember that finding ways to maintain dignity, even in the face of failing capacities, may be vital when other sources of satisfaction and meaning are no longer readily available.

### Honoring Values and Beliefs

Another aspect of spirituality involves values and beliefs. You and your loved one with dementia and his family may identify with the religious beliefs and values of a particular faith and its specific holidays, events and rituals. It is important to find ways to continue participation in these observances to the extent that they hold meaning and offer support and comfort. Relationships with clergy and spiritual leaders, and participation in the life of the religious community, should continue as long as possible.

Some personal beliefs and values may have little or nothing to do with established religion. These might include:

- The importance of psychological growth and positive thinking;
- The meaning of health and healing;
- The value of wisdom and experience; and
- The importance of service.

You and your loved one may find yourselves grappling with your beliefs and values as you look for inspiration and guidance to cope with the challenges of living with the illness. Old beliefs may give way to new ones as you search for ways to deal with difficulties and loss without giving way to anger or bitterness.

### Preserving Relationships

For your loved one with dementia, a continued sense of connection to others will depend greatly on the immediate caregivers, family and community:

- Regardless of one's illness or cognition, people need to know they are loved, feel good about themselves, be respected, feel secure and be included in activities.
- People with dementia still celebrate the joy of life, feel the approval of others and enjoy being stimulated in body, mind and spirit.
- It is not necessary to engage in discussion in order to benefit from the physical and emotional presence of others but, to the degree that your loved one

### Caregiving Tip

In addition to attending to the spiritual needs of the person with dementia, it is important for the caregivers to pay attention to their own:

- While you may recognize the value of growing when faced with adversity, you must acknowledge that it is not easy and that you have limitations.
- While you seek to be gracious, accepting, patient and always comforting, you may have feelings of guilt, inadequacy, fear and loneliness.
- It is vital to avoid becoming isolated by cultivating connections with others who can listen, encourage and find ways to affirm what is working.
- Continue affiliations with spiritual groups and seek out support networks. These may be found by contacting the local Alzheimer's association or looking online at [www.alz.org](http://www.alz.org). Support groups offer socialization, support, knowledge, problem solving and the opportunity to help fellow caregivers.

can still express feelings, he or she will benefit greatly from being heard by others willing to sit, listen and bear witness to their pains and joys.

- Your loved one will appreciate eye contact, smiles and conversation from others even when he or she has little to say or is no longer able to express thoughts or fully understand what someone else says.

Many people find spiritual inspiration in art, music, beauty and nature. All of the human senses play a role in connecting with people who have memory loss:

**Sight:** Seeing beauty, connecting with others by making eye contact and seeing facial expressions of joy and satisfaction can be very pleasurable.

**Touch:** Physical contact can be very soothing – holding hands, hugging and massaging, for example.

**Smell:** Fragrance can be a powerful source of enjoyment, particularly scents that are associated with past experiences, including flowers, candles, incense, or a favorite cologne.

**Hearing:** Familiar or soothing music may help lull one to sleep, bring back pleasant memories and even calm a person who is upset to the point of behaving in a difficult manner. And an individual may be able to sing along with a favorite tune even when speaking becomes difficult.

**Taste:** Pleasant tastes and familiar foods are a source of comfort and may bring back feelings associated with happy social occasions.

Until the dementia is advanced, your loved one will be able to recall deeply meaningful events and relationships, some more than others. As a caregiver, remember that:

- Recent memories disappear first, but the recall of long-term memories may be prompted by familiar cues from pictures, photographs or music.
- Family albums, stories from the past, or books with pictures or photographs from the past may be helpful in stimulating conversation.
- Correcting a misperception or a faulty memory will most likely prove embarrassing and distressing to your loved one with dementia and may shut down further interaction. It is more helpful to provide pleasant companionship than to attempt to “teach” or insist on “the facts.”
- It is also possible that invoking a memory that gave pleasure may at other times provoke a negative response. Particularly if the memory is shared – one that is meaningful to the caregiver as well as to the patient – it is important that you, as caregiver, remember that your role, your gift to your loved one, is to understand and validate whatever emotion arises, rather than to defend your own recollections.



# Adding Value to Each Day: Celebrating Life Throughout the Journey

**T**he journey through Alzheimer's disease and other forms of dementia is very difficult, but you can have many enjoyable times even in the midst of the difficulties. Along the way, you will almost certainly learn to adapt and think of new ways to do things together or separately.

## Adapting Activities for People with Dementia.

One of the common symptoms of Alzheimer's disease is a prevailing lack of initiative. It is very difficult for people with dementia to plan and organize their own activities. As a result, the caregiver must not only tend to physical needs, but also provide meaningful activity and entertainment. Creating activities on a daily basis for someone with a short attention span and declining ability can be exhausting.

One helpful solution is to find an adult day health center, such as IONA Senior Services' Center. Individuals with dementia can attend most adult day centers from two to five days per week. At the center, they will find structured, therapeutic activity, meals, assistance with personal care, medication supervision, medical oversight, field trips and much more. Participation in adult day health care allows the person with dementia to remain active and to socialize with friends in a safe environment. It also gives you, as caregiver, time to get things done and to do some things you enjoy.

Some organizations, including IONA, have special day programs or clubs for people in the early stages of memory loss. Such programs are usually held for a portion of the day and involve field trips to local sights, discussion groups and other mentally stimulating activities aimed at keeping your loved one functioning at as high a level as possible.

While at home, it is important to engage your loved one in a variety of activities, including physical exercise, mentally stimulating activities and the opportunity for creative expression – all of which should be provided on a regular basis. In addition, the person with dementia needs to feel productive, just like everyone else. Daily chores can be adapted so that he or she can continue to participate and feel helpful:

- If the person loved to cook, but can no longer prepare a favorite recipe, he or she can still stir batter or chop vegetables.
- Someone who loved to build things can still sand wood or paint woodwork.
- Someone who can no longer carry the laundry, can still match socks or fold towels.

### Caregiving Tip

It may be helpful to post a daily schedule so that the person with dementia can know what to expect throughout the day. A regular routine is also helpful. Try to have similar activities at the same time each day. This will reduce agitation and help him to feel more in control of his time.

Keep in mind that with activities, the process, the act of doing and engaging, is much more important than the final outcome.

Activities can be adapted to allow continued success in daily participation in the life of the household. Even if your loved one does not perform the activities perfectly – putting the dishes away in the refrigerator, for example – accept the help. You can always move the dishes later. Keep in mind that with activities, the process, the act of doing and engaging, is much more important than the final outcome.

Research tells us everyone, including people with dementia, needs regular physical exercise to function at their best:

- Physical activity sends necessary blood and oxygen to the brain for improved cognitive function.
- It reduces anxiety and agitation, and promotes restful sleep at night.
- Exercise improves balance and coordination, thereby reducing frustration and possibly preventing falls.
- Physical activity enhances mood and decreases the risk for depression, a common consequence of Alzheimer’s disease and other dementias, as well as a risk for caregivers.

So take a walk, play golf, rake leaves, toss a ball or do chair exercises. Make sure that physical exercise is a part of your daily activity, whether you are a person who has received the diagnosis or are a caregiver.

In the early stages of the disease, brain activity can significantly help a person dealing with dementia to function at his or her best. Picture games, crossword puzzles, word games or fun math problems can be completed together. Make sure the games do not become frustrating. As long as the individual can continue to succeed and enjoy the games, they are worthwhile.

Music can hold great power, particularly in caring for someone with brain dysfunction. Even when words are hard to find in conversation, your loved one may be able to sing every verse of an old, familiar tune. So make music part of the daily routine. It can be used to signal mealtime or bath time. Music is also especially effective in calming an agitated person. Consider:

- Playing familiar tunes and having a sing-a-long;
- Playing your loved one’s favorite song each morning when it is time to get out of bed;
- Dancing to music while dressing; and
- Playing soft, soothing music in the late afternoon when agitation and anxiety tend to increase.

Television can provide entertainment for the person with dementia. But be aware that some television programs might also frighten and agitate your loved one because he or she may have difficulty distinguishing between what is happening on television and what is happening in the real world. If someone is hurt or killed on television, your loved one may fear that the family is in danger. Sometimes patients with dementia will refuse to get dressed with the television on for fear that “all the people” on the television are watching. It’s important for you, as caregiver, to make sure that television does not dominate the life of the person with dementia.

**Here are some suggestions for filling the day with meaningful activities:**

- Clip coupons from the newspaper
- Pull weeds in the garden
- Rake leaves
- Sweep the floor
- Sort crayons, poker chips or coins
- Fold towels
- Sort and match socks
- Polish silver
- Sand wood
- Stir batter
- Tear lettuce
- Peel potatoes
- Knead bread dough
- Look at photo albums and talk about the pictures
- Make a card for someone
- Water house plants
- Plant flowers in pots
- Arrange cut flowers in a vase
- Wipe off counter tops
- Sort playing cards
- Roll yarn into a ball
- Have a picnic
- Put together a jigsaw puzzle
- Mold with clay
- Dust furniture
- Play miniature golf
- Visit a museum
- Walk in the park
- Visit a pet store
- Make sandwiches for a shelter
- Sort clothing for a shelter
- Paint a picture
- Read out loud
- Visit a friend
- Invite a friend in for coffee
- Listen to music

Almost any activity can be adapted to the remaining abilities of your loved one. Likewise, all activities will have to be continually adjusted throughout the course of the disease. As caregiver, focus on your loved one's current skills and interests to determine daily activities. Be sure to maintain a sense of humor and be flexible with your time. Remember that activities add quality of life and an opportunity to feel normal. Structured, daily activities can decrease boredom, enhance mood and significantly reduce behavior challenges. Everybody wins.

