

ELDER'S FAMILY
LEARNING INITIATIVE:
A GUIDE TO CARE
FOR AN AGING PARENT



Elder's Family Learning Initiative: A Guide to Care for an Aging Parent

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INTRODUCTION

In 2003, Cedar Sinai Park, a Portland, Oregon-based nonprofit organization that provides residential and community-based care to elders and adults with special needs, developed an education program designed to help families navigate and understand the system of long term care. Since then, long term care has undergone significant changes – including a growing focus on aging in place, increased use and existence of community-based services, and greater focus on informal caregiver supports.

The ways in which family caregivers access information has also changed. A greater number of people are now going online for quick access to information. In addition, with the growing use of social networks, more and more people are turning to these social platforms to share experiences and connect with others.

The Elder’s Family Learning Initiative is a much-needed response to these contemporary changes. The program assists families in coping with the long term care system. A program of education training classes, EFLI aims to help families through challenges and struggles associated with the process of placing their aging relative in long-term care.

The program assists families in understanding many areas of long-term care, including:

- Aging process and related health issues
- Housing options
- Insurance, including Medicare and Medicaid
- Family dynamics
- Legal issues
- How to work with staff in long term care facilities to facilitate optimum care

The ELFI program offers an innovative approach to working directly with family members, at their own pace and comfort level. EFLI helps to educate and empower family members to become partners with social service and medical staff in providing the best care for their elders. It offers not only caregiving support, but also critical information that helps to educate family members on the natural aging process, challenges elders experience as they age, and information on the complex systems of long term care. Additionally, the EFLI program’s online learning component is a new approach to educating family members on long term care and elder care topics that will offer on-demand access to both local and national resources as well as an opportunity to connect and learn through shared experiences.

“Elder’s Family Learning Initiative: A Guide to Care for an Aging Parent” is the basic text for the course, covering all its topics. The Elder’s Family Learning Initiative consists of two parts, each, in

turn, divided into two lessons. The first part is a “General Family Training” course, intended for families new to the long term care setting as well as community members considering the issues of aging. This section covers what leads people to need intervention and care, understanding elder care options and planning. Part Two, “Advanced Family Training,” covers family interaction and involvement, planning and care across different settings and end-of-life issues. It is intended for families already in the long term care setting.

The Guide is but one part of the program toolbox, supporting in particular the 8-hour in person class. In-class tools also include verbal and visual presentations, including slideshows, written, written introductory exercises, group sharing, handouts, fact or information sheets, local resources and policies, and Q&As. The course itself is adaptable to the needs of any facility, teaching method, and presentation and learning styles.

We hope the “Elder’s Family Learning Initiative: A Guide to Care for an Aging Parent” will help you in navigating the elder long-term care system. We welcome any comments, suggestions, or other feedback about this publication or the course overall; please feel free to email the EFLI Program Manager Sarah Wheeler at sarah.wheeler@cedarsinai.org.

EFLI Project Team
Cedar Sinai Park

LESSON ONE:
UNDERSTANDING ELDER
CARE OPTIONS

GOAL: EXPLAIN THE RANGE OF LIVING AND IN-HOME CARE OPTIONS

Objective: Participants will leave the class with a basic understanding of the “alphabet soup” of acronyms used to describe options, costs, availability.

A. Health Care Issues

Even normal aging requires a higher level of maintenance and preventive medical care than earlier in life. Some older people will provide their own management and transportation but most people will eventually desire or require some intervention from other family members even when they are still living alone in relative independence.

All older persons benefit from an annual physical examination from their primary care provider who may be a physician, a physician’s assistant or a nurse practitioner. While many people prefer to keep the same physician as long as possible, a geriatric practitioner is often more responsive to the needs of aging patients. The annual exam usually includes tests for areas that require intervention for older patients:

- thyroid function
- colon health
- blood pressure
- lab tests for blood sugars and cholesterol
- nutritional health
- cardiac health
- total review of skin for growths and changes
- vision and hearing tests
- vaccinations for flu and pneumonia

Dental health should also be reviewed at least annually even with gum checks for patients with dentures.

In addition to traditional medical providers, many older persons seek attention from providers of alternative medical care. Chiropractic has long been favored by older persons but in recent years massage, acupuncture, and naturopathic therapies have been more widely accepted by older persons as well as the rest of the population.

As interventions are required in these areas, older persons may need more assistance with managing care. Prescriptions can be mailed or delivered to a home. Transportation services can escort people

to medical appointments. If some cognitive losses, such as short term memory loss, occur, people may need assistance with taking medication. Devices exist for reminding people to take medications or to prevent taking medications before the appointed time.

Other mental health issues may arise as part of normal aging requiring interventions. As noted, depression is often the underlying cause for many aberrant behaviors, including substance abuse. It is often under-diagnosed or misdiagnosed in older persons for many reasons. If an older person lives alone, her daily routine may not be known to others and increasing inactivity and isolation may go unnoticed. Late onset depression may be triggered by grief and loss. While the latter should be honored and may not require treatment, they may lead to pathological depression and should be monitored. Older persons with long histories of mental illness need special attention as medications may become toxic and treatment modalities may be limited by accessibility, cognitive deficits, and hearing and vision loss. It is noted, however, that some chronic mental illnesses, including personality disorder and some psychotic conditions, improve with age.

Dementia is, of course, the condition that most frightens older persons and their middle-aged children. Dementia is a cognitive disorder with deficits in memory and executive function—the ability to manage one’s activities. Related to health care, however, it should be noted that dementia requires a diagnosis and that many conditions can cause a reversible dementia. These include over-medication, nutritional deficiencies, hypothyroid disease, and depression. Some dementias are not reversible but will not progress if the cause is treated. These include dementias caused by substance abuse and stroke. Such conditions should be ruled out through testing and detailed physical history before a diagnosis of Dementia of the Alzheimer’s Type is made.

The management of health care may remain at a maintenance level throughout life until a brief acute event ends life. Although that is the path most people desire, it is not the norm. Maintenance of some chronic conditions may remain stable but can quickly and without warning escalate to a more acute level requiring interventions and the assistance of family or other caregivers. The most interventions are needed for older persons living alone or independently since those in supervised settings may have some or all care needs arranged. However, as conditions escalate not all care levels can provide the attention needed.

B. Activities of Daily Living

Daily life is defined by a series of tasks that must be performed or directed in order to function with any level of capability and thus, independence. Only the person in a vegetative state, a coma, makes no decisions and does not direct any aspect of care. From complete independence to dependence on caregivers, the ability to perform the Activities of Daily Living describes the level of care that a person will need to maintain health and safety. Just as noted above, roles can never be predicted by age, and neither can social and functional capability.

The Activities of Daily Living include:

- toileting
- eating
- preparing food
- dressing

- grooming
- bed mobility
- transfers
- ambulation
- bathing

Each category can be refined in order to determine the level of an individual's independence. For example, a person may be able to groom herself when someone gathers all items and products and places them in front of her. However, her cognitive deficits may prevent her from performing the set-up activities herself.

In addition, the activities are not necessarily equal in difficulty or importance to one another. A person may be able to ambulate one hundred feet but be unable to roll to the side and sit up in bed. Another may be able to ambulate only five feet but can roll to the side and sit up in bed alone, thus enabling a transfer to a wheelchair and travel to the toilet where the five foot walk is sufficient to be independent in a room. Bed mobility—rolling to the side and sitting up—is both difficult and under-rated as a key to functional capability.

Toileting is another complex issue. A person may be occasionally incontinent of bowel or bladder and be unaware of the deficit or unable to manage the hygiene related to it. Another person may be completely incontinent and be able to wear and change incontinence products and clean the affected skin area to avoid infection, offensive odor, and skin breakdown.

Social capability is largely dependent on cognitive status, assuming the absence of major mental illness prior to any cognitive losses. The symptoms of mental illness can prevent persons of any age from performing the Activities of Daily Living related to preoccupation with internal stimuli, such as voices, delusions, hallucinations, or perseverative thoughts. Absent such a diagnosis a person who has social capability with poor functional capacity can often direct her own care using caregivers, assistance devices, even therapy animals, to perform tasks. A number of factors feature in the decision to remain outside of a care setting using more informal support, including tolerance for risk and isolation, judgment, depth of support system, and ability to provide sufficient recreational diversion. While income is often a factor, an adequate public and community service system can enhance private funds.

Performing the Activities of Daily Living depends more on cognitive and social function than on physical ability. Another set of activities that can determine level of care needed is the Instrumental Activities of Daily Living, which include:

- using the telephone
- obtaining and preparing food
- paying bills
- keeping house
- doing laundry

All can be performed with assistance from an informal network of providers, including family and devices. However, one, taking medication appropriately and safely, may require more formal intervention if cognition and judgment are impaired. Such intervention is available in the form of mechanical devices that open locked compartments and sound alarms triggered when that medication is due.

C. Health Changes Leading to Higher Levels of Care

When an older person retains cognitive and social functions, there are many simple mechanical interventions available to maintain independent living at home. However, some medical conditions require a higher level of care than can usually be supported at home without formal, professional intervention. Issues around diabetic care, such as skin care, may require daily nursing intervention. But assistance with homemaking, bathing, shopping and bill-paying can be addressed with family or paid, companion, or aide-level involvement. Most of this assistance involves only a few hours a day.

