Caring For
Your Aging Loved One

by Melissa Allen, Nurse Practitioner

This article describes the need for individuals and families to plan for the physical and mental decline associated with aging. It also describes various ways in which these plans may be accomplished. The author is a licensed Gerontological Nurse Practitioner with both professional and personal experience in this field.

Acknowledgements: Thank you to my extremely supportive wife, Elisabeth Andreason, without her cheerleading and prodding this project would not have been completed. To my parents who graciously allowed me to share details about our personal family situations and offered input into the text. To my writing coach, Wendy Lichtman, I offer gratitude for positive, enthusiastic support as well as organizational guidance. To my friends, Dr. Susan Londerville, who helped ensure accuracy of information, and Jo Gelinas, who provided a lay person's perspective, I offer thanks. And to my friend, Juniper Greist, I am incredibly grateful for providing copy editing so that this article would be more readable. This document would not be possible without the countless patients and their families who have allowed me the honor of providing care during very difficult times in their lives.

Introduction

Very few of us are ready for the decline of elders in our lives. It is sad, frustrating, and often brings up long buried family issues. As a health care professional and friend, I have observed families coping with these changes. I have advised them on navigating the health care system and the social care system so they could better provide care for aging relatives. I have watched the decline of three grandparents and am grateful to have been able to provide care for them.

Whether your loved one lives nearby or far away, the first step is to gather the information you *might* need before a crisis begins. While it is human nature not to prepare until a crisis is upon us, having a few simple steps in place will eliminate some especially messy parts. If you have lost that opportunity because you are already in a crisis, then use this as a learning experience for your own personal planning. Planning ahead for your own future can be a gift to your family.

The initial conversation about the need for additional care can be difficult. Begin the discussion early when there are no problems on the horizon. In this way, the subject can be broached in a non-threatening manner and the rest of the family can hear what options appeal to the elder. For some people, moving into a nursing home would be devastating. For others, moving in with family would be the choice of last resort. Planning ahead is especially important if the family lives at a distance from the elder. Planning will also allow for the elder to be involved in the decision making process and

perhaps to initiate a move if warning signs of decline appear. Overall, it makes sense to have the discussion regarding a potential move as early as possible.
My parents and I assumed care for my father's mother upon the death of her youngest daughter who had been living in the same town. At that point, my parents and I began to search for an assisted living facility. We put my grandmother's name on waiting lists at several nursing homes in Pennsylvania, where she lived, and in California, where I live. We also placed her name on a waiting list at the assisted living facility we all agreed was our first choice. We waited for a bed to become available and for my grandmother to be ready to move. About 18 months later, a bed became available at the assisted living facility. The transition went smoothly.

Long term care of elders in the home or a facility is generally not paid for by Medicare or medical insurance. Either long term care insurance or personal resources are required; thus early planning also requires financial planning. Though financial planning is beyond the scope of this article, professional financial planners and estate planners offer resources to help with this essential task.

For more information about how to find a financial planner, visit this web site http://www.cfp.net or http://www.letsmakeaplan.org

You may be reading this because you or your parent has recently visited a physician or the emergency room and you are beginning to acknowledge the potential of decline. This article is designed to help you navigate the often choppy waters of elder care.

1. Overseeing of Care

When we are called on to oversee care for a loved one, it can feel overwhelming and frightening. Normal emotions also include anger, resentment, and frustration, especially if this means another responsibility has been added to your already busy schedule. This section will outline some of the first steps to take when you begin this process. These steps include identifying a care manager and selecting the appropriate level of care for your loved one.

Identifying a Care Manager

The term "care management" refers to the overseeing and arranging of care. This may be provided by family members or by a hired case manager. ***When a larger family exists, consider how each family member can help. This will divide the burden and help everyone to feel involved.*** For example, my friend is the medical consultant for her family and acts as medical decision maker for her parents. Her brother deals with the legal and financial issues. When the time comes, another sibling will take up managing the household tasks such as food preparation, housekeeping, and personal care. Some family members may live close by and some may live far away, others may not be able to care for a loved one because of other responsibilities**.**

As with any difficult situation family communication and consensus are essential. Tensions can rise and make matters significantly more difficult. Sharing

information and discussing decisions are the keys to involving family members.

As an alternative to having family members oversee care, you may choose to hire a professional care manager to be on site and provide a variety of services. These services might include short-term assistance with placing your loved one in an appropriate living situation. Other services may include long-term management of private caregivers, finances, and physician appointments. Costs vary depending on the level of service. Professional care managers are privately paid (not covered by insurance) and can be expensive. A professional may be the best answer if your family does not have time to provide the level of care required, lives too far away from the elder, or does not have experience navigating the health care system.