### **Preserving Memories**

Preserving memories together can be a wonderful activity and a gift for the whole family – current and future. Together with your loved one you can:

- Create a family scrap book;
- Put together a photo album with simple easy-to-read labels;
- Interview your loved one using a camcorder; and
- Bring an audio recorder to the lunch or dinner table and reminisce about growing up, work and family; then transcribe the tapes into a family history book or copy them to a CD.

As memories begin to fade, these can be wonderful tools to trigger fond recollections, and they can serve as conversation starters when interacting with family and friends.

If and when the time comes for your loved one to move to a nursing or other facility, make sure his or personal history goes with him or her.

- Write up a short biography and post it in the room;
- Make a poster with photos and information on family, work and hobbies and put it up on the wall; and
- Sew or use fabric paint to write the names of family members, past experiences and interests on a jacket your loved one can wear indoors to help the staff better connect with the real person for whom they are caring.

## Blending Past, Present and Future: Leaving a Legacy

**C**oping with a diagnosis of dementia is demanding for all involved. In the early stages of the disease, caregivers and the person with dementia have the challenging tasks of getting affairs in order and making choices about the future. But it is also important, not just at the beginning but throughout the journey, to leave time for healing connection and conversation between your loved one and family and friends.

A dementia diagnosis, while not something people would wish for, does at least provide advance warning of what lies ahead. Unlike a sudden death that takes everyone by surprise and allows no time to say “goodbye,” life’s final chapter for dementia patients is long enough for meaningful leave-taking. Making the most of the opportunity will certainly be bittersweet. And while saying goodbye can be hard, it carries lasting value.

One recent innovation in this area is the “ethical will.” An ethical will is written by a person while still mentally competent, as a legacy to those who will survive him or her. It might include words of wisdom, blessings, lessons learned, the story of his or her life, and anything else the person wishes to pass on to those who have been closest.

Another opportunity for someone who carries a serious diagnosis is a family meeting. Such a gathering can allow all members of the family to come together and share feelings, confess, express regret, apologize, ask for forgiveness, give blessings, and express their love and concern for each other. Indeed, it need not take a serious illness for us to pause and share our feelings with each other in this way. But such gatherings take on extra meaning when dementia has been diagnosed. If it is not possible for the entire family to come together, at the very least, and possibly in addition, it would be wonderful for your loved one with dementia to have at least one conversation with each family member to exchange these thoughts while still able to do so. This experience is almost always helpful and healing for everyone involved and will provide comforting memories to those left behind after your loved one is gone.

In fact, one of the most significant blessings that can come from a diagnosis of dementia, as with any other serious illness, is the realization that our lives and the people closest to us are precious and deserving of our time and attention. Elisabeth Kubler-Ross, famous for her work with the dying, had this to say on the subject:

*It's only when we truly know and understand that we have a limited time on earth – and that we have no way of knowing when our time is up, that we begin to live each day to the fullest, as if it was the only one we had. By get-*

*ting comfortable with the notion of dying, even feeling prepared to die, we free ourselves to live more fully.*

That lesson is central to many spiritual disciplines and well worth remembering. Celebrating the people and the capacities we have in our lives, while we still have them, while letting go of concerns about things that do not really matter, is central to making the most of life with dementia. It is also central to living a good life in general.

# Caring for the Caregiver

**T**aking care of someone with dementia is a long and demanding journey. No one can do it alone. As caregiver, you may sometimes feel that it is your duty to do all of the work, no matter how difficult the job. But, if you do not take care of

yourself, you may not be able to help your loved one at all. Without a great deal of assistance and support, the job of caregiving can make you very stressed, physically ill and ultimately unable to provide the necessary care.

As soon as you can, talk about the caregiving situation with family members and/or friends:

- Are you in good health, and able to provide both physical and emotional care?
- Are there other family members nearby who can provide ongoing assistance?
- Are there neighbors or close friends who can assist with caregiving?
- Are you a member of a church congregation that might be able to provide some support?
- Are there support groups in the area for caregivers?
- Are there support groups in the area for the diagnosed person?
- Is there an adult day health center nearby?
- Are there funds to make necessary changes in the home to accommodate the patient's changing abilities and/or hire live-in help?
- Are there funds for home health care or residential facility care?
- Are there services available through your local area agency on aging?
- Would you or another caregiver consider moving in with the person with dementia if you do not already live together? If so, is there someone (or an organization) who can help with that move?
- Would you consider moving to a retirement village or assisted living facility when necessary for your loved one?

Each situation is different, but it is important that you identify sources of support and assistance that can be called upon as needs evolve.

Here are some coping and stress-reducing tips for the primary caregiver:

**Educate yourself, your family and friends.** Dementia and resulting behaviors are often difficult to understand and manage. Workshops and classes on dementia are offered through the Alzheimer's Association and other senior service organizations. An educated caregiver has more control over his or her situation, and can plan more effectively for the future.

**Join a support group.** Support groups offer wonderful opportunities to learn caregiving tips, help provide emotional support by reminding caregivers that they are not alone, and can be an excellent source of referrals to local resources. Many support groups meet in person, but you may also seek out discussion groups online.

**Don't try to do it all yourself.** It is important that you learn how to ask for help from family, friends and local organizations, and that you get in the habit of asking. Similarly, you will need to learn to accept help when it is offered. You might want to begin keeping a handy list of suggested tasks for friends who offer their help. As a caregiver, you need time away from the person with dementia and your responsibilities to them, so that you can renew your energy and gain perspective.

**Maintain social contacts.** Friends tend to fall away when someone is diagnosed with a memory disorder. It is important for you to remain socially involved and not isolated from the world. A support group may be a source of new friends who understand your situation and can offer encouraging words.

**Take care of your own health.** Maintain a regular daily routine, both for your benefit and that of the diagnosed person. Be sure to eat well and exercise daily. If you are having difficulty sleeping at night, try to find time for a nap during the day.

**Enroll your loved one in an adult day health care program.** Adult day health care programs, such as the one offered by IONA Senior Services' Center, provide an opportunity for seniors with memory loss to interact socially with others in a safe and stimulating environment. The day is filled with social and recreational programs designed to stimulate memory and maximize physical ability such as Tai Chi exercise, music, art and pet therapy, local outings, intergenerational programs and much more. The Center is staffed daily with licensed nurses who are able to administer medications, monitor blood pressure, weight and nutrition, maintain communication with physicians and provide support and guidance to caregivers.

**Arrange for help at home.** If you have the resources, consider hiring someone to watch your loved one during the most difficult times of the day or night as the disease progresses. Contact your local area agency on aging, senior service organization, church or synagogue to find out about any low-cost options for care or volunteer support.

**Accept the fact that you cannot provide perfect care.** The disease will continue to progress, no matter how excellent your efforts. The care you are providing makes a significant difference in the quality of life for your loved one, but some behaviors and challenges will still be beyond your control. Give yourself credit for what you are able to provide.

**Allow yourself to grieve.** As the disease progresses, the person you knew and the relationship you enjoyed will slip slowly away. Give yourself permission to grieve and take time and emotional space to do so.

**Enjoy the good times.** Despite the changes and losses, you will still find that you are able to enjoy time spent with your loved one with dementia. Don't lose your sense of humor. Enjoy the days, the hours, the moments when you can share a walk, a hug, a precious memory, a laugh or a smile.



**Explore options and plan for long term care.** Make sure all your financial and legal issues are finalized before the diagnosed person becomes too ill to sign papers. Visit day health programs and long term care facilities before a crisis emerges. Contact home health agencies so that you are aware of their services and fees. Check with local government agencies to see what other services might be available for those with dementia. Finally, be sure to have a back-up plan for care as the disease progresses.

**Seek counseling, if necessary.** Sometimes caregiving can become overwhelming. You may feel exhausted and depressed. Talking with a professional counselor can help you sort out the situation and identify effective ways to cope.

# Back to the Basics: Understanding Dementia

**F**or many of us, dementia is associated with frightening images. But care and treatment for those with dementia has improved dramatically over the past several years, and research for better treatments is ongoing. In the meantime, patients and caregivers can benefit from learning more about the disease.

Dementia is not a specific medical disease, but rather a general description of symptoms caused by a variety of different brain disorders. The most common form of dementia is Alzheimer's disease, accounting for more than half of all diagnosed dementia patients. But there are other forms of dementia with different causes.

Most people experience some degree of increased absent-mindedness and distraction as they grow older, but people with dementia experience more serious difficulties. While Alzheimer's and many other forms of dementia are more common as people grow older, none of them are considered part of the normal aging process. They are the result of physical changes in the brain. Common signs of dementia include:

- Memory loss;
- Difficulty performing familiar tasks;
- Trouble finding words;
- Getting lost in a familiar place;
- Putting things away in the wrong places;
- Not taking usual care with grooming or dressing;
- Trouble managing one's affairs;
- Difficulty with numbers;
- Poor judgment;
- Mood changes;
- Personality changes; and
- Social withdrawal.

Not every person with dementia will have all these problems, particularly early in the illness, but patients typically have problems in more than one of these areas, with increasing difficulty as time goes on.

## The Diagnosis

Once an individual begins to experience some of the problems noted above, it is very important to undergo a medical evaluation to establish a diagnosis,

preferably with a neurologist or geriatrician. A medical diagnosis is important for several reasons.

