Transitions in Life Due to Aging and Illness: Resources for Care

Presented by
Paula Wolfson, LCSW

Avenidas™
Resources and programs for positive aging

What Lies Within?

"What lies behind us and what lies before us are small matters compared to what lies within us."

- Ralph Waldo Emerson

Avenidas

- Avenidas has provided community programs and critical services to older adults and their families on the mid-Peninsula since 1969.

- Information & Assistance Line
- Recreational classes
- Health and Wellness Programming
- Private Counseling & Consultations
- Door-to-Door Transportation
- Handyman Services

- We provide a wide range of support options, information, and services that enable people to stay active, maintain their independence, help their aging parents, or care for a spouse.

- Call 650 289 5400 or go to www.avenidas.org for more information

Presentation Outline

- Caregiver's Role
- The Check List
- Age Wave
- Sensory, Cognitive Decline
- Neurocognitive Disorders
- Dementia, Alzheimer's
- Dementia, Delirium, Depression
- Warning Signs and Safety
- Monitoring Behavior Triggers
- Compassionate Communication
- Medical Interventions
- Primary Care
- Hospitalization
- Discharge Planning
- Insurance
- Appealing your Discharge
- Resources for Dementia Care; Skilled Care vs. Custodial Care
- End of Life Care
- Community Resources

Caregiver Role

- If you are a primary caregiver you are the CEO of someone else's life.
- You mediate, delegate, negotiate, facilitate, and sometimes terminate services.
- You manage health care decisions, money, insurance, documents, legal decisions, daily care needs, emotional-well being of self and others.
- This is a full time job.
- The main benefit is knowing that you are doing the right and noble thing.

Planning for the Unknown: The Check List

- Being a family caregiver is work. One needs to be organized and set priorities. Create a family check list. What are your loved one's wishes re end of life care? Have a family conversation with everyone sharing their feelings and requests.
- Start with reviewing your loved one's insurance, financial resources, long term care plan, retirement resources.
- Complete an Advanced Directive, POLST, Durable Powers of Attorney for Health and Finances. Make sure you have a team in place, family on the same page and that the right people know your loved one's health care preferences and where their legal documents are located. Assign roles and tasks. Have duplicate sets of forms.
- Have informed medical consent to speak to your loved one's care providers at all times. If your parents resist this process become a role model! Have them witness your asking a sibling to become your health advocate.
- Find out the local caregiver and aging resources in your community.
- Find peer or caregiver support groups.
- Read books. Check up on the latest research. Stay informed.
- Take care of yourself. Caregiving is noble and exhausting work.

The Age Wave

- 65.7 million caregivers make up 29% of US adult population providing care to ill, disabled and aged.
- 14.9 million care for someone with Neurocognitive Disorders (Dementia or Alzheimer's disease)
- By 2030 the aging population will increase from 35.1 million to 71.5 million.

Data from Family Caregiver Alliance

Caregivers

- The informal, unpaid family caregiver is the main resource for long term care in this country.
- Caregivers are mostly women and often take care of one or two members of the family.
- The senior population in American will double by 2030 and most of us will become caregivers at some point in our lives.

Transitions in Care Due to Aging

- Sensory Changes
- Functional and Cognitive Changes
- Cognitive Decline
- Dementia
- Alzheimer’s Disease
- Warning Signs and Safety Issues

Sensory Changes

- As we age some of us experience changes in the following areas that may impact our functional abilities:
- Hearing, vision, mobility, balance, taste, appetite, sleep, reflexes.
- We may find it difficult to manage our homes and finances, keep track of money, sleep well, drive safely, read fine print, use our phones or computers, hear certain sounds, negotiate stairs and transfer from bed to chair.

Functional and Cognitive Changes

- The impact of sensory changes with cognitive loss impact one's independence and activities of daily living.
- Most older adults have at some point a cognitive evaluation by their physician to monitor significant changes in orientation, long and short term memory, abstract thinking abilities, mood, behavior changes, lack of initiation, decreased focusing abilities, increased anxiety levels and agitation.
- Patterns and symptoms of these changes vary from person to person. The good news is that not everyone develops cognitive decline or dementia.

Cognitive Evaluation

- Mental Status Exams
- Memory and Reasoning
- Orientation
- Attention
- Immediate Recall
- Arithmetic Calculation
- Abstract Thinking
- Information
- Construction
- Copy-eye hand coordination.
- Long term recall

Cognitive Impairment

- Cognitive impairment is usually a slow process with stages that overlap.
- The American Journal of Psychiatry (1982) has published a global deterioration scale for assessment of primary degenerative dementia. Alzheimer's is the most progressive form of dementia. There is no cure. Dementia and Alzheimer's are diseases of the brain.
- The current Diagnostic and Statistical Manual designate these as Neurocognitive Disorders.

Dementia

- Dementia involves multiple cognitive deficits manifest by memory impairment and disturbances in abstract thinking and executive brain functioning involving;
- Aphasia - Inability to recall words
- Apraxia - Mobility and gait disturbances
- Agnosia - Loss of recall of familiar objects
- Impaired decision-making is manifest with anxiety, mood and behavioral changes.

Dementia of the Alzheimer's Type

- Alzheimer's Type is the single most common cause of Dementia and accounts for up to 65% of all cases.
- It involves a gradual onset of symptoms, progressive cognitive decline within a series of stages.
- Alzheimer's is the most severe form of dementia.
- Dementia and Alzheimer's are names for a disease process and a condition.
- Symptoms fluctuate and do not present as the same in every person.
- Main rule: Do not take person's behaviors or what they say personally. They have a brain disease.