For more information about professional case managers the professional organization web site is http://www.caremanager.org/

From a health care provider's perspective, I recommend one person act as the main contact with medical staff.

Especially with large families or if there are conflicts within families, having one contact person allows the health care provider to focus on the care of the patient as opposed to repeating clinical information to multiple family members. The family contact is responsible for distributing information to the remainder of the family.

In case of significant medical changes or difficult decisions, a family meeting with all family members present may be necessary. A family meeting is also useful if there are multiple decision makers or if there is a lack of consensus. A family meeting may be requested by the medical team or the family. In the case of conflicts within the family, the designated primary decision maker needs to be the person medical staff consults for decision making.

Levels of Care

Considering facility placement of a loved one can be painful and difficult for both the family and for the loved one. I say this from personal and professional experience. For most of my career I have provided primary care to nursing home residents. And yet when the time came to visit assisted living facilities for my grandmother, I found it very upsetting. A facility is not necessarily the only option; care in the home can also be arranged. I will outline further options below. In my experience, once an older person is placed in an appropriate setting, he or she will adjust well despite initial resistance to change.

Plan ahead. Even if the current situation is stable and safe, it is helpful to have a list of facilities well in advance that would be able to accommodate an elder in the event of a crisis.

For example, if Dad, who currently provides 24-hour-care for Mom, has his own medical crisis, a short nursing home stay might be necessary for Mom until

Dad is released from the hospital. Knowing which nursing home could care for Mom in Connecticut while you are living in Iowa will help you have a little more peace of mind until someone can arrive to supervise the situation. Having a list of several facilities or home health agencies is helpful in case there is not a bed available or sufficient staffing on short notice. I have seen some situations where the dependent spouse is temporarily hospitalized with the non-dependent ill person until a bed can be found at an appropriate level of care.

The following chart summarizes the four levels of care that are described in this section.

Categories of Care	Type of Facility	What is Provided
Independent Living	1. Home	No personal care
	2. Older living community	No personal care
	3. Multi level community	Options for increased care as needed; often meals provided
Assisted Living	1. At one's own home with private caregiver or homemaker	Personal care, housekeeping, meal prep
	2. Assisted living community	Meals, caregivers for personal care
	3. Adult day care	Personal care at local facility (6-7 hrs/day)
Nursing Home Care	Nursing home	Full personal & medical care
Hospital Care	Hospital	Acute medical care

Independent Living is just what it sounds like. One lives in one's own home or in a community designed for elders. Some communities are developed specifically for those over age 50 or 60 and include single family

homes, condos, and apartments. No additional care is provided but one lives in a community of one's peers.

Multi-level communities or continuous care communities provide different levels of care on the same campus. These communities provide:

- Independent living (apartment, condo, or home)
- Assisted living
- Nursing home care

In these communities additional care can be provided for residents in their own homes (i.e. independent living) for an additional fee. Many communities advocate an "aging in place" model that encourages people to stay in their homes or apartments for as long as it is safe. Given regulations or requirements of the facility however, it may be necessary to move the elder to an area of the campus that can accommodate increased care needs. In other words, if someone is at risk for wandering, a move to a locked dementia unit may be required for safety. Another example might be someone who requires assistance with toileting and therefore needs to be in a location closer to staff.

In most multi-level communities, an initial investment is required. Monthly rates then cover the care that was provided that month. The rates include room, board, and level of care which is re-evaluated on some regular basis. Sometimes people with certain medical diagnoses are excluded. One benefit of multi-level facilities is that once the elder moves in (and can continue to pay), he or she does not need to leave except to go to the hospital. A disadvantage is that the facility staff determines the

level of care, and the staff is sometimes limited in the services they can provide. For example, in the state of California, staff members are not allowed to inject insulin or administer suppositories.

Friendships and a familiar environment can make these communities wonderful places to age and still have increased medical or personal needs met. For families living far away, the multi-level community can ease transitions with minimal need for families to travel to help the elder move.

I strongly recommend unexpected or "surprise" visits to assure your loved one is comfortable and to communicate with the facility about changes family members see in the elder (see below under Nursing Homes). Often one or more meals per day are included and transition to increased care can be easily provided with agreement on a plan of care and costs. Costs are usually paid privately unless a long term care insurance policy includes this type of care.