- **The symptoms could be caused by a condition that is treatable and reversible.** Many conditions can cause difficulty thinking, including: problems related to the nervous system other than dementia, medication side effects and interactions, depression, thyroid disease, vitamin deficiency, infection, liver disease and even abnormal blood sugar levels. Symptoms due to these problems go away when the underlying conditions are treated. For example, sometimes older people who are in an unfamiliar environment – a hospital, for example – or who are very ill or under the influence of medications, can become confused and agitated. This is a short-term, reversible condition that is called “delirium,” and is not a kind of dementia.
- While there is no cure for dementia, medications used to treat some of the symptoms of Alzheimer’s disease and other dementias may make a difference and are thought to be most effective in the earlier stages of the disease. These medications may help to slow the early decline in mental functioning in some people. In addition, some forms of dementia can be made worse by certain medications, so making the right diagnosis can help to avoid this problem.
- When the diagnosis is made early, patients and family members have time for discussion and planning about the future. Arrangements can be made and legal documents can be signed while the person with early dementia is still thinking clearly enough to do so. There is also time for the entire family to prepare emotionally and come to terms with what lies ahead.

Doctors have no specific test to confirm the diagnosis of Alzheimer’s disease, although the diagnosis can be made after a person dies by looking at samples of the brain under a microscope. Nothing in the blood can be measured to make the diagnosis, and no brain scan studies can make a definite diagnosis. However, the diagnosis can be made with 95-percent accuracy by doing a medical evaluation that finds no other causes for memory loss or evidence of other forms of dementia. The evaluation will usually include:

- A careful medical history and family history;
- A review of medications to check for side effects or interactions;
- A physical examination;
- A mental health evaluation looking for depression or other emotional issues;
- Blood tests to rule out vitamin deficiencies, infection, thyroid disease, or other medical problems that could affect mental function; and
- Testing to evaluate memory, language skills, reasoning and judgment. If the memory problems are still relatively mild, sophisticated testing may be required to detect features that point toward early dementia.

The evaluation might also include a brain scan to look for signs of stroke or other neurological conditions.

## **Kinds of Dementia**

The most common form of dementia is Alzheimer’s disease. As of 2007, an estimated 5 million Americans were living with Alzheimer’s.

The disease generally progresses over a period of five to twenty years. Memories and abilities are lost in roughly the reverse order in which they were gained over the course of the one's life. For example, in the early years of the disease, people with Alzheimer's often have difficulty writing checks, calculating numbers, remembering recent events and working on new projects. As time passes, individuals lose the ability to prepare a meal, dress themselves or manage their own personal care, and they start losing older memories. Eventually they lose the ability to recognize close friends or even family members. Most irreversible dementias follow a similar course, but there are some differences between them, because different conditions affect different areas of the brain. Memory problems are common with nearly all types of dementia. The most common forms of dementia other than Alzheimer's include:

- **Vascular dementia.** The word "vascular" refers to blood vessels. Vascular dementia is caused by brain damage from a series of small strokes due to blockages of small blood vessels in the brain. Each of these strokes may not be noticeable at the time it occurs. Because the damage to the brain with each one is small, no obvious effects – paralysis of part of the body, for example – are immediately observable, as might be expected with a larger stroke. But over time, as these small strokes continue to occur and damage to the brain mounts, a step-like decline in mental function becomes apparent. In later years, the progression of Alzheimer's and vascular dementia are very similar.
- **Dementia with Lewy Bodies.** The term, "Lewy Body," refers to deposits of a specific kind of protein in the brain that can only be seen with a microscope. People with Lewy Body dementia have memory and language problems, but also develop difficulty with coordination early in the disease. They may walk with short, jerky steps instead of long smooth ones. This "shuffling" pattern of walking, as well as poor balance, tremors and increased muscle tension, is also common in Parkinson's disease. People with advanced Parkinson's disease may also develop dementia with Lewy Bodies, so there is often confusion about which diagnosis is the primary one. People with Lewy Body dementia may also have hallucinations, seeing or speaking with people who aren't there.
- **Fronto-temporal dementia.** People with this type of dementia have damage to the fronto-temporal part of the brain, which enables us to monitor our behavior, refrain from doing impulsive things we might later regret and keep track of social conventions. Personality, language skills and reasoning are also found in this area of the brain. As a result, the person with fronto-temporal dementia may be uninhibited, impulsive and abrupt in his behavior, with little awareness of what is socially appropriate. The onset of this kind of dementia is usually between the ages of 40 and 65 and is diagnosed with the use of brain scans or imaging.
- **Mixed dementia.** Some patients have dementia that has more than one cause. For example, people with Alzheimer's disease may also have small strokes that damage the brain. And people with vascular dementia may also develop Alzheimer's disease. Likewise, a person might develop the behavioral characteristics of both Alzheimer's and Lewy Body dementia, with the changes in the brain that are found in both.

## What to Expect as Time Goes On

To help families and caregivers gain a better understanding of what to expect, the medical community commonly divides the progression of most dementias into three stages, Early, Middle and Late. Alzheimer's disease and related dementias can last anywhere from five to twenty years, with an average span of eight years from diagnosis to death.

It is important to note that the individual experience of a person with dementia may not fit neatly into the typical stages of the disease. Stages are described below to help explain the way symptoms generally progress, so that patients and loved ones will know what lies ahead. While each person experiences dementia differently, many aspects of the progression occur in nearly all cases.

- **Early Stage** usually lasts two to four years. The disease is usually diagnosed at this stage. During this time, people with dementia begin to have difficulty with their job or daily activities, may become lost while driving, exhibit difficulty with bill-paying and keeping up with appointments, show poor judgment and may seem to lose interest in activities they once enjoyed. In addition, they may talk about memory loss or complain that their brain is “not working the way it used to.” But even patients who do not talk about these concerns are usually aware of changes in the way their brains are working, and may be embarrassed or frightened by this development.
- **Middle Stage** usually lasts two to ten years. People with dementia enter this stage able to care for themselves and tend to most of their personal needs. But during this time, memory loss and confusion increases. So while it is not unusual for affected people to have good days or moments when their mental abilities are better than at other times, they will lose the ability to remember whole events. Over time, they begin to need help with dressing, bathing and brushing their teeth. It is not uncommon for them to lose things, sometimes accusing others of stealing them. Waking and getting up in the middle of the night may become a problem. They will be less careful with eating, dressing and personal hygiene. At some point during this stage, they will likely become incontinent and have a difficult time getting the right words out when talking.
- **Late or Terminal Stage** usually lasts one to three years. At this point in the progression of dementia, patients can no longer care for themselves. They may have few words left or talk in sentences that are not understandable. They may rely on physical movement and gestures to communicate. They may no longer recognize family and friends, and may not even recognize themselves in a mirror. They are incontinent, and may have problems with muscle control. They may lose the ability to walk or even sit up without assistance. Seizures are not unusual during this time. As the end of life draws near, they have difficulty swallowing food and liquid, have frequent infections, and the body begins to shut down. Not all dementia patients reach this stage, of course. Those with other illnesses may pass away from other causes before reaching this end stage.

## Treatment for Dementia

While modern medicine has no cure for irreversible dementias, some medications may be helpful in improving some of the symptoms of Alzheimer's and other dementias in some people. At the time this toolkit was written (2008), none had been shown to reverse the overall course of the disease. Medication options should be discussed with a physician well versed in treating people with dementia, to take advantage of the latest information available as research continues.

In recent years, researchers have also looked at the best ways to manage symptoms so that the quality of life for both people with dementia and their caregivers can be as good as possible. Much has been learned about making use of the person's remaining abilities to compensate for those that have been lost. It is important to:

- Encourage physical activity;
- Understand the basis of challenging behaviors;
- Structure the environment to minimize distress;
- Allow the individual as much personal choice as possible; and
- Promote safety.

In addition, evidence suggests that a diet rich in whole fruits, vegetables and grains, with less meat and fat than the typical American diet, is optimal in preventing and treating many chronic diseases common in the western world, possibly including dementia.

Individuals with dementia who participate in mentally stimulating activity may function at a higher level than those who have no regular activity during the day. Such activity helps to keep the brain active, minimizes agitation and helps the person feel useful. Physical exercise is also an important part of treatment for those with dementia. Physical activity may:

- Improve brain function;
- Help the person sleep better at night;
- Decrease anxiety and depression; and
- Help maintain balance and overall physical well-being.

Research also suggests that social activity is helpful. A good environment for those with dementia includes a structured, daily routine with flexibility; good nutrition; and frequent reassurance and assistance when needed. All of these features can be found at an adult day health center. These programs, such as the one operated by IONA Senior Services, make the most of each participant's abilities, engaging them socially, monitoring them medically, and helping them maintain their mental and physical skills. Most programs are open Monday through Friday, allowing caregivers to have their days free and their loved ones to continue living at home.

# When the Time Comes: Facing Tough Decisions about Medical Care

**I**t is difficult to face the idea of living with a progressive condition that will eventually rob you of the ability to have much control over your life. People who are aware of having a progressive dementia may fear living in an institution, or worry about becoming a burden, financially and emotionally, to their families. They may worry that, instead of being remembered for the vibrant and unique lives they once lived, they will be remembered as a person in the last stages of dementia, unable to recognize family or friends or participate in self-care. And they may worry that they will live and die alone or among strangers.

Even though most people would like to avoid these things, most realize that if they live long enough they will not be in a condition to make decisions that would stop aggressive, life-prolonging care if that is their choice. They will not be able to say when the time comes, “Enough!” or “Just make me comfortable and let me go.”

As noted earlier, it is important to have conversations as early as possible with your loved one and with family members so that you can make choices that will guide subsequent care decisions. Following are some of the issues that can arise in the late stage of dementia – decisions that will be much easier for caregivers to make if they have discussed the matter with their loved one and family members in advance.