Higher levels of care are often indicated by the amount of time the caregiver spends with the person, the nature of the tasks performed, and the time of day they are performed. A person who is unable to toilet herself or manage her own incontinence care will need someone with her at all times to maintain skin safety and hygiene, as will a person who is unable to access many medications throughout the day and night. Finally a person who is medically fragile with many attacks of pain and weakness will require constant companionship, if not care, to avoid the multiple 911 calls which often signal to the community the need for a higher level of care. Many persons who are medically fragile but with no cognitive deficits are impaired by a level of anxiety that affects their social functioning and requires constant attendance of an aide or companion.

Such needs are usually met by admission to a structured environment, from foster care to assisted living to a nursing facility. They can be addressed by live-in assistance from family members or paid caregivers, but such interventions can be stressful for families and expensive or unreliable using paid caregivers. Day services programs can also provide an alternative and respite for families.

The most frequent reason cited for requiring interventions and higher levels of care is the decline of cognitive function. An older person with cognitive deficits may live at home safely for some time. The variables that provide for care and safety at home include:

- a healthy spouse or other adult in the home
- familiarity
- routine
- a strong, informal support system
- the personality and course of the decline of the impaired person.

The three reasons most cited by exhausted caregivers as the precipitating factors for placement are: wandering, combative or assaultive behavior, and inappropriate behavior related to toileting. Wandering out of the house at all times combined with day/night confusion means that the caregiver does not sleep or the impaired person is not safe (persons with cognitive impairment retain amazing ability to open locked doors or windows or to disable alarms). Assaultive behavior endangers the caregiver and often brings forceful intervention from the rest of the family or the physician. Urination throughout the home combined with smearing and hiding fecal matter becomes intolerable at times combined with other behaviors and caregiver exhaustion.

Pre-morbid personality is not necessarily a predictor of personality during the course of any dementia. Some impaired persons are quiet, placid, suggestible and cooperative throughout the course of the disease. If they have an Alzheimer's type dementia they may remain at home until the disease itself stiffens their bodies to point where a smaller caregiver cannot move or dress them. Others deny their

impairments, become paranoid and combative, refuse medications, bathing, dressing and all other assistance and quickly escalate to the behaviors noted above that lead to placement. For some, that occurs in the first months of the diagnosis; for others it can take many years.

D. Positive Intervention

Whenever an intervention is needed to provide appropriate and safe care, the outcome depends on planning, tailoring the right match of care and caregiver for the older person, and implementation that is respectful and empowering. Even with the best of intentions, there are losses involved for the individual and family. Independence, privacy, and some personal choice are reduced when outside forces enter the individual or family system.

E. Tying Levels of Independent Function with Service Options

Although the number of options may appear confusing when facing a choice of living situations for a loved one, the plethora of living arrangements is a response to the dearth of options thirty years ago. At that time, the least impairment, such as the inability to prepare meals, could propel an older person into a nursing facility at great personal and financial sacrifice. Today, the concepts of “lowest level of care” and “continuum of care” are in place to assure that older persons who do require assistance have the option to receive it in their home. If they do have to leave their homes, they can move into settings where they have the most independence and opportunities to continue as many familiar life patterns as possible.

Retirement Living

This option is usually initially chosen for comfort, convenience, and companionship rather than for the actual assistance provided. Such facilities range from high-rises with housecleaning, linens, and meals served in a communal setting to huge colonies of homes restricted to persons over 55 and featuring golf, tennis, and country club opportunities. Facilities limited to retirement options do not offer the continuum of care that can allow an older person to “age in place” and have services added as needed.

Assisted Living

This option provides a true continuum of care and specializes in meeting individual needs. Most assisted living facilities have residents who can move in with no needs other than those provided by retirement facilities. As they become frail and need more care, services are added to their plan up until care is required in a nursing facility. The limits of care available differ by facility with each state overseeing facilities according to its regulations.

Residential Care Facility

This option may simply be another name for assisted living. However, in some states, there are different regulations and licensing requirements for each. A residential care setting may have fewer lower

levels of assistance than assisted living. More care options may be available and a resident may be admitted at a higher care level than is permitted in assisted living.

Skilled Nursing or Intermediate Nursing Facility

This option usually follows a hospital stay and is ordered by the physician as part of the discharge plan. Terminology has changed over the years but this is the setting formerly known as nursing home, convalescent home, rest home, or home for the aged. Current terms also include rehabilitation center or facility. Throughout the nation, such facilities are licensed by the state and regulated by state and federal policies. Most provide both skilled and intermediate care.

Skilled care is limited to that requiring the daily implementation, provision, management, observation, and evaluation of care by licensed professional staff, such as registered nurses and physical therapists. All other care is intermediate or custodial, such as assisting patients with getting in and out of bed, using the toilet, dressing, and eating. The line between skilled and intermediate care is rarely clear to the consumer and is even at times a matter of disagreement among insurance providers, physicians, and nursing facility staff (the reason the demarcation is so important is that Medicare and other health insurance pay for most skilled care and not for most custodial care). Some facilities provide only intermediate care and some hospitals have facilities on their campus, which they try to maintain for skilled care. However, if a patient converts to intermediate care and wishes to remain in the facility with appropriate payment, the facility must oblige.

Adult Foster Care

Although the availability and regulation of such facilities differs in each state, foster homes are generally privately-owned facilities in single-family dwellings. A caregiver sees to the custodial needs of up to five persons. Most such facilities do not provide skilled care and are unable to provide for the night needs of residents who need toileting. However, some specialized homes do provide such care and some are owned by licensed nurses who provide a higher level of care. In most states, homes are licensed and overseen by state regulators who visit and have the power to close the homes, just as in the other previously noted facilities.

Home Health Care

Home Health Care is a specialized service that follows a hospitalization or a skilled nursing admission and responds to an acute illness, surgical procedure, or injury. The costs are often covered by health insurance, it is provided only with a physician's order, and by a licensed home-health agency. Providers are nurses, licensed social workers, rehabilitation therapists, and certified nursing aides who are usually designated as bath aides. The care is rarely provided for more than a limited period of time over weeks and for no more than one hour at a time from each discipline. The services cannot provide supervision of a patient or respite for a caregiver.

Home Care

Home Care is provided by agencies and individuals who may or may not have any kind of license or oversight. It ranges from companionship to assistance with dressing; and from one or two weekly

visits to full-time overnight care by two persons for transferring and toileting. It can be performed by a family member or friend, for reimbursement, room and board, or without remuneration.

Hospice Care

Hospice is a concept and not necessarily a place. While there are hospice facilities located in larger cities, most hospice care is provided in nursing facilities, foster homes and private homes. Hospice staff include the same licensed professionals providing home health and the programs are often co-located in the same agency. The hospice focus is on comfort care, not on treatment or curing a disease or condition. Spiritual support, counseling, and some volunteer services are also provided. Hospice services are covered by Medicare and are sometimes covered by other insurance; they require a physician's order which will include a prognosis, orders for care and medication, and agreement to follow the care. Outside of a hospice facility, the person must have their custodial care needs met by someone other than hospice staff, who will provide only specialized, intermittent care.

F. Changes in the Level of Care

There is a great deal of fluidity among many of the above levels. People may remain in one setting receiving additional care while others with the same needs might be admitted to a higher level of care. Why do such incongruencies occur? How are level of care changes determined?

Initially, the level of care determination is based on the setting in which the decision is made and the urgency of the timing. Almost no time may be allowed from the moment a hospital discharge is ordered to the time the person must leave the hospital or pay privately. However, if a decision is being made from home and the person is safe or supervised, the process can be more planned and relaxed. In the first case, a hospital discharge, the initial placement decision may not be the final one and another care level change may be appropriate later. From every structured setting—hospital, nursing facility, assisted living, residential and foster care—facility staff, medical providers, and insurance case managers all have more input than if the decision is made from an informal setting. From home, the resident and family select the input they need and make decisions based on family history, culture, finances, geography and convenience. External providers may provide information for the decision, but they do not make the decision itself.

Facilities decide to request level of care changes based on two criteria: the care needs of the resident and the caregiving ability of the facility. If a resident in an assisted living facility is going to require the services of a licensed nurse several times per day as an ongoing care need and the facility does not have a licensed nurse on staff, the resident will be asked to make a level of care change. The once-a-day requirement may be met by a home-health nurse but not more than once a day and, possibly, not for a prolonged period.

Most facilities would want to allow a person to “age in place”, but may determine that staffing levels could not accommodate the transfer issues of a 300 lb. person vs. a 110 lb. person. On the other hand, if a resident or family member can be taught to provide a service, such as testing for blood sugars, when a licensed nurse is not available, the person may remain at a lower level of care.