Assisted Living can include living at home with a private caregiver, an assisted living community, or an adult day care program. Most of the care described below is not covered by Medicare or Medicaid. It may be covered by long term care insurance depending on the policy. Cost may be an important factor in determining the type of care selected. I recommend that one also consider the care that might be needed in the future in making a decision about the elder's initial care needs. For example, my grandmother lived in both an independent and an assisted living facility in

Pennsylvania so that her funds would last longer. Once she needed more care, our family chose to move her closer to me in California as she was less of an advocate for herself with her declining mental status.

Home with Private Care may include a homemaker, a personal care attendant, or a companion. A homemaker provides light housework, shopping, laundry, and other tasks to help maintain the functioning of a household. A personal care attendant provides assistance with bathing, dressing, walking, transferring, and eating. Companions offer companionship and supervision for lonely, handicapped, or isolated elders. You may choose to hire a private caregiver directly or through a home care agency. If you choose to use an agency, be sure to interview both the agency and the person who will be caring for your loved one. Your goal in this interview is to ensure that their services meet your loved one's needs and that you are fully comfortable with them. A benefit of choosing to hire a caregiver through an agency is that the agency usually has done a background check including Department of Motor Vehicles, fingerprinting, and references. Ask during the interview for the results of the background check. Also verify that the agency can provide a replacement caregiver if yours calls in sick. When the hired caregiver is a no-show, it may mean a day of missed work for you. This is similar to the challenge of what to do with a sick child who cannot go to childcare. It can be a nightmare.

Most home care agencies will also provide a licensed nurse to assess the care provider. The agency will also provide insurance, tax reporting, and payroll. You always want to ask how the staff is screened and find out what the staff or agency insurance will cover (i.e. disability, car insurance for driving the elder, liability). Agencies tend to be a bit more expensive than hiring someone directly but also decrease the risks and some of the responsibilities of having a household employee.

Non-agency caregivers, hired directly, provide different advantages. You may have the advantage of hiring the caregiver based on a reference from a trusted friend or on personal knowledge. This type of situation also may provide a more personal and flexible working arrangement. ***If the elder is having an especially bad day, consider staying at home and asking the caregiver to run errands. This could be an added advantage of a non-agency caregiver.***

If you choose to hire a caregiver directly, you will become the employer and will be responsible for paying employment taxes. In addition, it is wise to consider additional homeowner's insurance or an umbrella policy to manage liability risk in case of injury.

Unfortunately, elder abuse is a reality. Once someone is hired, check in regularly. When the caregiver is not around ask your loved one about how they like the person. Stop in unexpectedly when the caregiver is present, and watch for signs of abuse (fear of going out, more fearful in general, anger).

Questions to ask when interviewing a private caregiver:

1) What types of services are provided? What are the costs?
2) Is there a background check done on employees? Can I see it?
3) How often is care oversight provided by the agency?
4) How much and what type of insurance is provided for staff?
5) Is there coverage if the caregiver is ill or cannot work a scheduled shift?
6) What skills and what level of experience do caregivers have?
7) How long have caregivers worked for the agency?
8) Can the agency provide references on the agency and the caregivers?

Assisted Living Communities may provide room and board; assistance with bathing, dressing, and medications; housekeeping; social and recreational activities; and nursing and social services. This care is all provided in a communal atmosphere. Most facilities are not required to have a licensed nurse on duty although some do. Usually each resident has a private or semi-private room.

If your loved one is living in some type of facility, including an assisted living community, drop in unannounced at varying times of day to evaluate the care.

Adult Day Care programs provide several hours of daytime care for elders while primary caregivers are at work. These programs also give caregivers some respite to complete errands and rest. Services provided by adult day care programs include supervision, activities, meals, and assistance with hygiene and toileting. Some offer

transportation to and from the program. The length of time the elder is in the program is usually limited to six or seven hours a day on weekdays. This type of service is usually paid for privately, but some programs may be covered by a long term care insurance policy. For those who would qualify for long term care (i.e. a nursing home), there is a Medicare alternative program called PACE (Programs of All-inclusive Care for the Elderly), available in some major cities.

Nursing Home Care provides three levels of care: skilled care, intermediate care, and custodial care. Skilled care includes management by licensed staff for elders whose needs are considered medically complex and/or require rehabilitation. If the elder has just been hospitalized for three days, the first 20 days in a nursing home may be fully covered by Medicare. Thereafter, a 20 percent co-pay is required for the next 100 days, if the person still qualifies for skilled care. It is rare for patients to qualify for all 100 days. Whether or not your loved one qualifies for skilled care can usually be answered by the facility. With Medicare, the skilled care benefit is only triggered after a three-day hospitalization. If the elder's Medicare benefits have been transferred to an HMO, the insurance company is required at minimum to provide the same care that Medicare would have provided.