Please make a point of talking with the doctor about these issues periodically or when your loved one’s medical or living situation changes. If he or she is admitted to a residential facility such as assisted living or a nursing home, take that opportunity to talk to the doctor about what the goals of treatment and care should be. Don’t be forced into making decisions during a crisis situation. Discuss the options now. In Maryland, nursing homes use a *Life-Sustaining Treatment Options Form* to guide this conversation and record the results. This form can be found on the Maryland Attorney General’s web site referenced in the Resources section in Appendix One of this guide. It or a similar form could be used in other situations or jurisdictions to guide and record conversations between doctors and health care agents to establish guidelines for care.

## Allowing a Natural Death

The most far-reaching choice you will face involves deciding at what point to make the primary care goal preserving comfort and dignity, rather than prolonging life. At that point, aggressive therapies and interventions of the sort that are appropriate when the goal is to keep someone alive as long as possible are not undertaken. When a potentially life-threatening complication develops, the

person is made as comfortable as possible and allowed to die a natural death.

Once this goal is established, it will guide more specific decisions. The point at which this occurs should be determined by the values and priorities of the person with dementia, values that provide the framework for the philosophy of care:

- Some people would prefer that aggressive interventions stop well before they become severely demented. They would willingly trade the possibility of extra time in which they might enjoy some reasonable quality of life, in order to avoid living for a long time with advanced dementia.
- Others would prefer to live as long as possible and do not wish to stop aggressive treatment as long as it's available.

Deciding at which point aggressive treatments should stop and life and death should be allowed to proceed as naturally as possible, while relieving discomfort or pain, is one of the major elements of the care philosophy that should be constructed as early as possible.

### Caregiving Tip

If a decision is made to abandon aggressive treatments, and life expectancy is six months or less, hospice care is an option. Hospice provides palliative care for the patient and also provides support and comfort to the patient's loved ones.

### Palliative Care

Palliative care is medical care that focuses on the relief of symptoms. It should be a part of care even when treatment is being aggressively pursued, such as when a person with cancer is undergoing chemotherapy. For that reason, always talk to your doctors about how to manage pain and other symptoms whenever they are an issue, and ask if there is a palliative care specialist on staff.

You might worry that when the decision is made to stop pursuing aggressive and potentially life-prolonging treatments, overall care might suffer. But in fact, the opposite is often the case: when aggressive treatments are not undertaken, the medical team can turn its emphasis to giving comfort. At that time, the goal shifts to maximizing the quality of life here and now, instead of compromising present comfort for potential future gain or prolongation of life.

### CPR

Even before a decision is made to discontinue aggressive care, a person with dementia or those empowered to make decisions on his or her behalf might opt for a “do not resuscitate” order. A “DNR” order, as they are sometimes called, is an order, written by a doctor at the direction of the patient or his or her health care agent, instructing health care professionals not to attempt to resuscitate a patient who has stopped breathing or whose heart has stopped beating. In the absence of such an order, health care professionals will typically attempt cardiopulmonary resuscitation (CPR). Some patients prefer not to have CPR attempted even in the early stages of dementia, because even if it succeeded in restoring heart and lung function without itself creating more disability, they would rather not have life prolonged to face increasing dementia.

In reality, however, the likelihood of an older person with medical problems being restored to his or her previous condition after suffering a cardiac arrest is very small. In almost all cases in which resuscitation is immediately successful, the person would face an emergency admission to an intensive care unit, which would likely be very frightening and disorienting for someone with dementia.



In addition, the person would suffer pain from the trauma of the resuscitation itself – it often results in broken ribs and bruises – as well as from treatment of the underlying conditions that caused the cardiac arrest. Moreover, a ventilator is often required afterward for some period of time. The resulting hospital stay is often painful, difficult, and prolonged, and the likelihood of hospital discharge at the previous level of physical and mental health is low.

Knowing these things, there might be a point in the progression of the dementia when a person might decide (in advance) to accept other aggressive treatments, but to stop short of resuscitation if his or her heart stops. Then at a later date, after certain milestones in the progression of the illness are reached and the quality of life has deteriorated, the health care agent, following the patient's wishes, might direct the medical team to avoid all aggressive treatments.

### **Ventilators**

A ventilator is a machine that helps a patient breathe. The circumstances under which a person might need a ventilator are uncommon in the absence of lung problems. That said, it is important to know that a person who has been successfully resuscitated from cardiac arrest by means of CPR will very likely require a ventilator for at least some period of time during recovery. That could pose a number of problems. Being hooked up to a ventilator is a frightening, disorienting and painful experience even for people who do not have dementia. Such patients often need sedation and sometimes even physical restraints to make certain they do not fight the mechanical breathing of the ventilator or pull the breathing tube out of their mouths. The tube prevents the patient from being able to talk. In most cases, the patient requires care in an intensive care unit.

For a person with dementia, these circumstances would be an overwhelming experience, a fact that must be considered when making decisions about the use of CPR.

For people with dementia who have respiratory or other medical conditions that might require the use of a ventilator for short periods to recover from a setback of that condition, the potential benefit should be considered in light of the burden, the overall status of the patient, and the goals of care. It is best to consider and discuss such situations with doctors in advance so that when and if the time comes, your loved one's wishes are well understood, and so that some criteria have been agreed upon for how to manage care. In some cases, it might be useful to try a ventilator for a brief period of time to see how your loved one adapts. Or a decision may be made to simply make your loved one as comfortable as possible using oxygen and medication for pain and anxiety, and allow nature to take its course.

### **Artificial Feeding**

Part of the natural progression of very advanced dementia is the eventual loss of interest in eating or an inability to swallow. At first, a person with advancing dementia may respond well to prompts and cues and then to hand-feeding. But at some point, patients begins to eat less, lose weight and eventu-

ally stop eating and drinking altogether. Progressive dementia is a terminal illness and, in the late stages, these symptoms may mean the end of life is approaching.

When a person loses the ability to eat or drink, it is natural to wonder about artificial feeding, using a feeding tube (usually surgically inserted through the skin into the stomach) and/or an intravenous (IV) line. Unfortunately, for late stage dementia patients, artificial feeding has not been shown to lengthen a person's life and can cause many complications, including:

- Increased risk of pneumonia;
- Restraints or heavy bandaging to keep the patient from pulling out the tube or IV;
- Discomfort from the surgery to insert the tube or the IV;
- Uncomfortable fluid buildup in the body; and
- Serious infections.

In fact, in *Hard Choices for Loving People*, a popular book about end-of-life decisions, author and chaplain Hank Dunn describes several benefits for dying patients when feeding tubes and IVs are not used. They include “a natural release of pain-relieving chemicals as the body dehydrates. Some have even described this as ‘mild euphoria’. This state that comes with no food intake also suppresses appetite and causes a sense of wellbeing.”

Chaplain Dunn explains that the person not eating or drinking is not “starving” but becoming increasingly dehydrated. “Whatever pain or discomfort is associated with malnutrition (starvation) is not relevant here because a patient will be affected by dehydration long before suffering any ill effects from the lack of nutritional support.” A sense of thirst and a dry mouth are the only uncomfortable symptoms of dehydration, and these symptoms can be relieved with sips of water, ice chips and swabbing the mouth.

### Infections and Antibiotics

Before the advent of antibiotics, pneumonia was often called “the old man's friend,” because it often helped ease people out of the advanced stages of a disabling condition. In fact, pneumonia and other infections are often the immediate cause of death in a person who has advanced dementia. While it might be possible to treat pneumonia successfully with antibiotics, it or another infection would likely recur, because the underlying cause of dying is really the advanced stage of dementia and the overall decline in bodily function that accompanies it. For that reason, aggressive treatment of infections in patients with advanced dementia is sometimes thought to amount to little more than prolonging dying, rather than healing and restoring the patient to a good quality of life.

As a practical matter, some infections might be managed with oral antibiotics. However, people with very advanced dementia often do not reliably swallow pills. Intravenous antibiotics impose more potential for harm, because they entail painful needle sticks, a higher potential for reactions and side effects, and possibly the need for sedation or the use of restraints to prevent the patient from pulling out the intravenous line. For that reason, health care agents often decide to forego antibiotics for their loved ones, or at least forego intravenous ones, and instead make the patient as comfortable as possible while allowing

nature to take its course. In such instances, pain and anxiety can be controlled by medication in liquid or other forms if necessary

### **Hospitalizations**

Hospitals are bewildering, even terrifying, environments for a person with advanced dementia. It is far more comfortable for your loved one to be seen by a medical professional in a familiar environment than to be sent elsewhere. In addition, it is often easier to ensure that your loved one's wishes are followed when the medical team knows and has worked with your loved one and family over the course of the dementia's progress. For these reasons, you may at some point decide to forego hospitalizations or even trips to an emergency room, and instead make your loved one as comfortable as possible at home or in a residential facility where he or she is in familiar surroundings.

### **Dialysis**

Dialysis is the process of filtering waste and excess fluids out of a person's blood when the kidneys stop working properly. While the likelihood of developing severe kidney disease is no greater in a person with dementia than in other people, if it does happen, the decision to undergo dialysis should be made very carefully. In making the decision, keep in mind:

- Dialysis sessions last several hours and must be done several times a week.
- They are tedious and painful, and involve access to blood vessels that requires a surgical procedure and excellent wound care.
- Most people conclude that, at some point in the course of dementia, such an invasive therapy is more of a burden than a benefit.
- End-stage kidney failure not treated by dialysis usually results in a relatively comfortable death. Patients have decreased awareness over a few days that may involve some symptoms easily controlled with medication, and death usually comes from a painless heart arrhythmia.

### **Other Life-Prolonging Therapies**

Given all the advances of medical therapies in recent decades, the usual presumption in making medical decisions is that we should treat any condition that might increase the risk of death. In most cases, this makes good preventive care sense. But in cases of progressive dementia, it is worth considering with doctors whether it is really consistent with the goals of care to initiate or continue such treatments as cholesterol-lowering drugs, pacemaker support, or ongoing monitoring that involves blood tests.