The initial decision by a facility to admit a resident is nearly as momentous as for the family because facilities do not easily ask for changes or request that a resident move. There is a philosophical

understanding that once a person is admitted, she will remain as long as she and the family desire within the limits of care possible. Thus, one may see an applicant for admission denied while someone in the same or more advanced condition is allowed to remain. This is a critical issue to remember when older persons say they want to remain at home as long as possible. They may be committing to admission to a higher level of care, perhaps a nursing facility, than if they had made an earlier planned and preventive move, perhaps to assisted living.

Finally, when a facility requests or suggests a level of care change and the resident or family disagrees, there is an appeal process at every level. If the skilled status in a nursing facility or from home health is changed to intermediate by the insurance case manager, physician or the facility staff, a formal appeal is offered at the time the change is communicated. However, at the assisted, residential, or foster care level, the process is informal and the decision probably follows several meetings or phone calls. If no agreement is reached, an appeal is possible to a manager, board, or ombudsman.

Above all, do not expect pre-existing problems to be resolved in a care setting. Personality issues, mental health problems and substance abuse will not improve in a care facility. They may be exacerbated by the pressure of new demands and surroundings and may be even less tolerated by staff and other residents than they were by family.

Most Skilled Nursing is covered, at least initially, by medical insurance. When that is exhausted, costs can range from \$250 per day to thousands of dollars, depending on care and medication costs. Most Intermediate Care is not covered by medical insurance but may be covered by long term care insurance. Costs range from \$150 to \$250 per day but vary because some facilities include all costs, except medications, in a daily rate, while others charge a lower fee, then add the cost of protective garments, nutritional supplements, laundry, medical supplies (dressings, needles, swabs), personal items (tissues and powder), oxygen, and restorative treatments from aides (exercise). Private rooms raise the cost even further.

Adult foster care can cost from \$1,500 per month up to about \$3,000, but, again, it is important to determine what is covered and not covered in a monthly fee. Private rooms increase the cost of foster care as in other settings.

Home-health costs are as high as \$120 per hour for nursing care, but agencies providing these services rarely serve individuals with care that insurance would not cover. However, once insurance is exhausted, costs for physical therapy are about \$65 for half-hour sessions, and baths can be about \$50.

Home-care costs have the widest range of all of the services. Full time overnight care can cost \$12,000 per month from an agency to \$400 per month to an individual who is also given room and board. Agency caregivers are referenced, trained, paid, and insured through that agency, and shifts must be covered. If a caregiver does not show up for work, the agency must provide a replacement, even a supervisor. Private caregivers cost less but the recipient of care is the employer with all corresponding tax and insurance responsibilities, and there is no assurance of competence, honesty, or attendance.

In-home hospice costs are the same as home care. Most insurance covers the professional services. Residential hospice runs from \$200-\$300 per day.

What happens to individuals and families when costs are not covered by insurance and when private funds are not sufficient to pay the enormous and growing expenses of long-term care? For the most part, adult children are not required by law to pay for the care of their parents. Married persons must share resources and income according to strict and complex federal and state laws. Once the

shared resources are used, the state uses Medicaid funds to supplement payment. However, because the Medicaid payments are consistently and considerably less than the cost of care, many facilities either do not accept Medicaid residents or they limit their numbers. Such facilities will require evidence of sufficient funds prior to admission of each resident.

Many older persons will attempt to avoid using resources to pay for long term care by transferring funds to adult children or other families. They should be aware that there is a three-year period called a “look back” during which transferred funds are still counted as resources and Medicaid will not cover costs. Such transactions are often the basis of family conflicts.

Many older and middle-aged persons are purchasing long term care insurance to provide for these needs. Financial planners and elder care attorneys should be consulted for their expertise in these areas.

LESSON TWO: PLANNING

GOAL: REVIEW THE STEPS FAMILIES AND INDIVIDUALS TAKE TO ENSURE THAT THEIR WISHES ARE FOLLOWED AND THEIR SAFETY AND WELFARE ARE PRESERVED

Objective: Participants will leave the class with an understanding of the documents and interventions that will be necessary in case of diminished capacity to make appropriate decisions.

Disclaimer: The information in this lesson comes from public sources available to anyone and from the experience of the course writers and presenters. It is in no way intended to consist of recommendations or legal advice. All participants are encouraged to discuss these issues with physicians, accountants, financial planners, and attorneys of their choice.

A. Advanced Directives

The documents that fall under this general rubric vary from brief check-off documents covering the basics of resuscitation orders to narrative living wills created from the spiritual and cultural values of an individual. Advance directive is a general term describing living wills and medical power of attorney. Either document allows to give instructions about future medical care and appoint a person to implement those instructions in case of inability to do so. Whether the document will have the intended legal status depends on the state and physicians' and family's choice.

Living Will

An outdated term for an advance directive in which individuals go into some detail about their wishes for medical treatment at the end of life should they be unable to communicate. It guides family and physicians in choosing treatment protocols. "Living Will" is no longer used as all advanced directives are referred to as just that. This term may be used by elders who created this years ago.

POLST—Physician's Order for Life Sustaining Treatment

POLST is also an advance directive. This is a shorter, more specific document that asks individuals a number of pertinent questions about immediate care. Its most pressing question relates to code status. It asks the person if she would want Cardiopulmonary Resuscitation ("CPR") treatment that attempts to restore breathing and circulation if the staff of the facility were to enter the room and find the person with no pulse and not breathing. Anyone who refuses or fails to sign this document is usually a full code in most facilities, meaning she will receive all treatments, paramedics will be called, and she will be taken to the hospital. Other questions involve antibiotic treatment and tube feeding

and do not have the urgency of the code issue.

The issues to be addressed by individuals and families when deciding what the Advance Directive will state are dictated by family values and culture related to end-of-life issues. Some individuals and families are determined to sustain life at all costs and direct physicians to provide life-sustaining treatment which replaces or supports essential bodily function(s), including:

- cardiopulmonary resuscitation
- mechanical ventilation
- artificial nutrition and hydration
- dialysis
- other treatments

Other individuals and families are determined to limit the interventions and direct physicians to provide palliative care to relieve suffering, control pain and symptoms and maximize function even if these efforts hasten death.

While it is impossible to foresee all of the possibilities for individuals at the end of life, it is easiest to make decisions well before events make them urgent. The emotional stressors at the time of illness and medical crises can make it difficult to consider values, culture, past experiences, and attitudes.

B. Power of Attorney

For many people, the term “Power of Attorney” connotes only financial issues, just as asking someone if they have a Living Will will elicit a positive response regarding distribution of assets. There is a whole new set of meanings related to end of life care. However, since care involves expense, it is equally important to address financial issues for a time when the older person is not able to manage resources.

A financial document called a Durable Power of Attorney is the usual tool used by families to ensure that they can access resources to pay for care when their loved one is unable to communicate or make judgments. This document is activated at that time and up until then, the owner of the income and assets remains in control of them. Many families will also have the names of adult children on bank accounts and with keys to safe deposit boxes. The process is easiest for local family members and can be difficult for long distance family members. But, as with most of these issues, good communication makes it less cumbersome.

When an older person is diagnosed with a progressive dementia or any condition that diminishes cognition, families may take a more formal approach.

A Medical or Health Care Power of Attorney is a step that can follow an Advance Directive or Living Will and is often attached to those documents. It is used to appoint one person, and often an alternate as well, to make medical decisions for a person who can no longer make them. In various states and medical communities it may also be called a healthcare proxy, a healthcare agent, a durable power of attorney for health care, appointment of a surrogate, or attorney-in-fact. A legal attorney is not required to complete this document.

The appointed person can make any health care decision the patient would make and have access to the same information as the patient. The appointee can change health care providers and facilities

but would need to be financial power of attorney to change insurance.

No matter how perfectly executed, Advance Directives and Health Care Power of Attorney documents are ignored at times. The directive Do Not Resuscitate is routinely disregarded by Emergency Medical Technicians because the law requires them to provide medical stabilization and transfer to a hospital. The law and their training assume that they were called to resuscitate. The status of Health Care Power of Attorney and the instructions given by that person may be disregarded in a hospital. Other family members may disagree with the instructions or the physicians and staff disagree with the treatment requested by the surrogate. Again, communication among family members and with health care providers prior to the crisis can smooth the process. In addition, advance knowledge of the philosophy of the hospital in which care may be provided can help avoid surprises and misunderstandings later.

C. Conservatorship and Guardianship

While most individuals and families cope with the activities and decision-making of surrogate care with advance directives and powers of attorney, there are situations which point to the need for a more formal, in other words, more legalistic, approach to surrogate decision-making. Such situations usually combine poor judgment related to decreased cognitive status, along with lifelong patterns of behavior. A person who is unable to care for herself, refuses to accept assistance in her home or leave her home for an assisted setting, but has a record of multiple, panicked calls to 911, is an example of someone who is unlikely to agree to or abide by the terms of a Power of Attorney.

The least intrusive step in the process of taking over decision-making is obtaining a conservatorship. This usually requires an attorney and may involve a judge if the person whose autonomy is affected is in active disagreement with the process. The outcome of the process is that the person no longer has access to her funds. Therefore, her house can be sold and she can be told to move into a more supervised setting. She cannot write a check, establish or manage a bank account, or enter into any financial agreement. A conservator may provide the individual with spending money or even establish a separate limited checking or charge account, but this is all at the discretion of the conservator, usually overseen to some extent by the court.