Intermediate care provides routine nursing care and assistance with activities of daily living. Custodial care provides room and board, social activities, and supervision. Intermediate care and custodial care are generally paid for privately or through state assistance

programs (Medicaid/Medicaid). If the elder is likely to lack funds at the end of life to pay for health care, the state Medicaid (in California, Medi-Cal) will pay for care in a long term care facility as long as the person qualifies.

When a nursing home is necessary, I recommend that an advocate be nearby. The advocate can be a family member, a friend, or someone privately hired. Quality of care can vary from facility to facility and while rare, there can be episodes of abuse or neglect**.** ***The advocate should stop in at different times of the day, attend quarterly care conferences, and be available to assertively ask questions should issues need to be addressed. Even if there are not concerns about quality of care, an advocate can provide information about the elder or be a familiar face in a strange environment.***

As an example, when my Grandmother first moved to a nursing home, she gave the impression of being fairly cognitively intact (even though she couldn't remember how many children she had – no one in the nursing home knew the right answer until I was asked), she could "fake it" pretty well. During the initial care conference (usually within the first fourteen days of stay) I raised concerns about my grandmother's diaper not being changed often enough. Overall the care in this facility is very good but they had not yet realized that she was more demented than she seemed on initial interaction.

Hospitals provide care for acute medical crisis with an average length of stay three to seven days. Hospitalization may be how you learn of your loved one's need for increased care. Generally eighty percent of hospitalization is paid for by Medicare, if the person has this benefit. In today's health care environment an acute or unplanned hospitalization indicates a severe medical issue and is cause for concern. A 90-year-old friend of mine has a family that assures someone is always present to act as an advocate when she is in the hospital.

2. Safety

Living Far Away

A widely scattered family is a reality in today's society. Given the challenges distance can present, planning ahead can relieve a huge burden during an emergency or crisis. ***Begin by compiling a list of important phone numbers and emails. Make sure health care providers, family members, neighbors, close friends, and the elder on the list have a copy of the numbers as well. Tape this contact information and a list of current medications to the door or the refrigerator. Update the list after each medical appointment and hospitalization.***

Come up with a plan as a family, including ***who will travel to be there in case of an emergency.*** Which family member has the most flexible schedule and the financial means to make the trip? It may be that other

family members travel later to help. With my family, I was the one who would have needed to travel as I lived in the United States. Although my mother's schedule was more flexible, she could not have returned to the U.S. for at least 48 hours given the distance she needed to travel.

Safety of the Living Situation is another factor to consider. Ask yourself these questions:

- Are there stairs?
- How often is the person falling?
- Should scatter rugs be removed?
- Does a cat or dog increase the risk of falling?
- Do electric wires increase the risk of falling or of fire?
- Does safety equipment such as a raised toilet seat and grab bars need to be installed in the bathroom?
- If your loved one has a cognitive deficit, is there a risk of fire from burning a pot on the stove or misuse of a microwave?
- Do financial concerns cause underuse of medications or prevent your loved one from properly heating or cooling the home in extreme weather conditions?
- Do medications have side effects that could cause falls or sedation or affect safety in another way?

A home evaluation by an occupational therapist can provide information about safety equipment needs in the home. A physical therapist will suggest strengthening exercises, recommend equipment for walking, and provide treatment to improve balance. A referral by the

primary care provider for physical or occupational therapy will often be paid for by Medicare.

If you suspect a memory problem, consider a neuropsychological or neurological evaluation to confirm your suspicions (see section on dementia).

Important Phone Numbers to Post:

Primary Health Care Provider
Specialist Health Care Provider
Dentist
Family members
Contact people at various agencies such as the Visiting Nursing Association, Council on Aging or Alzheimer's Association
Local hospital
Church and clergy
Police and Fire departments, the direct phone number (not 911)
Funeral Home
Close friends and neighbors

Personal Alarm System

If there is a risk of falls or a history of falls, an alarm bracelet or necklace is an important safety consideration. This is a device that connects to the phone line. When the button is pushed, a call is made directly to the company providing the service through a speaker phone in the home. If the elder verbally responds during the phone call, he or she can either ask for help or let the agency know no further help is needed (if the button was pushed in error). If there is no response from the elder, the agency contacts the emergency response system to initiate help.