All treatments and testing entail some risk or burden. For patients with advanced dementia, prolonging life may not be worth taking that chance. Some people with dementia might decide early in the course of their illness that they would prefer not to wait until the end-stage to discontinue such treatments. They may prefer to let nature take its course, with the goal of avoiding a prolonged period of time with advanced dementia, if the opportunity presents itself. Such views should be respected and made known to family, doctors and others involved in care.

## Appendix One

# Resources You May Need: Getting Help from Organizations that Understand and Finding Helpful Books

Caring for a dementia patient can be difficult work. But you needn't do it alone. A number of organizations and websites can provide a variety of services to help. They include:

### Organizations and Websites

#### **ADVANCE PLANNING FOR HEALTH CARE AND ADVANCE DIRECTIVES**

##### **Aging with Dignity**

Phone: 1-888-5-WISHES (1-888-594-7437)

Website: [www.agingwithdignity.org](http://www.agingwithdignity.org)

Aging with Dignity publishes *Five Wishes*, an easy-to-use advance directive form that is recognized in at least 40 states. It can be viewed online for free and printed for a small fee, or it can be ordered as a hard copy and mailed. *Five Wishes* includes personal, emotional and spiritual elements as well as a traditional living will and appointment of a health care agent.

##### **Caring Connections**

Website: [www.caringinfo.org](http://www.caringinfo.org)

You can download free state-specific advance directives and information about advance care planning from Caring Connections, a program of the National Hospice and Palliative Care Organization. The state-specific advance directives here may not be the latest versions available, however.

##### **The Center for Practical Bioethics**

Phone: 1-816-221-1100 or 1-800-344-3829

Website: [www.practicalbioethics.org](http://www.practicalbioethics.org)

This nonprofit organization, located in Kansas, publishes the *Caring Conversations Workbook*, which is both a helpful tool for guiding conversations about values and wishes, and an advance directive. It is available in English or Spanish. You can download it free from a link on the home page, or order a hard copy by phone for a small fee.

### **The Coda Alliance**

Website: <http://codaalliance.org>

This is the website of a California nonprofit whose mission is to optimize end-of-life care. Under the “Advance Directive Forms and Resources” link you can find the “Go Wish” game, which is a helpful tool for stimulating conversation within the family about values and priorities relevant to medical decision-making and end-of-life care. This “game,” which consists of two decks of cards printed with specific wishes or priorities and instructions, can be ordered for a nominal fee. This approach has been used successfully with people who have mild dementia.

### **Commission on Law and Aging**

American Bar Association

Website: [www.abanet.org/aging/publications/home.html](http://www.abanet.org/aging/publications/home.html)

Click on the “Publications” topic on the home page to find links to several helpful online resources including the *Consumer’s Tool Kit for Health Care Advance Planning*, *Shape Your Health Care Future with Health Care Advance Directives*, *10 Legal Myths About Advance Medical Directives*, and *Making Medical Decisions for Someone Else: A Guide for Marylanders*.

### **Maryland State Attorney General's Office**

Website: <http://www.oag.state.md.us/publications.htm>

Click on the “Advance Directives” tab to find the Maryland advance directive, a very helpful guide for health care agents, and other information and tools for advance planning, including the *Life-Sustaining Treatment Options Form*. The latter form is used in Maryland nursing homes, and could also be used in other jurisdictions or situations, to guide conversations with the doctor and to formulate treatment plans near the end of life when aggressive medical interventions may not be desirable.

### **Montgomery County Coalition for End-of-life Care**

Website: [www.mccelc.org](http://www.mccelc.org)

The “Resources” tab on this site offers translations of the Maryland Advance Directive form into 6 languages as well as a simplified *Choice of Health Care Agent* form. The latter avoids complex terminology and is very easy to understand. Because it does not include a Living Will section, it avoids the difficulty of trying to make specific medical decisions ahead of time, but it does encourage and provide suggestions for a statement of values to guide medical decision making. This form is applicable to Maryland, Virginia, and the District of Columbia as well as many other states.

### **“Put it in Writing” website**

Website: [www.putitinwriting.org](http://www.putitinwriting.org)

From this website, provided by the American Hospital Association, you can download a wallet card that states you have an advance directive as well as who to contact for more information.

### **U.S. Living Will Registry**

Phone: 1-800-LIV-WILL (1-800-548-9455)

Website: [www.uslivingwillregistry.com](http://www.uslivingwillregistry.com)

The Registry is a private business that electronically stores advance directives, organ donor information and emergency contact information, and makes them available to health care providers across the country 24 hours a day through an automated system. There is a one-time fee for lifetime service.

### **ALZHEIMER'S AND OTHER DEMENTIAS**

#### **The Alzheimer's Association**

Phone: 1-800-272-3900

Website: [www.alz.org](http://www.alz.org)

The national Alzheimer's Association website has a wealth of information about the disease, including a section on brain health and many publications related to living with Alzheimer's. It also links to the Green-Field Library, (search "Library Services") which offers a variety of research and reference services. There are also links to local chapters in every state and the District of Columbia, with information about local services.

#### **The Alzheimer's Association National Capital Chapter**

11240 Waples Mill Road, Suite 402

Fairfax, Virginia 22030

Phone: 703-359-4440

Hotline: 1-800-272-3900

Website: [www.alz.org/nca](http://www.alz.org/nca)

This is the main office of the local chapter encompassing the entire Washington DC metropolitan area and surrounding suburbs in Maryland and northern Virginia. There are also two offices in suburban Maryland that are part of this chapter. The website has information about local educational and support resources as well as special events.

#### **The Alzheimer's Disease Education and Referral (ADEAR) Center, The National Institute on Aging (NIA)**

Phone: 1-800-438-4380

Email: [adear@nia.nih.gov](mailto:adear@nia.nih.gov)

Website: [www.nia.nih.gov/alzheimers](http://www.nia.nih.gov/alzheimers)

A public U.S. Government-funded resource, the ADEAR Center strives to be a current, comprehensive, unbiased source of information about Alzheimer's disease. The organization's information and materials about the search for causes, treatment, cures and better diagnostic tools are carefully researched and thoroughly reviewed by NIA scientists and health communicators for accuracy and integrity.

The ADEAR Center has a staff of Information Specialists available to assist with:

- Answers to specific questions about Alzheimer's disease;
- Free publications about Alzheimer's disease symptoms, diagnosis, related

disorders, risk factors, treatment, caregiving tips, home safety tips, and research;

- Referrals to local supportive services and Alzheimer's Disease Centers that specialize in research and diagnosis;
- Spanish language resources;
- Clinical trials information;
- Literature database searches for further research and reading; and
- Training materials, guidelines, and a newsletter for health care and caregiving professionals.

### **The Alzheimer's Foundation of America (AFA)**

Phone: 1-866-232-8484

Website: [www.alzfdn.org](http://www.alzfdn.org)

AFA's hotline provides information, counseling by licensed social workers and referrals to resources across the nation, including community organizations that offer hands-on support services. AFA's website includes information about Alzheimer's disease and related illnesses, caregiving strategies and behavioral issues, as well as daily news about Alzheimer's disease and links to AFA member organizations and AFA divisions.

### **Association for Frontotemporal Dementias (AFTD)**

Phone: 1-866-507-7222

Website: [www.ftd-picks.org](http://www.ftd-picks.org)

This is a nonprofit devoted to education and support for people coping with fronto-temporal dementia.

### **Lewy Body Dementia Association (LBDA)**

Help Line: 1-800-539-9767

Office: 1-404-935-6444

Website: [www.lewybodydementia.org](http://www.lewybodydementia.org)

The LBDA assists and informs families, caregivers and medical professionals. Outreach services include caregiver help lines (phone and e-mail), a quarterly newsletter, brochures, e-mail and chat groups, local support groups and other events.

## **BEREAVEMENT**

### **American Association for Retired People (AARP)**

#### **Coping with Grief and Loss Web Site**

Website: [www.aarp.org/griefandloss](http://www.aarp.org/griefandloss)

This website provides information about grief and loss and how to find local support, as well as links to national organizations. There is also useful information about the practical steps that need to be taken after a death in the family.

### **The Dougy Center**

Toll Free: 1-866-775-5683

Phone: 1-503-775-5683

Email: [help@dougy.org](mailto:help@dougy.org)

Website: [www.dougy.org](http://www.dougy.org)

The mission of The Dougy Center for Grieving Children is to provide support in a safe place where children, teens and their families grieving a death can share their experiences as they move through their grief process.

### **Grief Recovery Online (GROWW)**

Website: [www.groww.org](http://www.groww.org)

GROWW, a not-for-profit internet community, was founded by widows and widowers but is for anyone experiencing the loss of a loved one. Support is provided by various chat rooms monitored by volunteers, newsletters, and scheduled online meetings on specific topics.

### **The Greater Washington Partnership for Palliative and End-of-Life Care**

Website: [www.gwpartnership.org](http://www.gwpartnership.org)

The Resources section of this website lists all hospice and palliative care providers in the Washington DC and suburban areas. Most hospices offer grief support groups that are open to anyone experiencing a loss whether or not the family has received hospice services. This website also lists other sources of bereavement support including resources within the DC area.

### **Wendt Center for Loss and Healing**

4201 Connecticut Ave., N.W. Suite 300

Washington, DC 20008

Phone: 202-624-0010

Website: [www.wendtcenter.org](http://www.wendtcenter.org)

The Wendt Center is a non-sectarian resource center that provides counseling, training, guidance and support for individuals and communities living with life-challenging illness, loss and grief.