The conservator process may sound quite limiting to the individual until one considers the effect of a guardianship. This process always requires intervention of a judge, and it is, in most states, very difficult and expensive to obtain a guardianship. In fact, for those reasons, it is also very rare. An individual with a guardian cannot vote, marry, divorce, cross state lines, agree to medical care, or join any organization or association. In effect, they no longer own their name. Guardianships are often granted only after all other interventions have been attempted and many warnings given. If mental illness is involved and medications or other therapies are followed by a period of stability, an individual may request termination of a guardianship, and unless there is an extreme history of noncompliance, a court is likely to grant it.

When the courts are involved in either conservatorship or guardianship, the judge will nearly always want to interview the individual affected by the process. It is amazing to families and the rest of the support system how often a person who is totally disordered at home can “pull it together” for a court appearance and impress the judge with her reasonable appearance and behavior. It is, in such situations, necessary to involve public safety officers to create a record of behavior that will impress

the judge more than appearances.

Many families and courts choose to appoint guardians and conservators who are not family members. Some such appointees are volunteers or professionals. The latter are paid a fee for the service so financial assets must be considered before taking this route. There are also public guardians and conservators but their resources are usually stretched very thin and are used in extreme situations. Nursing and assisted living facilities may become conservators in fact when no other options are apparent but administrators and staff of these facilities worry, appropriately, about the appearance of a conflict of interest.

Even if a family member will serve as guardian or conservator it is recommended that an attorney specializing in this procedure be employed to implement it.

D. Competency and Elder Rights

All of the steps described above relate to limiting the autonomy of older persons. Autonomy is independence—acting on one’s own without control by others. Autonomy is very much a societal value and varies sharply among societies. Clearly, autonomy is generally perceived as highly valued in the United States but not in some subcultures of the nation and not for every member of some subcultures. Autonomy is also only an abstract value, even in the USA, where laws, zoning regulations, societal norms, and other boundaries limit independence. That said, most of us have a great deal of autonomy, especially in decision-making. Limiting autonomy negatively affects the quality of life of the individual and should be considered seriously before being invoked.

Autonomy is limited by level of competence but competence is impossible to define broadly. It can be defined narrowly by area or absence. Competency involves the ability to make decisions. It is defined by the process, not the product. For example, a woman living alone in her own home with a documented history of falls may say: “Yes, I fall, and I will probably continue to do so, but I accept that risk because I want to stay in this setting, alone.” Another woman in the same situation may say: “I never fell and I won’t fall.” The product is the same; both are saying they want to remain at home but the first woman acknowledges facts, risk and outcome. The second is making a statement clearly contradicted by the facts, denying the risk and ignoring the outcome. Her competence could be questioned although she might simply later tell an investigator or judge: “I knew all of that—I just didn’t want to discuss it with them.”

A competent person possesses and retain values, can communicate and understand information, and can reason and deliberate about choices. A person with cognitive deficits may be competent in one functional area and incompetent in another. A man may be unable to understand his mail or pay his bills but be perfectly capable of continuing his routines at home, from bathing and hygiene to cooking and cleaning. There would be no reason to limit his autonomy beyond financial restraints.

Most of the time in our society, the concept of elder rights promotes freedom over safety: a person can choose to live in harm’s way if she is competent to make that choice, does not place others at undue risk, and does not break the law. There are many caveats in that statement but they are usually decided by courts and not family members.

E. The Family Dynamics of Planning

All of the steps noted in this session involve decisions being made by individuals and families across the nation every day. Sometimes the process is smooth and at other times it is very difficult. There are many factors involved in how the process evolves but the major indicators related to the family are as follows:

- family communication patterns by skill and history
- family resources available as defined by finances, time and energy
- family history of conflict and troubled relationships
- family experience with change over time
- shared family values or absence thereof

Other indicators relate to the experience, flexibility and communication skills of the medical providers, facility staff, and community aging network staff involved in consulting with the family and advocating for the older person.

It should not be surprising that family patterns of relating to and communicating with one another become more cemented in times of crisis, such as a sudden, acute, life-threatening, or life-altering medical event experienced by a family member. Families whose members have a history of relating to one another smoothly with effective, ongoing communication, tolerance of each other's life choices and shared values that translate into medical decisions can usually come together to support one another in a crisis. If communication has been effective they probably already know the health care decisions and who is making them.

On the other hand, families who have a history of negative or distant relationships, who avoid or have difficult communications and judge each other harshly with little history of support or shared values, are unlikely to face the difficult decisions involved in planning medical care mid-crisis with ease. Local adult children who have been making decisions may suddenly be confronted with a sibling from across the country who demands input into the process of determining end-of-life care or medical treatment.

While it is good advice to begin working on communication at an earlier stage and encourage the older person to document health care choices with medical providers, many people face these issues as the crisis is unfolding. Families in this situation have several options for relief:

1. The facility in which the older person is currently being treated—hospital, nursing facility, or home-health agency—may have staff with experience in assisting families to focus on necessary immediate decisions without dwelling on the family issues that prevent effective communication. However, staff of smaller facilities may be reluctant to act beyond advocating for the known, documented wishes of the client since they will have an ongoing role in care and interaction with the family.
2. There may be one second degree relative, friend, clergy person, attorney, or other professional acquaintance who has established a relationship of trust and mutual respect with all family members who wish to be involved with the decision making. This person may agree to be the

spokesperson and if the medical providers agree or if legal arrangements are made, she may be appointed to facilitate discussions and interpret decisions.

3. Professional case managers are retained to develop basic directions for care by consensus and can speak for the family to care providers.

Staff in hospitals, and other care settings, often have difficulty negotiating the paths of relationships with and among family members. One reason is that they focus, appropriately, on the person in the bed receiving care. Without training in family therapy they may find it difficult to view that person as part of a family system that needs care as well. Even with that view, protocols and legal constructs require that one person make decisions regarding care. If family members have any ability to predict the kind of conflict that will complicate care, they would avoid entering that territory by encouraging advance directives and appointing a neutral spokesperson as early in the process as possible.

LESSON THREE:

FAMILY INTERACTION AND

INVOLVEMENT

GOAL: DEVELOP UNDERSTANDING OF THE DECISION-MAKING PROCESS IN A HEALTH CARE SETTING

Objective: Participants will understand the roles of residents, family, friends, staff, and medical providers in the operations of a long-term care facility. Participants will be familiar with some steps to take to interact positively with residents, each other, and providers.

A. Who Is in Charge?

In a long-term care setting, we are usually looking specifically at decisions related to medical care. However, there is consistency in the process and, again, the resident is given every opportunity to make the decisions. Residents may have physical challenges to overcome or learn to tolerate, but unless otherwise demonstrated, staff in a facility assume the resident will direct her own care.

Most residents admit to long term care from a hospital setting, following an acute event, or at the end of a progressive illness. Any scenario presumes the need for a higher level of care than total independence at home. There are documents from medical settings and providers which describe the resident's medical status and usually include some indication of mental capacity for decision-making. In some situations, the resident, then a patient in a hospital bed, was not responsive and family members were allowed and even required to make decisions. This status will usually be reviewed at each change in the level of care.

If the resident is incompetent, unable to communicate, unresponsive, or refuses to direct her own care, one family member will be asked to do so. This may already be clear at admission since someone, usually a family member, arranged for the admission, toured the facility, and so on. In some instances, tasks are divided among family members and the person arranging the care will not continue to make decisions after admission. This is especially true in the event of a family member visiting from another community.

Long-distance caregiving is a special challenge within any family and difficult for the facility to address. An adult child living in a different community may want very much to help and to be involved and may feel very guilty about her perception of not sharing the burden of care with her parent or another sibling. These feelings may result in very energetic decision-making which may not be compatible with the culture of caregiving and decision-making that has evolved locally. The local caregiver may feel resentful which can lead to conflict and exhaustion. Besides staying in regular contact, long-distance caregivers should accept discrete, ongoing tasks which can be performed from afar, complete

them as promised, acknowledge the devotion of the local family, and make some sacrifices to visit often and provide some respite.

Some residents and families are reluctant to make any decisions when an acute event has occurred. Their expectation is that medical staff, from the doctor in the hospital to the nurse in the long term care facility, will tell them what to do. There was a time in the history of medical care when this was the predominant pattern, but this is no longer the case. For both legal and ethical reasons, medical providers require full disclosure to patients and families and full involvement from them in the decision-making process. Providers will offer information about available treatment options and even make recommendations but they will require some input from the patient and family as to their preferences and understanding of risks and benefits.

B. Interactions in Long Term Care Facilities

Staff in long-term care facilities will always assume without additional information that a resident will have significant interaction with her family of origin or intimacy—her parents, spouse, siblings and adult children—and the staff will follow her cue. In some situations, the resident has no remaining family of origin but has extended family members—cousins, nieces, nephews, or grandchildren—who have become her family of intimacy. In other situations, there is no one related by blood or marriage but close friends have taken on the important roles.