The person wearing the device needs to agree to wear it. Some people choose not to wear the device because they are embarrassed or do not feel that they need it. Others do not wear it in the shower for fear of getting it

wet (the devices are waterproof). The system can be very helpful if there is need for emergency help and a phone is not within reach. Some home security companies provide remote elder monitoring services. In the age of cell phones, the elder might simply be asked to wear a cell phone on a neck lanyard.

Alarm safety systems:
SOS industries 800-225-4848 http://www.seniorsafety.com

Driving

In the U.S., driving is a major means of independence, and it is therefore extremely difficult to address driving safety with your aging loved one. Several different issues may affect driving safety. These include vision, cognition, dexterity, pain, and medications. ***Create some options so that the elder can still get out of the house – be it in a taxi, on public transportation, with a friend, or with a hired driver. Having these options can be a tremendous relief for many elders.*** The isolation associated with not driving can dramatically affect one's mood, mobility, and nutrition. Some grocery stores and pharmacies provide delivery service. In some situations, walking is not safe because of the neighborhood or because there are no sidewalks. Most communities have some sort of public transportation system for elders for a nominal fee. These generally require pre-registration and a reservation 24 hours in advance. Long waiting times and variable reliability can often be frustrating.

The topic of driving can be difficult to broach, especially given the risk of isolation and loss of independence. You can enlist the assistance of the medical provider in the case of dementia or decreased vision. In many states, the diagnosis of dementia requires the health care provider to report to the Department of Motor Vehicles (DMV). The DMV then becomes responsible for assuring the elder is safe to drive. Usually this involves more frequent written and driving tests. The DMV is also responsible for testing vision of drivers. These evaluations increase in frequency with aging drivers.

If the concern for safety is grave, some families opt for the more aggressive approach of removing the car keys or the car. It can be helpful to remember that an elder with a cognitive problem is unlikely to have insight into their deficit. Even if it is obvious to others that it would be dangerous for the elder to drive, the demented person may adamantly deny that a problem exists. In such cases, it is the responsibility of the family and the medical team to work together to assure public safety is maintained. However, if the elder is still deemed to have "capacity" to make decisions (see Legal Questions below), removal of the car can be a very sticky legal situation. In other words, the elder might still have decision making capacity, but may be using "bad" judgment to make decisions. In this situation, the family does not have legal grounds to remove the vehicle.

Financial Safety

If the elder has given up managing his or her own finances, but is still living at home, you need to consider how to manage money. An elder probably needs to have some cash at home in case of emergency. Yet the risk of financial abuse or robbery also needs to be taken into account. One option is creating a separate bank account especially for emergencies. Other options include sending a monthly check to be cashed or opening a credit card account with a limited credit line. If the elder is in an assisted living or nursing facility, a cashier service is usually available for residents.

If the elder is still managing his or her own finances, it is a good idea to ensure that a caretaker or friend is not financially taking advantage of the elder. Other concerns include internet, phone, and mail order schemes. You can address these concerns by monitoring the accounts regularly or having a duplicate statement sent to a trusted family member.

3. Legal Questions, Preparations

It is helpful to find an attorney who specializes in elder law. This legal focus addresses issues that affect older adults such as estate planning, disability planning, and guardianship.

Sources for Legal Support:

1. Referral from family attorney
2. Bar Association. Link to American Bar Association http://www.abanet.org/
3. Council on Aging. Link to National Council on Aging. http://www.ncoa.org/
4. Legal Aid Society (recommend Googling Legal Aid Society with your closest metropolitan city).
5. Alzheimer's Association. Link to national organization, http://www.alz.org. Recommend then contacting your local chapter for local resources.

There are several legal issues related to health care decisions and medical decision making. Depending on the state in which you live, different documents are recognized. It is wise to consult with an expert in your state in the field of estate and financial planning. The following are the different types of documents related to health care decisions.

Power of Attorney for Health Care

The Power of Attorney for Health Care (POAHC) is a document that names someone to make medical decisions in case of incapacity.

Incapacity refers to a state in which someone is no longer able to make decisions for him or herself. Some people fear that their rights may be removed prior to losing capacity. This is not accurate. It is the lack of capacity that allows the POAHC to begin to assist the person. This state of incapacity may be temporary (i.e. when someone is under anesthesia during surgery) or permanent (due to a stroke, dementia, coma, etc). The bottom line is the person is not able to think through a decision regarding treatment for a medical issue. The decision may be as simple as taking an antibiotic or as complex as surgery or life support.