### **CAREGIVER SUPPORT AND PRACTICAL HELP**

#### **The Alzheimer's Association**

Phone: 1-800.272.3900

Website: [www.alz.org](http://www.alz.org)

The national office of the Alzheimer's Association offers a number of services. They include:

- a 24-hour helpline for reliable information and support;
- CareSource, an online guide helping individuals and families find the right care options;
- Safe Return, a nationwide registry and proactive search-and-locator service for patients who wander;
- the Senior Housing Finder, to help locate licensed facilities in a given area; and
- many other resources.



There are also links to local chapters in every state and the District of Columbia, with information about local services such as support groups.

### **Carepages.com**

Website: [www.carepages.com](http://www.carepages.com)

This is a website that offers families the opportunity to create a free web page that can keep them in touch with each other and friends during an illness.

### **CaringBridge**

Website: [www.CaringBridge.org](http://www.CaringBridge.org)

This is a nonprofit organization that offers the opportunity for families or caregivers to create a web page during an illness.

### **Family Caregiver Alliance**

Toll Free: 1-800-445-8106

Phone: 1-415-434-3388

Website: [www.caregiver.org](http://www.caregiver.org)

The Family Caregiver Alliance offers education and support for families and friends providing long-term care at home. The website offers information about a variety of topics useful to caregivers and sponsors programs at the national, state and local levels to support and sustain caregivers.

### **IONA Senior Services**

4125 Albemarle St., NW, Washington, DC 20016

Phone: 202-895-9448

Website: [www.iona.org](http://www.iona.org)

IONA Senior Services is a focal point for health, wellness and creative fulfillment for adults in the Washington DC area. IONA provides a broad range of programs that support seniors, caregivers and their families and can link individuals with services across the country. Services include: adult day health care, club programs for individuals with early memory loss, consultation on options for care for yourself or a loved one, ongoing care management, support groups, workshops, information and referral, transportation assistance and more.

### **National Family Caregivers Association**

Toll Free: 1-800-896-3650

Phone: 301-942-6430

E-mail: [info@thefamilycaregiver.org](mailto:info@thefamilycaregiver.org)

Website: [www.nfcacares.org](http://www.nfcacares.org)

The National Family Caregivers Association website offers information as well as links to other educational, advocacy, and support organizations. There is also a national network of caregiver support volunteers who have been caregivers themselves and can offer advice and tips.

### **Senior Drivers**

#### **AAA Foundation for Traffic Safety**

Website: [www.seniordrivers.org](http://www.seniordrivers.org)

Under the Links tab, on the Driving Safely page, there is a link to a helpful online booklet *Alzheimer's Dementia and Driving*, with practical information and tips from families who have dealt with this issue.

### **Well Spouse Association**

Toll Free: 1-800-838-0879

Phone: 1-732-577-8899

Email: [info@wellspouse.org](mailto:info@wellspouse.org)

Website: [www.wellspouse.org](http://www.wellspouse.org)

Well Spouse is a national, not-for-profit membership organization that gives support to wives, husbands and partners of the chronically ill and/or disabled. It lists local support groups on its web site and hosts online discussion groups.

### **LEGAL ASSISTANCE**

#### **AARP Legal Counsel for the Elderly (LCE)**

601 E St., NW, Bldg. A, 4<sup>th</sup> floor, Washington, DC 20049

Phone: 202-434-2120 or 202-434-2170

Website: [www.aarp.org/states/dc/dc-lce/](http://www.aarp.org/states/dc/dc-lce/)

AARP Legal Counsel for the Elderly (LCE) is a free service for people Washington D.C. residents aged 60 or older in need of legal assistance. If you meet LCE's eligibility requirements and are having problems with your housing situation or benefits, or if you think you need a will or help with your finances, LCE has lawyers who may be able to work with you to find solutions.

#### **American Bar Association**

##### **Commission on Law and Aging**

Phone: 202-662-8690

Email: [abaaging@abanet.org](mailto:abaaging@abanet.org)

Website: [www.abanet.org/aging](http://www.abanet.org/aging)

Resources webpage: [www.abanet.org/aging/resources](http://www.abanet.org/aging/resources)

Publications webpage: [www.abanet.org/aging/publications](http://www.abanet.org/aging/publications)

The Resources webpage has links to state-specific resources for finding legal help for aging-related issues, locating sources of legal aid for those with limited funds or finding an elderlaw attorney, as well as links to other organizations helpful to seniors dealing with legal issues. The publications webpage has links to several helpful articles including *Health & Financial Decisions*, *Legal Tools for Preserving Your Personal Autonomy*, which can be accessed by clicking on "Online Publications for Consumers."

## **PALLIATIVE AND END-OF-LIFE CARE**

### **The Greater Washington Partnership for Palliative and End-of-Life Care**

4125 Albemarle St., NW  
Washington, DC 20016

Website: [www.gwpartnership.org](http://www.gwpartnership.org)

The Greater Washington Partnership for Palliative and End-of-Life Care website has information about local palliative care and hospice organizations in the entire Washington metropolitan area, under the Resources tab.

### **Caring Connections**

Website: [www.caringinfo.org](http://www.caringinfo.org)

Caring Connections, a program of the National Hospice and Palliative Care Organization, offers information about palliative care and end-of-life issues, as well as advance planning for health care decisions.

### **Dying Well**

Website: [www.dyingwell.org](http://www.dyingwell.org)

This is the website of Dr. Ira Byock, a longtime palliative care physician, advocate for improved end-of-life care and past president of the American Academy of Hospice and Palliative Medicine. It provides written resources and referrals to organizations, websites and books that empower persons with life threatening illness and their families to live fully.

### **Growth House, Inc.**

Website: [www.growthhouse.org](http://www.growthhouse.org)

Growth House, Inc. provides a portal to resources for life-threatening illness and end-of-life care. Its primary audience is health care professionals but it contains much useful information and links to resources that can also benefit laypeople.

### **Hospice Net**

Website: [www.hospicenet.org](http://www.hospicenet.org)

Hospice Net provides information and support to patients and families facing life-threatening illnesses, as well as links to locate hospice care anywhere in the U.S.

## **SENIOR SERVICES**

### **Area Agencies on Aging**

Every jurisdiction in the U.S. has a designated State and Area Agency on Aging providing information and referral and certain direct services to older adults and their caregivers. The agencies below serve the Washington Metropolitan area:

**Alexandria Office of Aging & Adult Services**

2525 Mount Vernon Ave., Alexandria, VA 22301

Phone: 703-838-0700

Website:

[www.alexandriava.gov/humanservices/info/default.aspx?id=8002](http://www.alexandriava.gov/humanservices/info/default.aspx?id=8002)

**Arlington Area Agency on Aging**

3033 Wilson Boulevard, Suite 700-B, Arlington, VA 22201

Phone: 703-228-1700

Website: [www.co.arlington.va.us](http://www.co.arlington.va.us) or directly at

[www.co.arlington.va.us/departments/HumanServices/services/aging/aa/HumanServicesServicesAgingAaaAgencyonAging.aspx](http://www.co.arlington.va.us/departments/HumanServices/services/aging/aa/HumanServicesServicesAgingAaaAgencyonAging.aspx)

**District of Columbia Office on Aging**

441 4th St., NW, #900 S, Washington, DC 20001

Phone: 202-724-5626

Website: [www.dcoa.dc.gov](http://www.dcoa.dc.gov)

**Fairfax Area Agency on Aging**

12011 Government Center Pkwy., Suite 708, Fairfax, VA 22035

Phone: 703-324-7948

Website: [www.fairfaxcounty.gov/aaa](http://www.fairfaxcounty.gov/aaa)

**Montgomery County Aging & Disability Services**

401 Hungerford Dr., 4th Fl., Rockville, MD 20850

Phone: 240-777-3000

Website:

[www.montgomerycountymd.gov/hhstmpl.asp?url=/content/hhs/ads/seniorsite.asp](http://www.montgomerycountymd.gov/hhstmpl.asp?url=/content/hhs/ads/seniorsite.asp)

**Prince George's County Dept. of Family Services/Area Agency on Aging**

Department of Family Services/Aging Services Division

6420 Allentown Rd., Camp Springs, MD 20748

Phone: 301-265-8450

Website:

[www.co.pg.md.us/Government/AgencyIndex/FamilyServices/aging.asp?nivel=foldmenu\(1\)](http://www.co.pg.md.us/Government/AgencyIndex/FamilyServices/aging.asp?nivel=foldmenu(1))

**Prince William Area Agency on Aging**

7987 Ashton Ave., Suite 231, Manassas, VA 20109

Phone: 703-792-6374

Website: [www.pwcgov.org/default.aspx?topic=01000900081](http://www.pwcgov.org/default.aspx?topic=01000900081)

**Health Insurance Counseling Project (HICP)**

2136 Pennsylvania Ave, NW, Washington, DC 20052

Phone: 202-739-0668

A project of George Washington University National Law Center, HICP provides free health insurance information, education, and counseling services to Medicare beneficiaries and seniors who live in DC.

## **IONA Senior Services**

4125 Albemarle St., NW, Washington, DC 20016

Phone: 202-895-9448

Website: [www.iona.org](http://www.iona.org)

IONA Senior Services is a focal point for health, wellness and creative fulfillment for adults in the Washington DC area. IONA provides a broad range of programs that support seniors, caregivers and their families and can link individuals with services across the country. Services include: adult day health care, club programs for individuals with early memory loss, consultation on options for care for yourself or a loved one, ongoing care management, support groups, workshops, information and referral, transportation assistance and more.

## **Senior Health Insurance Program (SHIP)**

Phone: 301-590-2819

Website: [www.medicarehelp.org](http://www.medicarehelp.org)

This office is located in Montgomery County, Maryland but offers useful information about Federal government programs, senior health insurance and Medicare. There is also information about Medicaid and other programs specific to Maryland.