All of these relationships are legitimate to the medical and long-term care staff as long as the resident expresses confidence, is competent to do so, and no clearly adverse actions or decisions are occurring. However, it is always preferable for the more informal relationships to have some basis in writing for the staff to feel confident that the resident concurs with the arrangement.

The variables among families related to planning decisions apply to the daily interactions related to care in the facility:

- nature of the diagnosis
- family characteristics, such as size, proximity, caregiving experience history
- family's culture related to values, education, experience and beliefs

All relationships, even those formalized by birth or marriage, can be damaged by the stress of illness and caregiving. Facility staff and medical providers have a legal responsibility to ensure that abuse of any kind—verbal, emotional, physical or financial—and neglect are prevented and addressed, in order for appropriate care to be provided and for the resident to have every opportunity to thrive. It is very difficult for staff to intervene in family interactions because they are not a part of or familiar with the unfolding family culture. In many cases, the conversational style has existed for many years, may have been initiated by the resident, and all family members are, if not comfortable, then accustomed to the style. Outside of the facility and after the facility and its staff are no longer involved, the family must continue to exist. Staff are, and should be, reluctant to damage a system of interaction and communication unless they are prepared to replace it—a daunting or even impossible task, even for experienced therapists.

However, staff are required to intervene in some way to ensure care. The provider staff and families will often use a facilitator, of the kind noted above, to filter interactions through a neutral translator,

if emotions have escalated to the point where care is being affected negatively.

Completing the more detailed Advance Directive or Living Will noted previously, discussing it with the physician, and safeguarding it with an attorney can assist individuals and families to avoid much of the emotional distress and conflict that occurs during a medical crisis for even those families with the most positive styles of interaction. Such a document is the most effective way to communicate the expectations the individual has of the medical provider, the values she has developed related to survival, and how she defines quality of life. Even the closest family with the most intimate ease of communication is often surprised by decisions made by the elderly member. The first-in-line decision maker, following the resident in the bed, may confess that without that input, it is not the decision she would have made.

Human beings do not act or interact in a straight line and conflict will occur among family members that staff and even the neutral translator noted above will be unable to manage. While everyone may want to resolve the issues, the care of the resident in the bed is the primary concern at the facility and there are times when the conflict has to be literally sent elsewhere. Family members or guests who appear to be potentially or actually disruptive in the facility will be asked to have an escort to manage behavior, to visit at times or in locations when or where other family members or staff can supervise, or to cease visiting at all. Such steps are rare because family support is so important to recovery but if the conflict hampers recovery, the visits are counterproductive. If real harm to the resident is considered a possibility, staff may contact the Adult Protective Services department of the state aging office to report incidents and conduct an investigation.

The scenarios that may precipitate the above actions are rare but memorable in most long-term care settings. Very often they involve untreated mental illness, including substance abuse, that is exacerbated by the medical crisis that led to the admission. Families have the responsibility to alert staff to the potential for inappropriate behavior and to attempt to contain disruptive activity if possible. Otherwise, families can expect that staff will act to protect all residents, staff, and the facility from inappropriate or dangerous behavior.

If a resident had a conflictual relationship with a family member or friend prior to admission, the facility is not the place to resolve the situation. It would be best for the rest of the family to discourage such visits until they can occur at home or in a setting where the family can direct the interaction according to its own history.

Exposure of family interactions which were previously “secret” can be embarrassing to all family members. Relationships which were difficult but tolerable and marginally effective may now be shredded and open to judgment by others. Emotions are raw and guilt from events of years and decades past may surface. While very painful, these emotions and events actually create opportunities for individuals and families to begin addressing the conflicts and seek resolution. Social workers in larger facilities, support groups in facilities and the community, and individual therapists, available through insurance, are all able to assist individuals and families to begin a healing process even to the point of improving communication and interaction related to the ongoing care of the resident.

C. Positive Visits

Despite the issues surrounding family interactions, most families are key to the recovery and adjustment of the resident in the long-term care facility. Visits and time spent with family are usually the

most positive indicator of recovery apart from individual motivation. The more time families and friends can create for diversion and support, the more positive the outcome that can be predicted.

Visiting time must, of course, defer to medical care and the energy level of the resident. However, most facilities can adapt to the needs of individual families:

- Are the resident and family late night people? Let staff know so they can make arrangements to visit privately and not disturb other residents.
- Do the resident and family enjoy eating together? Families can alert staff to plans and eat in the dining room or in a private setting. Families should be aware of facility protocols related to outside food, use of dishes and flatware, and clean up. The dietary orders prescribed by the physician for the resident must be followed as well.
- Is the family planning a large gathering? The facility can arrange a large, relatively private place.
- Is there a birthday, anniversary, or other celebration? Staff would like to know and offer greetings as well.
- Is the family planning a surprise? Be sure to include that information and tell only one staff person.

Visits are easier and take less energy with residents who are alert, oriented, and interactive. All residents, even those in a vegetative state, benefit from attention from family and friends. They get bored with staff and enjoy visits from nearly anyone. Most facilities have volunteers, students, interns, and others who visit residents, especially those with less support from family and friends.

Primary Caregiver Visits

Some visitors, usually spouses and adult children, spend hours, if not the entire day, at the facility. They were and remain the primary caregiver and will resume the role formally if and when the resident discharges. Staff can rely on them to be alert to needs and to provide some casual care such as assistance with eating, set up for grooming, and getting fluids and snacks as appropriate. Facility staff are accustomed to this attention and value these visitors. Rarely does conflict arise over staff retaining the ability to provide appropriate care related to privacy or caregiver insistence on providing care in a manner that conflicts with facility protocols. Equally rare is the situation where staff are concerned about the health and welfare of a caregiver, usually a spouse, who is sacrificing her own well-being to be in attendance at the bedside at all times.

Facility staff can help familiarize caregiver visitors with routines and schedules, alert them to special activities, and provide support. These routines actually are of most value when the home routine, prior to admission, is recreated as closely as possible to make the resident comfortable and hopeful.

Casual Visitors

Most visitors, even some spouses and children, visit for defined time periods. If a resident is weak and ill, short frequent visits, daily for no more than an hour or less are most effective. If the resident is interactive, note interests and energy and provide a glimpse of the world she is missing and to which she is likely to return. If she is not responsive, or just too weak to hold up the usual interactions, bring a book to read, magazines, tapes or read letters, cards and e-mails from home.

Begin visits with a greeting, stating your name and some identifier to residents who cannot see well or have poor short term memory. Bring gifts, small but pleasant—flowers, books, magazines, cards, or food for those who are not on restricted diets. On the trip to the facility, try to review some positive topics of conversation to present—a phone call, another visit made, a religious service or community event, a joke heard, an incident witnessed. Pets and children make good topics of conversation and can even make good visitors if plans are made ahead of the visit. Neither the visiting pets nor children need to do anything—their presence alone brightens the area. Both should be rested, clean, and in good health for a visit. Check with the facility for protocols.

Visitors may note that some residents at the facility have few or any visitors of their own. Staff can confirm this and would be delighted to facilitate appropriate relationships with other residents. Such visits may be convenient when one's own family member is receiving care, therapy, or is asleep. Such networks help to turn facilities into communities.

One universal element of visits throughout the continuum of long-term care is that any facility which generally discourages visits at reasonable times from involved family members and friends should be avoided as a potential placement and reported to the local aging services system.

D. The Culture of the Family and the Facility

Culture, in this discussion, does not imply ethnicity, race or religion. It describes the norms—actions, attitudes, behaviors, beliefs, and values—of groups of people who live, work, or even just play together. The norms of cultures change as people enter or leave the group and as crises arise. The illness of a beloved parent is a crisis to a family group and affects the culture. The culture in crisis will be in contact with other cultures which are not in crisis—the hospital, the clinic, the nursing facility, the assisted living facility. The cultures have to interact with one another and clashes can occur.

Aside from the culture that develops with any group of people working together, some medical and long term care facilities are identified with another distinct culture—faith-based, fraternal lodge, ethnicity—as opposed to a private facility. Some staff and many residents and families may be drawn to a facility by the familiarity of the culture. Other families may be drawn to that facility for other reasons and disregard the impact of the cultural identity of the facility environment, only to come into conflict with it at a later time.

Hospitals, clinics and nursing facilities operate on a medical model where care is directed by physicians and implemented by nurses and other licensed and certified staff. Residential, assisted living, and foster care facilities operate on a more social model and informal input from families can shape the care plan accordingly. The formality of the medical model and the informality of the social model can both lead to cultural clashes among family and staff. Medical staff are required by training and regulation to be task and detail oriented. This is exactly what patients need and want related to such areas as surgery, wound care, distribution of medication, and diagnosis. However, in long-term care facilities, families and residents may want more control over their care and the option of creating a more holistic environment where social and cultural needs have equal priority. Even in the most acute medical setting, families demand and can achieve some status in providing care or at least being present to oversee care.