It is essential that the person who is named as the decision maker in the POAHC have the strength to take on this responsibility. I have cared for patients who were very sure that one child would be able to execute their wishes as agent, but that the other child would not be able to do so because of personality or relationship issues. The designated decision maker must agree to understand the wishes of the person he or she will represent and to act upon those wishes. For example, a daughter might want a feeding tube for her own body, but her mother has clearly stated she does not want artificial feeding. As the designated decision maker for her mother, it is the daughter's responsibility to speak her mother's wishes and to decline the placement of the feeding tube.

The surrogate decision maker is to speak for the person who no longer has capacity and is to honor the wishes of the person represented.

It is common to name a spouse as the surrogate decision maker and to name an alternate decision maker if the spouse predeceases the person. For example, if the husband, Joe, is the caretaker for his demented wife, Joan, and he dies, Joan would not have the capacity at this point to name an alternate decision maker because of her dementia. Prior to her dementia, Joan had named Joe as her primary agent and their child as the secondary agent. Thus she had in place an alternate decision maker upon Joe's death.

Once the POAHC document has been executed, the physician or health care provider should be provided with copies. When the health care provider receives the document, he or she can clarify any questions while the patient still has capacity. If the patient no longer has capacity, the surrogate decision maker (the agent) will deliver the POAHC document to the health care provider. The POAHC provides legal documentation that allows the health care provider to work with the agent to make decisions on behalf of the patient.

If an elder is already incapacitated and a power of attorney document does not exist, most states have legal guidelines for family members to make decisions. However, if a situation arises in which family members disagree over plans of care, legal interventions can be costly and time consuming. If there are no living family members, often an ethics committee or a governmental court system is introduced to act as advocate for the patient. The greatest risk in this situation is that the elder's wishes are not honored.

Power of Attorney (POA) for Finances

The Power of Attorney (POA) for Finances is a document that allows a designated person to make financial decisions on behalf of the person who is **incapacitated**. In other words, the designated decision maker can pay bills as well as sign legal and financial documents on behalf of the incapacitated person. If the elder has dementia, is in the hospital, or is recovering from a medical issue, home finances can easily be handled by the surrogate with the POA document. For example, I have been managing my grandmother's finances for the past nine years. Initially it was her preference and I would consult her regarding decisions. Now she has had a stroke, cannot speak coherently, and is not able to read. Clearly it is now necessary for someone to manage her financial and legal affairs. The POA for finances document is often required by financial institutions before a surrogate can perform any actions on behalf of the incapacitated person. Financial institutions sometimes also require letters from health care providers which state the person is not capable of handling financial affairs.

The Living Will

The Living Will is a document that defines the type of medical care you wish to receive in the event of **incapacity.** The living will is not required in every state, but can be useful to outline your wishes, especially if you are concerned about disagreements amongst family members. The document should be as specific as

possible to avoid confusion and potential legal battles. Examples of health care procedures to address in this document include: life support, cardio-pulmonary resuscitation (CPR), use of a ventilator for breathing, a feeding tube (tube feeding is used for swallowing problems and sometimes if someone with advanced dementia is no longer eating), dialysis (filtering of the blood for toxins in the case of kidney failure), chemotherapy, and surgery. The living will document also can address your wishes about procedures as specific as administration of antibiotics or being fed by another person. You might also state wishes regarding administration of pain medications. Some people wish to feel no pain whatsoever even if it means significant lethargy. Others want the opportunity to be alert to spend time with family. Including statements to give an overall guideline such as, "I don't want to live as a vegetable," "I hate the feeling of choking," "My main goal is to be comfortable with minimal interventions" can provide valuable information to surrogate decision makers.

The importance of documenting wishes and discussing them cannot be overstated. Making a decision as a surrogate when wishes have not been clearly stated is an incredible hardship on a family member or friend. Don't assume that someone will intuitively "know" what you would want.

I was witness to a very difficult decision making process in which the patient had not discussed her wishes with her family at all. Joan (all individuals' names have been changed) was not willing to have a discussion about

what she would want if a tragedy occurred. She then had a massive stroke which left her unable to eat, walk, talk, or care for her personal needs. This left her husband, Robert, and daughter, Deborah, with the job of deciding whether or not to maintain her life, long term, in this condition or to stop the tube feeding and allow her to die naturally. The family postponed the decision for about six weeks following the stroke to give Joan an opportunity to recover. When Joan did not recover and it became clear that she would never again be able to read, cook, or walk in the garden – all things she had loved to do – the family requested an ethics consultation. Robert and Deborah made the agonizing decision to stop the tube feeding, as they felt that Joan would not want to live in such a dependent manner. This decision could have been made a great deal easier if Joan had given Robert and Deborah an idea of what she would have wanted. Such planning, although difficult, can be a gift to loved ones. As a side note, Robert has clearly written down and discussed his wishes with Deborah so that she may act on his behalf, if necessary, knowing she is carrying out his wishes for care.