## **The Eldercare Locator**

Phone: 1-800-677-1116

Website: [www.eldercare.gov](http://www.eldercare.gov)

The Eldercare Locator is a public service of the U.S. Administration on Aging. The Eldercare Locator links those who need assistance with state and local area agencies on aging and community-based organizations that serve older adults and their caregivers. The toll free phone number is staffed from 9:00 a.m. to 8:00 p.m. (ET) by both English-speaking and Spanish-speaking information specialists.

## **Helpful Books**

### **CAREGIVING AND DEMENTIA**

*A Dignified Life: The Best Friends Approach to Alzheimer's Care, A Guide for Family Caregivers* by Virginia Bell and David Troxel. Paperback, HCI, 2002. This book emphasizes ways to work with a person's strengths utilizing a sympathetic approach to caregiving that preserves dignity and respect above all.

*American Medical Association Guide to Home Caregiving*. Paperback, Wiley, 2001. A basic guide that can help families decide whether they can take on home caregiving; also serves as a manual of skills needed.

*Caring for Yourself While Caring for Your Aging Parents: How to Help, How to Survive* by Claire Berman. Hardcover, Diane Pub Co, 1996. A very helpful resource for adult children.

*The Comfort of Home: An Illustrated Step by Step Guide for Caregivers* by Maria Meyer and Paula Derr. Paperback, CareTrust Publications LLC, 3<sup>rd</sup> edition, 2007. This very useful guide has lots of information about caring for an aging or disabled loved one at home and covers all aspects of care through dying and funeral planning.

*Fierce Blessing: A Journey into Alzheimer's, Compassion, and the Joy of Being* by Wayne and Terry Baltz. Paperback, Prairie Divide Productions, 2003. This true account of one family's experience with Alzheimer's has proved an inspiring read for other caregivers as they face the challenges of coping.

*How to Care for Aging Parents* by Virginia Morris and Robert M. Butler. Paperback, Workman Publishing Company, 2004. A comprehensive practical guide covering many aspects of caregiving.

*The 36-Hour Day, 4th edition: A Family Guide to Caring for People with Alzheimer Disease, Other Dementias, and Memory Loss in Later Life* by Nancy L Mace and Peter V. Rabins. Hardcover, The Johns Hopkins University Press, 4th edition, 2006. This classic resource has been updated several times and contains a wealth of information helpful to families caring for people with dementia and aging. Much of it has been gleaned from families who have found ways to deal with the problems often encountered. It is reassuring and supportive as well as informative.

*What If It's Not Alzheimer's?: A Caregiver's Guide to Dementia* by John Q. Trojanowski, M.D. (Foreword), Lisa Radin and Gary Radin. Paperback updated and revised ed., Prometheus Books, 2008. This is a comprehensive source of information and caregiver guidance for fronto-temporal dementia.

*When Your Loved One Has Dementia: A Simple Guide for Caregivers* by Joy A. Glenner, Jean M. Stehman, Judith Davagnino, Margaret J. Galante, and Martha L. Green. Paperback, The Johns Hopkins University Press, 2005. Highly recommended by the authors of *The 36 Hour Day*, this book combines guidance for the practical aspects of caregiving with sensitivity to the emotional needs of the caregiver.

#### **END-OF-LIFE**

*Dying Well* by Ira Byock. Paperback, Riverhead Trade, 1998. Written by a well-known hospice physician, this book gives inspiring examples of the transformation, reconciliation, and emotional healing that can take place when people die at home with the help of hospice and loved ones. Very moving and comforting.

*Final Gifts: Understanding the Special Awareness, Needs, and Communications of the Dying* by Maggie Callanan and Patricia Kelley. Paperback, Bantam, 1997. This poignant book contains many true stories about life's last chapter. It is reassuring for anyone close to a terminally ill person or for those wanting to understand more about the dying process.

*The Good Death: The New American Search to Reshape the End of Life* by Marilyn Webb. Paperback, Bantam Books, 1999. A very well-written and thought-provoking exploration of the issues surrounding dying in America today, how to define and follow one's own path, the history of the movement for autonomy, and the issues that remain unsolved. Inspiring stories of those who have faced death their own way.

*Handbook for Mortals: Guidance for People Facing Serious Illness* by Joanne Lynn and Joan Harrold. Paperback, Oxford University Press, 2001. The author of this practical guide about many of the issues faced by people with a life-threatening illness, is a well-known physician expert on end-of-life care.

*Hard Choices for Loving People: CPR, Artificial Feeding, Comfort Care, and the Patient with a Life-Threatening Illness* by Hank Dunn. A & A Publishers, 4<sup>th</sup> edition 2001. This excellent 80-page paperback was written by a hospice chaplain and provides a very balanced and reassuring framework within which to approach end-of-life decisions. The companion book, *Light in the Shadows: Meditations While Living with a Life-Threatening Illness*, offers supportive explorations of some of the difficult feelings that may accompany such decision-making.

*How We Die: Reflections on Life's Final Chapter* by Sherwin Nuland. Paperback, Vintage, 1995. Dr. Nuland, a Yale surgeon, describes many of the various ways that life may come to an end, from both the clinical and psychosocial perspective. He also offers insights into the ways patients, families and doctors themselves are misled into making sub-optimal decisions, by their fears of dying. Excellent.

*Intimate Death: How the Dying Teach Us How to Live* by Marie de Hennezel. Hardback, Vintage; American Ed, 1998. This inspiring little book takes us into the practice of a French psychologist who works with dying patients. Her compassion transcends the usual distance therapists keep from clients, and her stories are touching and intimate. They illustrate how meaningful being present with someone who is dying can be.

*Last Rights: Rescuing the End of Life from the Medical System* by Stephen P Kieran. Paperback, St. Martin's Griffin, 2007. A look at the difficulties facing patients and families dealing with end-of-life issues in America, this very well-written book makes the case for moving toward better palliative care instead of continuing to reach for miracles when potential returns are diminishing and the cost and suffering associated with aggressive technology are high.

*Life Lessons: Two Experts on Death and Dying Teach Us About the Mysteries of Life and Living* by Elisabeth Kubler-Ross and David Kessler. Paperback, Scribner, 2001. A distillation of everything Kubler-Ross and David Kessler have learned not only from working with dying patients and their families but also from living. It's also an easy, enjoyable read.

*A Midwife Through the Dying Process: Stories of Healing and Hard Choices at the End of Life* by Timothy E Quill. Paperback, Johns Hopkins University Press, 2001. A

collection of clinical stories that illustrate the challenges but also the transformation possible with compassionate care at the end of life. Dr. Quill is a professor of medicine and psychiatry at the University of Rochester who is an outspoken leader in palliative care circles and has taken courageous positions on helping people attain a peaceful death.

*To Die Well; Your Right to Comfort, Calm, and Choice in the Last days of Life* by Sidney Wanzer and Joseph Glenmullen. Paperback, Da Capo Lifelong Books, 2008. This is a comprehensive guide to maintaining as much control over care at the end of life as possible, and the options for having control over the timing and circumstances of death when there is unrelieved suffering or an unacceptable quality of life is imminent.

### **COPING WITH LOSS (BOTH AFTER A DIAGNOSIS AND AFTER A DEATH)**

*A Grief Observed* by C.S. Lewis. Paperback, HarperOne, 2001. This classic, short memoir is composed of entries from journals the famous author kept of his thoughts and feelings after his wife died. He writes of grief and questions his faith in God as he tries to make sense of his loss.

*Dying: A Book of Comfort* by Pat McNeese. Paperback, Grand Central Publishing, 1998. A practical and helpful book comprised of passages from multiple authors about dying, helping the dying, and grieving.

*The Grief Recovery Handbook: The Action Program for Moving Beyond Death, Divorce, and Other Losses* by John W. James and Russell Friedman. Paperback, 2d rev ed., Collins, 1998. This book contains a series of specific exercises designed to work through the process of grief.

*Living When a Loved One Has Died* by Earl A Grollman. Hardcover, Beacon Press, 1997. A slim book written as poetry, very helpful to those ready to move beyond the acute phase of grief.

*Man's Search for Meaning* by Viktor E. Frankl, Washington Square Press, 1984. In this influential book, Frankl describes his experience in a Nazi concentration camp and how he found meaning in life and reasons to live.

*Necessary Losses: The Loves, Illusions, Dependencies and Impossible Expectations that All of Us Have to Give Up in Order to Grow* by Judith Viorst. Paperback, Free Press, 1998. This classic book instructs us to recognize and deal with all the losses that mark our lives in ways that help us grow and move forward.

*The Orphaned Adult: Understanding and Coping with Grief and Change After the Death of Our Parents* by Alexander Levy. Hardcover, Diane Pub Co, 1999. This book explores the loss of one's parents as an adult, and speaks most directly to middle-aged adults with families of their own. It is not a self-help book for the acute phase of grief so much as it is a well-written and thoughtful guide that will promote self-reflection and empathy for others as they deal with parental loss.



*A Time to Grieve: Meditations for Healing after the Death of a Loved One* by Carol Staudacher. Paperback, HarperOne, 1994. This little book is a collection of individual meditations or thoughts about loss, each about a page long. Each begins with a statement from someone dealing with a loss, adds a quote from a famous person or author, then a short paragraph or two expanding on the issue, followed by a resolution or inspiration to take from these thoughts.

*The Year of Magical Thinking* by Joan Didion. Paperback, Vintage, 2007. This account of the year following her husband's sudden death is a poignant picture of the experience of grief and the emotional journey it entails.