With effective communication, a balance among the needs can be achieved and consensus built among the resident, family, and staff. Supervisory or social work staff can intervene to help with

communication. If families or residents feel that they need the intervention of mediators or representatives outside of the facility, all states have a long-term care ombudsman program through which professional staff and trained volunteers visit facilities and assist them in finding a voice for their concerns. In addition all states have aging services staff who are assigned to specific facilities. Their responsibilities are mainly for residents who receive Medicaid (or welfare) benefits but they can also provide some representation for other residents and families if it is requested. All states also have some form of adult protective services which can provide access to intervention by residents, families, and facility staff.

Some families find that family history is too negative and communication too complex to manage long-term care effectively. They hire private case managers to formally direct care and focus on emotional and social connections with the resident.

It is very rare for facilities and families to become entangled in conflict to the point of requiring attorneys but if this does occur, it is important for the family to choose an attorney with elder law experience.

LESSON FOUR:

PARTICIPATION IN PLANNING AND
CARE ACROSS SETTINGS

GOAL: INTEGRATE RESIDENT AND FAMILY INTO FACILITY COMMUNITY LIFE

Objective: Participants will understand the roles of staff in a facility and how the resident's welfare can be addressing the routines of that facility.

A. Care Conference 101

All care facilities that meet minimum standards offer residents and family members opportunities to meet with facility staff to discuss the status, progress, and care or service plan for the resident. The care or service plan is the basic document which addresses all care, including treatments and medication, that the resident will receive in the facility. The meeting is usually described as a care conference and some form of care conference is legally required in nursing and assisted living settings. If the resident is able to direct her own care and wishes to do so, she may invite whomever she chooses to attend the conference with or for her. Such conferences are unique to each facility and reflect the culture of that facility. However, some facets are likely to be present in all settings.

The issues discussed will include the resident's current health status, with reports about any incidents, medical tests, illnesses, injuries, physician orders, or other events that occurred during the period covered. Each discipline involved in care will have an opportunity to report on the status of the resident. These disciplines include nursing, dietary, recreation or activities, rehabilitation, and social work. The goals and objectives of care are discussed. Any challenges to the goals and objectives are raised together with opportunities for problem-solving. If the resident is expected to discharge to another level of care, steps required for a safe and effective discharge are discussed at that time.

The resident is at the center of the care conference and, if she directs her own care, she should have all of her information needs addressed during its course. Her input is also valuable to the staff for improving care at the facility. With the information she receives at the conference she should be able to continue effectively directing her course of treatment to meet her goals.

When a placement is long-term or the resident is physically or cognitively impaired beyond being able to participate in care planning, a family member usually represents her at the care conference. Those family members who attend conferences regularly become more effective partners in the care team. They arrive with lists of issues, concerns, questions, and suggestions to make the best use of the time. When unable to attend they call a staff person, usually a nurse or social services staff, to introduce issues for the conference and then to receive a report of the issues discussed at the conference.

Staff from most disciplines will attend all care conferences, but because time conflicts may arise other disciplines may read some reports from notes provided by those absent. Each discipline will focus on the strengths exhibited by the resident and the challenges remaining to reach stated goals. The presentation of staff information should be holistic with the interdependence of the various

disciplines being evident by the close of the conference.

If the resident is receiving specialized rehabilitative treatment, such as physical therapy, other disciplines should seek to support a positive outcome from that treatment. Nursing will attempt to stabilize the resident medically and provide effective pain control in order to maximize rehabilitative efforts that require focus and energy. Dietary staff will focus on sufficient nutrition to promote healing, skin health, and energy for rehabilitation. Activities or recreation staff will introduce diversions for promoting focus, socialization, gentle use of all muscle groups, skill building and relaxation, all of which will maximize the quality of the time spent in rehabilitation. Social services staff will follow up with the discharge plan that will reflect goals met and challenges to overcome in order to move to a lower level of care. The latter are not necessarily for the residents and families to address. Challenges may include staff tasks, such as equipment to purchase and home health services to arrange.

A resident who is expected to remain at the current level of care for a time will receive the same attention to care planning but without the time pressures for change to a lower level of care. Instead, the focus will be on positive adjustment to the facility with meaningful relationships and activities developed to match the resident's personality, history, and expectations.

Care conferences are usually arranged within a week or two of a skilled-nursing admission and within the first month of a longer-term admission. The first conference is likely to last about 30 minutes. Regular quarterly conferences are held for long-term residents and these can last from 15 to 30 minutes. Quarterly conferences are usually held on a schedule and families and residents receive formal notice. After a period of adjustment, some families stop attending care conferences, perhaps content that staff will provide the expected care. This is not necessarily a signal that families do not care, since most do visit and provide for needs as requested. However, the care conference is a special opportunity for some staff to interact more directly than usual with families. It can be disappointing to consistently report only to other staff and for the record with no input from families to enrich the care plan.

B. Interaction with Providers

The term “providers” is a general title for all of the staff involved in direct care in a long-term care facility. Several reasons exist for encountering providers and various ways to make the encounter a positive and care-enhancing experience.

Administration

Every facility has at least one administrator identified as the supervisor of the facility. Most have some licensing status, such as nursing home administrator and assisted living administrator. These licenses require classroom hours and testing and must be renewed periodically. Administrators would generally like to meet every resident and family and are the people to address at any time with any issue if other avenues have not been successful.

Administrators usually make the final decision whether a resident is admitted to the facility. They look at the information from the hospital chart, at their own staffing availability, and at the acuity of their residents. The latter term describes the amount of care that the current resident census requires. A facility may have unoccupied beds but if the residents in the occupied beds require an unusually

high level of care, the administrator may choose to keep an empty bed rather than admit another resident with high care needs. Administrators in nursing facilities make these decisions in collaboration with admissions staff, often located in social services. In assisted or residential care facilities, and in foster homes, admission decisions are usually made by one person.

Reception

Except for foster homes, most facilities have some kind of reception desk or area with a person answering the phone. This is the first person anyone will meet at every visit or phone call. It is very unlikely that the individual at the phone or desk will have any medical or other information about your family member that can be shared without input from a nurse or administrative staff. The desk at most facilities is a very busy place with many demands upon the receptionist. New requirements for added security to limit access to facilities and residents to staff, families, and invited friends have added new responsibilities to that position. Inquiries and interactions to the receptionist are best kept brief and specific.

Housekeeping and Maintenance

Although there is a great deal of contact, with housekeepers especially, these staff members do not have much input into the care plan for the resident and should be counted on mainly to clean the environment and provide supplies to the resident. Most facilities have means of contacting maintenance for repairs and equipment through nursing or reception staff.

Medical

Every resident in a licensed long-term care facility must have a primary care provider who is able to write medical orders. This is often the long-time physician for the resident and the relationship may have been established prior to admission. At other times, the medical director of the facility takes over the care of the resident. In skilled and intermediate nursing facilities a resident cannot receive even a vitamin or an antacid without the written order of the physician of record. Some facilities allow a physician to order self-administration of some medications. The usual pattern of interaction is for a charge nurse in a facility to recognize a need and call the physician with the appropriate medical information. The physician will then order medication, treatment, transfer to hospital or another level of care, or take no action at that time.

When a situation warrants a call to the physician, the family is also usually notified. The family may even have brought the issue to the nurse's attention. There may be lapses of time while waiting for the physician's response. This is frustrating for the nurse and other staff as well as for the family. Physicians have many demands on their time and attention and cannot respond to all requests at one time. In addition, some medical offices operate more according to their traditions than to maximize efficiency. However, if a pattern of delay is apparent and the facility appears to be making requests in an appropriate and timely manner, the resident or family would do well to be proactive and discuss the issue with the physician. In extreme cases where a delayed or absent response endangers resident care, the facility will have a protocol to provide appropriate medical care.

Nursing Staff

Licensed nurses direct the care plans in nursing facilities and oversee medications and care plans in most assisted facilities. Licensed nurses may be registered nurses (“RN”) or licensed practical nurses (“LPN”). Licensed practical nurses typically have one year of education and are limited in providing some areas of care. Registered nurses have two years of education, a four-year bachelor’s degree, or a master’s degree. Although doctorates are available to nurses they are usually limited to positions at research and teaching institutions.

Certified nursing aides, or CNA’s, are the majority of staff in nursing facilities and provide most of the care. Requirements for education differ by state but tend to be in the range of six to eight weeks of training with continued in-service training required. Certified nursing aides can enrich their credential with about two weeks of additional training in medication administration to become CMA’s, or certified medication aides. These aides work under the direct supervision of nursing staff. While they can respond to requests for assistance in providing transfers, repositioning, food, cleaning, grooming and personal care, they cannot administer medication that has not been cleared as part of the care plan and if they are not CMA’s. They can, however, bring concerns to the nurse.

Responsible facilities will attempt to provide as much continuity of care as possible, allowing the same aides to work with a resident as much as possible. This builds confidence, trust, and comfortable relationships that assist residents in recovery and adjustment to facilities. It also provides families with familiar faces and confidence in the treatment team. However, in many facilities there is high turnover in aide staff related to low pay, limited benefits, the field attracting young people in transition. This may force some facilities to use temporary staff from agencies, limiting the continuity of care.