The living will and wishes outlined in a POAHC do not supersede the person if he or she can still speak for himself or herself. These documents provide guidance only if the patient no longer has a voice to speak for him or herself.

Guardianship

Guardianship is a legal proceeding often pursued if there is a conflict in a family, if there are no family members available, or in the case of neglect. Ideally, with advanced planning, guardianship can be avoided, as this is a costly and time consuming process. Additionally, it essentially removes all legal adult rights from the person being conserved. During this process, the court, based on medical evidence and statements from health care providers, finds a person legally incompetent and unable to make decisions regarding his or her care and the management of his or her assets. The court then appoints a guardian or conservator for the person. The guardian has the legal authority to make decisions regarding the care, custody, and management of the person's assets.

First, a Petition for Guardianship is filed. Second, the individual is notified to appear in court and a copy of the petition, which includes the name of the person seeking to act as guardian, is given to the individual. The individual has an opportunity to object. If there are no objections by the individual or others, a guardian is appointed. If there is an objection, a court hearing may be held. This process can often be avoided if a POA has been named. The guardian may be a family member, but can also be a person designated by the state depending on the specific situation.

If there is a medical, mental, or cognitive crisis, most states have a law that allows people who are gravely disabled and no longer able to care for themselves to be

hospitalized. In California, this is called"5150 hold," which refers to the civil code section. This may occur because someone is medically ill, demented, or psychologically unstable. If the person in question is refusing medical or psychological care and is a danger to him or herself or a danger to others, that person can legally be hospitalized for 72 hours until the situation either resolves or becomes clearer.

Letter of Direction

The letter of direction is a letter to the person's family explaining the contents of the will/trust; wishes for funeral and burial ceremonies; and the location of legal documents, financial records, and other important records such as insurance policies. ***A copy of this letter should be left with the attorney and a family member. The letter should include all of the information above as well as name of attorney; safety deposit box location and keys; computer pin numbers; property management issues; family history, documents, photographs; taxes; and anything else of importance.***

I will eventually act as my aunt's POA and help with the distribution of her estate. To ease the distribution of tangible property I have suggested to her that she label her possessions with the names of those she wishes to receive the items. She was excited about directing special items to specific family members and friends.

4. Dementia: Cognitive or Mental Decline

Dementia encompasses many types of cognitive decline. The most common type of dementia is Alzheimer's disease, but it also can be caused by multiple other diseases (multi-infarct or vascular dementia, Lewy-Body dementia, Korsakoff's dementia).

Dementia is a disease we probably all fear for our loved ones and for ourselves. It can be hard to notice, especially if you are living at a distance, but may also be missed if family is living in the same house. My maternal grandmother was living with my family. In hindsight, I can see that she probably began developing dementia about two years before we started to notice a problem. She had become more withdrawn and wasn't performing self-care, which we attributed to depression. We found ourselves compensating for her deficits, and also getting frustrated because of them. Only when the problem became more severe did my family start to put the pieces together. After a visit to the neurologist confirmed our fears, we all felt validated yet very sad.

Dementia is a devastating disease to watch and a challenge to deal with as a caretaker and a family member. There are support groups available and community resources to deal with increased needs. Support groups are often available through the local chapter of the Alzheimer's Association.

Warning Signs to Watch For

Some of the warning signs of dementia may be very easily overlooked. Strange events may seem isolated, family members are busily involved in their own lives, and we tend to deny or sub-consciously compensate for early deficits. Behaviors to watch for include, but are certainly not limited to, a change in personality (someone who was once tidy becomes more disheveled); repeating statements or stories; an inability to cope with a new or different situation; lack of personal hygiene; losing personal items (and sometimes accusing people of stealing); and lack of interest in previous hobbies. Good recollections of the past, but poor memory for recent events are also common signs.