*When Bad Things Happen to Good People* by Harold S Kushner. Paperback, Anchor, 2004. This classic book is a comfort to anyone who asks "Why me?" after suffering a loss or receiving a diagnosis.

### **INSPIRATION AND COMFORT**

*A Short Guide to a Happy Life* by Anna Quindlen. Hardback, Random House, 2000. This very short book reads like a letter of advice. It is full of wisdom and illustrated by charming pictures of people celebrating life while they still can.

*Kitchen Table Wisdom: Stories That Heal* by Rachel Naomi Remen. Paperback, Riverhead Trade, 1997. The author is a well-known physician concerned with compassionate care and spiritual healing, and a survivor of serious chronic illness herself. Very inspiring.

*Who Dies? An Investigation of Conscious Living and Conscious Dying* by Stephen and Ondine Levine. Paperback, Anchor, 1989. This reassuring yet provocative book deals with the issue of what part of ourselves dies with the body and what part endures. Written from a spiritual and somewhat Buddhist perspective, it proposes that the higher consciousness that constitutes our awareness, apart from the individual mind, persists and may be reborn. Excellent.

## Appendix Two

# Checklists You'll Need

### Conversations within the Family

- Talked with family and friends who need to know the diagnosis;
- Let them know how they can help, and when
- Found and provided information about the disease

### Legal and Financial Issues

- Executed a will
- Put financial affairs in order
- Identified someone to have power of attorney for financial matters, and executed the necessary documents

### Future care

- My loved one has told me what circumstances he or she would prefer as the disease progresses, and what circumstances to avoid
- Developed a personal philosophy of care with my loved one or with family and friends recalling past conversations with my loved one
- Written and executed an advance directive for health care that includes the naming of a health care agent
- Discussed financial resources available for future care and how that might influence decisions about care.
- Made sure other family members and friends understand my loved one's wishes about medical care in the future to avoid surprises and help prepare them for the future.
- Talked with my loved one's doctor about medical care at the end of life.

### Taking care of the caregiver

- I'm accepting help when offered.
- I'm asking for help.
- I'm being specific with people about what help they can give.
- I'm taking care of my health.
- I'm talking to someone or several people about what I'm feeling during this journey.
- I'm in a support group or seeking support from others caring for a loved one.

### Doctor visits

- Preparing questions in advance of doctor's appointments
- Bringing a list of medicines and/or the bottles themselves to the doctor's office

- Keeping a record of all doctor visits
- Making sure the doctor finds out everything he or she needs to know during, or in advance of the visit if that's necessary to guard against embarrassing my loved one.
- Bringing completed doctor's visit form to each appointment

**Interacting with Your Loved One**

- Treating my loved one with respect and dignity
- Paying attention to symptoms, aware of what he or she can and cannot do
- Allowing my loved one to help with tasks around the house
- Planning activities that involve the things my loved one enjoys
- Making sure physical activity is part of every day.
- Working to preserve family memories.

## Appendix Three

# Doctor's Visit Form

Health Care Visit for: \_\_\_\_\_

Professional seen: \_\_\_\_\_ Date of visit: \_\_\_\_\_

Purpose of this visit: \_\_\_\_\_

Question #1: \_\_\_\_\_

Answer #1: \_\_\_\_\_

Question #2: \_\_\_\_\_

Answer #2: \_\_\_\_\_

Question #3: \_\_\_\_\_

Answer #3: \_\_\_\_\_

(use space on next page for more notes/questions)

### Current medications (include non-prescription and supplements):

Drug name	Strength	# taken and when	Change recommended

More notes or questions: \_\_\_\_\_

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**Referrals or tests planned:**

Name: test or doctor	When	Where	Phone number

**Other instructions or plans:**

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Return visit date and time: \_\_\_\_\_

Reason for return visit \_\_\_\_\_

Patient or advocate/agent signature: \_\_\_\_\_

Doctor/professional signature: \_\_\_\_\_

## Appendix Four

# Choosing a Health Care Agent

**N**o one can predict when a serious illness or accident might happen. When it does, you might need someone else to speak for you or make medical decisions for you. If you plan now, you can increase the chances that the medical treatment you receive will be the treatment you want.

In Maryland, Virginia, and the District of Columbia, you can choose someone to be your “Health Care Agent.” The health care agent is the person you trust and legally designate to make medical decisions for you if you do not want to *or* are unable to make them yourself. These decisions should be based on your personal values and wishes.

### **What will happen if I do not choose a health care agent?**

If you are too sick to make your own medical decisions, and have never written down the name of your choice of a health care agent, your doctors will ask your closest family member to make decisions for you. There are four reasons why this may be a problem:

1. The closest family member available at the time might not be the person you would want to make decisions for you.
2. Some family members might not be able or willing to make decisions as you would want them to.
3. Family members may disagree with one another about the best decisions.
4. Family members cannot legally make all of the decisions that may be needed. *Some decisions may have to be made by someone appointed by a judge or possibly someone who does not know you at all if you have not named a health care agent.*

### **What kind of decisions can my health care agent make?**

Your agent can:

- Talk with healthcare providers about your condition
- See medical records and approve who else can see them
- Give permission for medical tests, medications, surgery, or other treatments
- Make decisions about treatments designed to keep you alive if you are near death or not likely to recover
- Choose among options for where you receive care and who your health care providers are

- Agree to donate your organs if you have not decided for yourself
- Sign for you to give permission for any of the above

### **Whom should I choose to be my health care agent?**

You can pick a family member as a health care agent, but you don't have to. Remember, your agent will have the power to make treatment decisions, even if other people close to you might urge a different decision.

Choose a family member or friend who:

- Is at least 18 years old
- Knows you well
- Can be there for you when you need it
- You trust to do what is best for you and is willing to carry out *your* wishes
- Would be comfortable talking with your healthcare providers and asking them questions if necessary
- Would not be too emotionally upset to carry out your wishes if you became very sick
- Is willing to accept this important role

### **What do I do with this form after I fill it out and sign it?\***

- Give a copy to your health care agent.
- Give another copy to your doctor.
- Take a copy with you when you are admitted to a hospital.
- Show it to your family and friends and others who care for you.

*\*You must sign this form and two witnesses must also sign it before it is official.*

### **What if I change my mind?**

You may change your mind at any time. To do so, fill out a new form and date and sign it with two witnesses. Then make sure everyone you gave the old form to has a copy of the new one.

*You are not required to use this form. There are other forms available or you can write your own statement. If you have questions about other forms, please talk them over with the person who gave you this one, your doctor, social worker, friends or family.*

## **Considerations for You and Your Health Care Agent**

### **What are the things you want your agent to know?**

Your agent will need to think about conversations you have had, your personality and how you handled other important issues in the past. It is important to think and talk with your agent and your family about such things as:

- The things that are most important to you in your life
- Whether you would rather be at home or in a hospital for the last days or weeks of your life

- How important it is to you to avoid pain and suffering
- Whether it is more important to you to live longer or to avoid prolonged disability or suffering
- The way you would like to be remembered
- Your religious beliefs
- Your hopes for your family if you are very sick or dying

Write down the most important thoughts you have about these things here to help your agent make good decisions for you:

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**Are there other people your agent should talk with?**

Write down the names and telephone numbers of anyone you would like your agent to talk with before making important decisions for you. These are only suggestions and your agent would still be the person who makes the decisions.

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**Choose Your Health Care Agent**

I want the following person to be my primary health care agent:

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First name	Last name		
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Street address	City	State	Zip code
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Home phone number	Work phone number	Cell Phone
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**Back-Up Health Care Agent**

If the first person cannot act as my agent, then I request the person named below to be my health care agent:

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First name	Last name		
------------	-----------	--	--

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Street address	City	State	Zip code
----------------	------	-------	----------

---

Home phone number	Work phone number	Cell Phone
-------------------	-------------------	------------

## When can my health care agent begin to do these things for me?

Do you want your health care agent to start making decisions for you now **OR** wait until you are no longer able to make them for yourself? Choose one and put an **X** next to your choice:

- I want my health care agent to be able to make decisions for me starting **now and continuing after I can no longer make them for myself**. This does not remove my right to make my own decisions if I want to, at any time I am able.
- I want my health care agent to be able to make decisions for me **only after I cannot make them for myself**. The doctors taking care of me will determine when I have lost this ability.

## Sign the Form

To make this form official, you must:

- Sign it in front of two witnesses; **and** have both witnesses sign the form.
- **Sign your name and write the date**. Your name must also be printed, with your address.

I understand this Choice of Health Care Agent document and its purpose. I made my own choices when I filled out this form.

---

Sign your name

Date

---

Print your first name

Print your last name

---

Street address

City

State

Zip code

## Witnesses

**Have your witnesses agree to what is written below, sign their names and write the date.** Their printed names and addresses must also be written in.

- I am over 18 years old and I saw this document being signed.
- The person who signed it appears able to make decisions and does not appear to be under the influence of anyone else.
- I am not the health care agent or back-up agent named in this document.
- I am not the person's health care provider or the owner or employee of a health, long-term care, or other residential care facility that is now or has in the past served this person.
- I am not financially responsible for this person's health care or an employee of a life or health insurance provider for the person.
- I am not related to the person by blood, marriage, or adoption.
- To the best of my knowledge, I am not named in his or her will. I will not be the person who manages his or her affairs after his or her death, and I do not stand to benefit from his or her death in any way.

**Witness # 1:**

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Sign your name

Date

---

Print your first name

Print your last name

---

Street address

City

State

Zip code

**Witness # 2:**

---

Sign your name

Date

---

Print your first name

Print your last name

---

Street address

City

State

Zip code

**Created by the Montgomery County Coalition on End-of-Life Care**

**Applicable in Maryland, Virginia, and the District of Columbia and most other states**

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