Families may discover that some aides in facilities have been there for some time and are likely to remain there; family members can then focus relationships and communication on those staff to address care needs. Turnover is also more limited in rural areas due to personal decisions to limit commuting time or to remain in the area, or due to the lack of other opportunities for employment.

In lower levels of care, aides who may or may not be certified provide assistance to residents as needed and are usually trained on the job. In most states, foster care providers must complete a certain number of hours of training prior to working in a facility and must continue their education annually with specified hours and subjects. Turnover in lower levels of care tends to be equally high for the same reasons as above.

Rehabilitation

Skilled nursing and most intermediate facilities employ or contract for the services of skilled rehabilitation staff. These positions include:

- physical and occupational therapists at bachelor’s or master’s level
- physical and occupational therapy assistants at an associate’s or bachelor’s level
- speech and language pathologists, informally known as speech therapists, who have master’s degrees

These services must be ordered by a physician or arranged for and paid privately by families. Unless paid privately, they are reimbursed by the resident’s insurance. If the resident has insurance from a

health maintenance organization, that company approves establishment and continuation of rehabilitation services. If the resident has Medicare insurance with or without a supplemental policy, the rehabilitation staff determine if the services are covered by Medicare guidelines and the facility assumes the risk that, if they are audited, Medicare will agree to the reimbursement. Families and residents may appeal these decisions but if the appeal fails, the families and residents are liable to pay privately for the services.

Families are encouraged to observe the rehabilitation staff working with the resident to benefit from learning how to safely transfer and assist the resident. It is important to avoid spending the limited time allotted for these services in conversation not directly related to the rehabilitative portion of the care plan. The rehabilitative staff have no control over the Medicare guidelines or the insurance case management staff. They appreciate learning anything relevant about the resident's prior function which was not available in the history and physical sent to the facility with the admission orders. This is best offered in writing for their ongoing use. Rehabilitative staff are also available at care conferences for further discussion.

Some family members may be distressed if the resident does not appear to be making much progress in rehabilitation. The rehabilitative staff are responsible for guiding the process safely, and competent staff are able to motivate residents to exert themselves more than they would if simply offered opportunities to participate in therapy. However, staff cannot force residents to participate, nor can they work with those who are sleeping, unresponsive, or in too much pain or discomfort to benefit from therapies. It is an unfortunate fact of the reimbursement system that residents who may need some time to recover from their illness or injury will lose the opportunity to have rehabilitative therapy reimbursed. Some residents pay privately for custodial care until they can participate in covered therapy at a later time.

Activities or Recreation

Staff who provide or direct the activities in any long term facility fill a vital role. Residents in nursing facilities do not require nursing care for more than a few hours each day and usually cannot tolerate rehabilitative therapy for more than two hours. This leaves many hours to fill when families and friends can visit, but meaningful activities and pastimes that link residents back to their community can help to motivate them toward recovery or comfort them if recovery is not expected. In assisted care and foster homes, activities are even more critical as residents may have more energy and certainly have more time.

Activity staff may or may not have college educations or degrees but most should have an activity certificate for about 36 hours of training. Activity staff value any input from residents and families about interests, abilities, previous experiences and activities and personality styles. They are not able to provide any information about medical or care issues but can pass on concerns to administrative staff. They cannot provide care but do sometimes assist with transfers and positioning.

Someone in the activity department works every day in larger facilities and some event should be available for about ten or twelve hours daily. Families should advocate for age-appropriate activities that vary from group events and outings to one-on-one visits. Age-appropriate activities acknowledge that the person who went out last week for Thai food after seeing a newly released R-rated film will soon tire of a diet of pot roast and World War II musicals. Many facilities use volunteers to enhance staffing and events. Performing and education individuals and groups are also seen in many facilities.

Culinary

Most large nursing facilities have a culinary department which includes a Registered Dietician, but state regulations vary as to specific staffing requirements. Assisted and foster care facilities may use the services of dieticians who are not on site. Culinary staff always seek input from residents and families through committees, surveys, and suggestion boxes. Individual requests in nursing facilities should be directed through aide or nursing staff and honored so that residents can obtain the nutrition needed for recovery and good health. It is most effective to share questions and complaints about food to the director of food services. Families and residents should be very specific about suggestions to help the culinary team develop food options that are more pleasing to the residents. They can also be discussed at care conferences with the representative of the culinary department.

There is some consensus in long term care settings that complaints about food relate more to boredom and lack of control than to the actual quality of the food. In addition, the deterioration of taste buds, effect of medications on appetite, and general malaise of some residents makes food seem unappealing that would be acceptable in another setting. Families and residents should be aware that a staff person listening to a concern about the food being too bland, may have just been told by someone else that it is too spicy. The suggestion box will indicate that one person thought a specific meal was wonderful while another found the same meal inedible. Culinary staff in most facilities will continue to attempt to please as many residents as possible.

Social Services

Admissions and social services responsibilities are often combined in long-term care facilities. There are no certificate, licensing or degree requirements for this position. Federal regulations require that a nursing facility appoint a “social services designee” to integrate the social needs, family issues, mental health concerns, and discharge potential for residents. This person may have a high-school education and some experience in the facility, or she may have a Master’s Degree in Social Work and even a License as a Clinical Social Worker (“LCSW”). More likely, she falls somewhere in between.

The long-time leading social work authority in the long term care field is Elaine Brody. She has written many books and articles about the field and describes the delicate issue of private facilities declining to provide professional social work while the voluntary nonprofits tend to do so. It is appropriate for families and residents to expect competent social services from every facility since that staff person usually provides the avenue to address concerns and access many services.

The social services department in many facilities has some responsibility for admissions. Information is gathered from hospital or other facility discharge planners, physicians’ offices, and families. It includes histories, treatment orders, chart notes, and admission forms. Social services staff meet with families and residents prior to and at admission and assist with adjustment to the facility. They attend and often arrange care conferences. They should be available for the family or resident to discuss any issue during the admission and even after discharge or death. The staff may not be able to answer questions related to care or finances and may not have authority to address all issues, but they should be able to assist families to find responses and advocate for residents and families to have their concerns addressed.

Some social services staff are competent to provide counseling and lead groups, and may do so.

Others will have to request consulting assistance through their administrator. All social services staff must use consultants for mental health evaluations of residents when mental health issues or medications are indicated. This ensures neutrality from a mental health professional. Some facilities hire their own consultant. Others use a system of referrals paid for by the state and federal governments using community mental health agencies or providers designated by the state to write evaluations and recommendations for mental health treatment. Facilities are required to implement the recommendations which may involve obtaining mental health treatment in the facility from an outside local provider.

C. Relating to Other Residents and Families

Long term care facilities are, by the nature of their services and structure, communities. While it is possible for people living in a retirement setting, receiving no services and requiring no interaction with fellow residents, to avoid all but voluntary contact, it is more likely that residents in long-term care facilities will have more daily contact with people other than family members than they have ever had in their previous lives. Assisted living residents may have their own apartments but they are eating with others and living in large complexes as opposed to the private homes they may have inhabited in the past. In foster care and nursing facilities, quarters are even closer and many residents share a room with another resident.

There can be tense and uncomfortable situations for residents and their families related to lack of privacy and unavoidable contact and interaction in these settings. In nursing facilities, families will often have very little time or choice in arranging discharge from a hospital. They may assume that since the resident had a private room in the hospital that she will also have one in the nursing facility. If this is a critical issue for that resident's recovery and well-being, and it can be, it is important to state this to the discharge planner in the hospital and make it the top priority when speaking to admissions coordinators at the nursing facility. Many facilities have a number of private rooms but many others have few. If privacy is more important than the reputation of the facility for rehabilitation or other care, make that clear from the beginning to everyone involved in the arrangements. It should also be noted that skilled care reimbursed by insurance, including Medicare, does not offer payment to nursing facilities for private rooms. Facilities cannot allow families to pay extra for such privileges. Only residents paying privately for intermediate or custodial care can be charged for private rooms and facilities may be reluctant to offer those rooms to short-term residents whose stay is reimbursed at a flat rate.

While a private room may not be possible, facilities should be expected to attempt to match a new resident with an appropriate roommate. No person recovering from a hospital stay should have to endure noise or inappropriate behavior, and if this occurs, families should approach the social services designee or the administrator and ask for a transfer for the resident. If the resident in a nursing facility is sharing a room, the facility is required to ensure privacy by using curtains to create separation, asking visitors to leave when personal care is being offered, and creating quiet time and space for rest and sleep. If at all possible, prior to admission or actually choosing the facility, the family should ask to see the room and ask about the roommate's routines and personality.

In most situations new residents and families get along well with the roommates and their families and even establish new relationships. These all depend on courtesy and mutual respect for privacy

and dignity along with some tolerance for the different expectations and routines of others. Such behaviors are not always easy to maintain in the middle of a crisis when families are already under stress. It is always best to request assistance from the staff in difficult interpersonal situations.

Residents moving into lower levels of care than nursing facilities usually have more time to adjust to the idea and adapt to the community, more choice and more privacy once they are settled. But all long-term care settings are communal by nature and the interactions in them may be difficult for some residents to manage.