One way to take a closer look at whether or not a decline has begun is to talk with other people in your loved one's life. This group might include other family members, friends, neighbors, and co-workers. These are good contacts to have as well if you are living far away, especially if you find you are in need of local support. Accompanying your loved one to health care appointments, if the elder allows it, can be incredibly useful. ***If you suspect dementia, find a way to meet with the health care team. The additional information you can provide will be useful and you can begin to develop a relationship with the health care provider.***

In my personal experience, I found it hard to notice decline. I mentioned earlier that my father's sister passed away and we subsequently took over care for my grandmother. My aunt was noticing changes and

sharing these with us. However, when my father and I visited, we did not notice these changes during our short stays. My grandmother was able to function at a higher level for the few days that we were visiting. Perhaps her excitement about our visits overcame early signs and minor deficits. Professionally, I have seen similar "improvements" when family members arrive from out of town or engage elders in short conversations over the phone***. Getting information from local sources close to the elder can provide increased insight that cannot be gained from a short visit.***

If you have a suspicion, get the diagnosis confirmed by a medical professional. You want to make sure something else is not going on that can be easily corrected. It is possible for someone to develop a thyroid disorder, diabetes, or an infection with symptoms that mimic dementia. Most of these disorders, once treated, allow the elder to continue living an independent life. A diagnosis of dementia is made by a health care provider, usually a primary care provider, a neurologist, or a medical center, which often house dementia clinics.

Neuropsychological testing, performed by a neuropsychologist, provides more specific information that can be helpful in dealing with the elder. These tests involve two to three hours of cognitive testing. The test results provide information regarding decision-making capacity, safety in the home, as well as strengths and weaknesses in cognitive function. ***With this specific knowledge, tools and plans can be put in place to help the person with early dementia and the caregiver cope. Overall, someone with dementia does better in a***

familiar environment with few changes or disturbances.

Once the diagnosis of dementia is confirmed, a plan to clearly address safety issues and future care needs is essential. The tasks outlined above regarding legal decisions, advanced directives, and care planning become imperative to complete prior to loss of decision making capacity.

5. End of Life Care

Palliative Care

Palliative care refers to care that is focused on maintaining comfort, rather than on curing disease. A comfort-focused approach can be incorporated into all the levels of care described above. This may involve hospice care, a benefit that can provide support to the patient as well as the family. However, comfort-focused care can be achieved with or without hospice in place. You can direct care providers in the home or in a facility on how to administer comfort-focused care. This may include avoiding hospitalization, no use of antibiotics, and administration of pain medications. It may also involve aggressive symptom management while receiving aggressive chemotherapy to treat cancer. Palliative care can be provided by family members, hired caregivers, licensed nursing staff, or staff in a facility.

Hospice

Hospice care is a benefit paid for by Medicare or insurance if a person is eligible to receive Medicare assistance. The services provided are not 24-hour care, but involve aggressive pain and symptom management with a hospice physician, licensed nursing staff, a personal care aide, social workers (to help make specific arrangements and to provide familial support), chaplains, and volunteers. Hospice programs also provide one year of bereavement counseling for the family following the death of the patient.

Funeral Arrangements

For many people, discussions about end-of-life plans and death are not comfortable and may be considered bad luck. However, it is worthwhile to discuss funeral services and disposition of remains in advance. It is also important to plan ahead for this financially.

Prior to the elder's personal funds running out, consider purchasing a life insurance policy to pay for funeral arrangements. Most funeral homes offer a policy and all arrangements can be made in advance, including planning the service, flowers, and internment costs. If paid in advance with a life insurance policy, the costs are paid in today's dollars, thus saving some expense related to inflation. This advance arrangement solves two problems. First, when the funeral is paid for in advance, the family of the deceased is not burdened with the expenses. Secondly, advance arrangements can

decrease some of the emotional pain surrounding the inevitably stressful event of the death of a loved one.

When my maternal grandmother was placed in a nursing home, my mother and I visited a local funeral home, purchased a life insurance policy, and planned her funeral arrangements. Being the only family member in the U.S. at the time of Granny's death, and having just had four wisdom teeth removed, I was incredibly grateful that we had planned in advance. I would not have felt comfortable making decisions without my mother's input, nor was I able to make rational decisions while taking pain medications.

Additionally, you can ask the elder about his or her wishes regarding disposition of remains and memorial services. I have a friend who was diagnosed with a fatal illness and planned her own service, wrote her obituary, and outlined all her wishes prior to her death. Houses of worship often keep a file of funeral wishes for members. I completed this process for my paternal grandmother following a discussion with her about what she wanted at her funeral. For some people, this sort of discussion is far too uncomfortable to consider; however, it is worthwhile and can offer peace of mind.