Residents who are simply shy and reluctant to initiate conversation may need some assistance in meeting other residents prior to moving to a retirement or assisted living setting. Families who are moving a resident from another geographical area should seek to make connections and introductions prior to the move. Residents moving into a facility in their own community are likely to know someone there and should be offered the opportunity to contact that resident prior to the move. In the least, families should attempt to take the resident to a meal at the facility prior to the move in order to introduce the most communal aspect of the environment within the safe confines of family accompaniment.

Residents who have had difficult relationships throughout life will not improve in personality with age. They are likely to experience difficult interactions with other residents in long-term care facilities. The family should consider smaller settings or even foster care as the stimulation of the larger assisted living environment may exacerbate personality tendencies like irritability, impatience, and intolerance. Some families choose in-home care for this reason.

Illness and cognitive impairment can also exacerbate undesirable personality traits and inhibit the restraints and discretion that people would normally impose on their behavior and communication. The person who was somewhat sarcastic and impatient earlier in life may be perceived as cruel and thoughtless in a communal setting.

Gossip is a poisonous form of communication and interaction that is endemic in long term care facilities. Perceived knowledge of the details of the community's life is considered to be powerful and, as in the larger community, is often distorted until it is unrecognizable from the actual event. Supervisors and family members should encourage staff and residents to refrain from any discussion about others in the community beyond expressing support and hope for recovery.

When a resident first settles into an assisted living or residential care community, the family may want to spend considerable time with her to ensure that her needs are met, to allay anxiety about being alone, and to offer support as she attends gatherings, receives care, meets her neighbors, and learns to negotiate the new environment. As the residents begins to become familiar with the new setting, family can slowly reduce the amount of time spent.

The time family members spend in a nursing setting depends on the nature of the condition, length of stay, and the impact on family of the stress already experienced prior to admission. If a resident is admitted to a nursing facility from a hospital, is doing well, and is anxious to discharge to home as soon as possible, one family member at least should be preparing for that discharge. If several members are available, the one least involved with the discharge can spend time with the resident when care and rehabilitation are not being provided. If a resident is not recovering and is not expected to leave in the near future, the family should set up visit times to provide companionship and begin to regain their own health and routines in order to cope with future stressors.

D. End of Life

The nature of long-term care communities is defined by the demographics of age and by impairment, both physical and cognitive. They are combined because the healthiest of older people will often remain living in the greater community, either alone, with a partner, or with extended family. When age and impairment coincide, death occurs in that community more frequently but with a different kind of shock than in the larger community. There is no surprise in the fact that sick, old people die, but there is shock in the constant changing of the environment in a long-term care community. More residents die or move to higher levels of care because there were more of them concentrated in the one community. This academic explanation cannot describe the impact of these changes on staff, residents, families, and other visitors. The remarkable swiftness of the passage from life to death should never cease to amaze us but the frequency of the passage in long-term care settings can be distressing to all involved.

In “How We Die” Dr. Sherwin Nuland points out that death has always been a subject of both terror and attraction to societies advanced and primitive. Since the beginning of the 20th century, people with access to modern medicine have expected that, if they did not die violent or accidental deaths, they could expect “a good death”—dignified, pain-free, with some conscious time to interact lucidly with loved ones. That rarely happens now and it rarely happened prior to the modern medical experience. The more medical interventions and the more sophisticated means used to defer death, the less likely the patient will experience whatever they perceived as “a good death.”

Families and residents are asked at the beginning of their journey into long-term care for directions on how they want care providers to proceed to address illness and imminent death. A request for advanced interventions to treat illness is usually a request to defer death and requires hospitalization at the end of life. A request to limit interventions to comfort care usually means no resuscitation, no ventilators, no tube feeding, possible surgery, or treatments like dialysis. It also means providing sufficient pain control to improve quality of life even if it may hasten death. It includes personal care for dignity and comfort, individual feeding of specially desired foods and liquids, and setting up space for the family to spend more time with the resident. Hospice staff can be brought to the facility at the end of life and assist other staff with special interventions to increase comfort. Paramedics will not be called when death occurs, rather the physician will be called to “pronounce” the time of death. The facility will notify family, if they are not present, and the funeral home, if appropriate.

Residents with progressive dementia, especially of the Alzheimer’s type, will, if they do not die sooner from another medical condition, enter a vegetative state when they will refuse food and liquids. It is fairly universal in the disease and leads to death. It is also painfully difficult for families to watch, not least because starvation seems unacceptable in our society, and there is a temptation to intervene. Artificial nutrition and hydration from tube feeding and intravenous treatments are available and families may choose this route. However, these interventions have not been known to extend life, as the body of the advanced Alzheimer’s patient appears unable to absorb the nutrients. These interventions also have medical complications of their own for the resident and family to navigate.

In long-term care facilities, nursing staff are on the front lines with death and usually communicate with families about its imminence. Physicians are called and orders for treatment and medication given, but nurses are best able to provide families with information and possible timelines. Receptionists, aides, social services staff, therapists, and administrators are not able to guide families beyond

what they have been told by nurses. When a resident is very ill and near death, families should request protocols for remaining in contact with nursing staff for their own comfort and reassurance.

While “the good death” we continue to see on television and in movies rarely occurs, the process of dying in a long-term care facility can be made relatively comfortable and pain-free with cooperation among staff, physicians and family members. The best way to ensure this is to think of the “unthinkable” ahead of time, plan, and utilize the staff of the facility to implement a care plan acceptable for everyone.

E. Grief Issues

Issues of grief are not limited to death in long-term care facilities. There are losses that occur prior to admission and certainly, after admission. Residents incur grievous losses when they retire from work; lose friends, family, pets, and partners to death; move from their large homes to apartments; stop driving; stop traveling to see family and friends; lose mobility and independence; and lose financial security. Moving into a long-term care facility may be the latest in what is perceived as a long series of insults to identity and self-esteem. Residents need to prepare for such changes and families can assist by involving them as much as possible in the decision and then acknowledging the losses and offering comfort.

One benefit of larger assisted living settings is that a new resident may encounter many people with the same experiences. This can help to normalize the feelings of loss and even provide some guidance in coping. Families can also attend support groups of caregivers with many of the same experiences and suggestions for interventions. Social services staff may facilitate such groups or provide information on groups to join in the larger community.

When death does occur in the long-term care facility, it has often been expected for some time, even years in the case of residents with Alzheimer’s type dementia. Grief for primary caregivers may have occurred over those years and the actual death may bring feelings of relief, followed by feelings of guilt. Residents who die of medical conditions like cardiovascular disease and cancer may have had many crises over a period of years and loved ones may have expected death many times only to have the resident recover or, at least, remain alive. The phenomenon is often called the “Lazarus Syndrome” and the result is so-called anticipatory grief, experienced many times but never finalized. When death does occur, grief may be less visceral than with a sudden, unexpected death and the loved ones may experience guilt because their grief is not demonstrative.

Facilities have a great deal of experience with these reactions and where staff are well-trained and long-term, there is little judgment of families—only empathy and a desire to help. Rituals and ceremonies for marking death are present at most facilities and are adapted to family personal, religious and cultural desires and needs. Staff are also often in need of rituals to mark the passing of long-time residents. Hospice staff and social services staff in facilities follow families after death and offer bereavement support, either in the facility or out in the community.

Family members and other loved ones often feel some conflict related to the facility following a death. The facility was an important part of their lives, often for a long time, but they may feel an aversion to returning because of the death. Family members should give themselves time and avail themselves of spiritual and community support before forcing a decision on whether to return to the facility to visit staff and other residents. Some former visitors return to become regular volunteers

while others never set foot in the facility again. The choice is individual and does not reflect on either the facility or the individual but rather on the range of experiences and interactions from a time well before the admission.

ABOUT CEDAR SINAI PARK

Mission

Cedar Sinai Park provides residential and community-based care to our elders and adults with special needs, allowing them to live with comfort, independence, and dignity in a manner and in an environment based on Jewish values.

Core Values

- Dignity: Value each person we serve, their family and our staff as individuals
- Jewish values: Provide secure, supportive, loving and stimulating environments and services based on Jewish values
- Quality: Provide a full range of state-of-the-art, high-quality services
- Charitable: Robison Jewish Health Center will provide services to people without regard to ability to pay
- Financially responsible: Develop financially sound programs and services commensurate with the community's ability and willingness to fund them

Family of Services:

- Rose Schnitzer Manor: independent and assisted living
- Robison Jewish Health Center: skilled, intermediate, and memory care
- Robison Residence: residential care
- Adult Day Services: daily respite care
- Rose Schnitzer Tower: affordable housing for seniors and people with disabilities
- Kehillah Housing: affordable housing for adults with special needs (in development)
- Sinai Family Home Services: in-home care (joint venture with Jewish Family & Child Service of Portland)

Cedar Sinai Park, a nonprofit organization, is committed to delivering a broad-based continuum of care that can be tailored to individuals' unique needs. Active consumer choice and a person-centered approach to care are at the heart of our mission. Our service delivery and development is about recognizing that people, including our eldest and most frail citizens, have the right to control decisions made about their lives. Our strategic goal is to seek and implement new ways to support those decisions.