Vascular Dementia

- A diagnosis of Vascular Dementia involves cognitive impairment and neurological signs such as exaggerated reflexes, weakness in extremity, gait abnormalities, laboratory evidence of cerebrovascular disease.
- This form of Dementia has a stepwise, fluctuating course with a patchy pattern of symptoms determined by location of brain damage.

Dementia, Delirium, Depression

- **Delirium** may look like dementia but is sudden, with a waxing and waning of changes in levels of activity. Confusion and delusions present. My result from infection, head injury, stroke, pain, addictions, metabolic changes in glucose and sodium. –Possible reason for hospital admissions.
- **Dementia** has a slow onset involving memory loss, loss of judgment, abstract thinking, and when severe changes in mood, behavior.—Not a reason of itself for admissions.
- **Depression** reflects a change in mood, loss of pleasure in normal activities. Not generally associated with memory loss or confusion. If mixed with dementia may appear as irritability, agitation, anxiety.-Not a reason for admissions unless one is suicidal or failing to thrive.
- Have your primary medical team conduct a **differential diagnosis** for you loved one who has any of these symptoms.
- For further discussion contact Dr. Elizabeth Landsverk of www.elderconsult.com. She is an expert on this topic, is a private pay MD who makes house calls and frequently speaks on this topic at local conferences.

Warning Signs… Driving

- Driving skills decline, reflexes have slowed down, vision and hearing impaired.
- Person gets lost, hits garbage cans in driveway, runs through stop signs or lights. Becomes lost in own neighborhood.
- Stopped by police.
- Needs to see MD and be evaluated to retake driver's test. You may anonymously call DMV to report a dangerous driver.
- Physicians will help hold a conversation with seniors when it is time to stop driving. If necessary they will notify the DMV.
- The loss of one's driving abilities is a major transition and should be treated by the family with sensitive support and concern for safety of one's local community. If a senior is at fault in a car accident they can find themselves without any financial resources as the result of legal actions. You do not want this to happen at the time when money is needed for caregiving and medical expenses.

Warning Signs… Unsafe Alone in Home

- Oven and stove top burners left on
- Frequent falls
- Water left on
- Heater left on
- Cannot use phone or manage cooking, cleaning
- Cannot clean self, is incontinent, skin sores, ulcers
- Person has poor hygiene, smells,
- Failure to thrive if left alone
- Home is cluttered, signs of hoarding

Memory Deficits: Vulnerability

- Senior is vulnerable for fraud and scams.
- Go through bank accounts and check books for payments to individuals you do not know.
- Monitor phone and computer use.
- Your loved one is a high risk for being victimized by fraud, having an accident, getting lost and injured.

Monitoring Dementia Behavior Triggers

- Most behavior is a form of communication.
- Log challenging behaviors: time, onset, duration to detect patterns.
- These include anxiety, agitation, combativeness, wandering, sundowning, paranoia, hallucinations, difficulties bathing, dressing, refusing food.
- Common triggers for people with dementia include noise, dehydration, too much stimulation, new environment, new people, demanding tone of voice, water too hot or cold, changes in temperature, pain, fear, not enough sleep, changes in routine and relocation.

Compassionate Communications

- Do not take anything personally
- Ask for permission, use a gentle tone of voice
- Provide clear directions, limit options
- Gentle touch, validate feelings
- Reassure person you are here to help
- Make sure person is comfortable; are they fidgeting, tapping hands, bored?
- Go slow, play calming, favorite music
- Pair good things with unavoidable things-we will (favorite thing to do) once we brush our teeth, shower, change clothes.
- Use of therapeutic lying; if they think you are your sister that is OK. Don’t bother with logic or reasoning if not necessary.

Medical Interventions

- Primary Team, Outpatient Care, Medications,
- Therapy, Counseling-continuous for some.
- Hospital Care
- Discharge Planning
- Skilled Care vs. Custodial Care
- Placement vs. Home Care
- Patient's Rights, Insurance Issues
- End of Life Care
- Community Resources

Primary Care Team

- Most outpatient medical care teams for seniors provide geriatric specialists who conduct cognitive evaluations and monitor patient's mental status.
- They will assist clients and families with documentation for services, placement and counsel families re levels of care; dementia care, palliative care, compassionate and end of life care.

Hospital Admissions is a Process

- Admissions to the hospital requires that a physician deems the patient in need of medical care and meeting Medicare criteria known as “ICD 9 Codes” within a DRG or diagnoses related group.

- It is ultimately the physician’s choice to admit a patient or not. A 3 day inpatient stay is required for Medicare to pay for skilled care post hospital discharge.

- A physician may place a patient on “observation status.” This is not considered an admissions.

Common Causes of Hospital Admissions

- Heart failure, cardiac arrhythmias, shortness of breath
- Diabetes, stroke, pneumonia, infections
- Medical regimen and medication non-compliance
- Depression, Addiction, Suicidal ideation
- Social Isolation, Abuse, Neglect, Failure to Thrive

Adult Protective Services

- Anyone may call their county APS office. Physicians, hospital staff, social workers, are mandated reporters. They must report any suspicion of elder neglect or abuse (physical, financial, emotional.)
- Paramedics and police may call APS if they enter a home which is unsanitary and unsafe.
- Santa Clara County APS - 800 414 2002
- San Mateo County APS - 800 675 8437

Team Roles

- Primary physician determines medical and medication interventions, tests, determines discharge plans with input of the patient's medical team.
- Physical, occupational and speech therapists evaluate patient's functional abilities and rehabilitation needs.
- Nurse case manager assists with skilled discharge placement and skilled home care services.
- Social worker provides emotional support, patient advocacy, resources, family and staff mediation, crisis intervention, assistance with non-skilled discharge needs. Community liaison for Adult Protective Services, high risk discharges, guardianship petitions, liaison services for insurance issues, liaison for funding for medication, placement for non-insured patients with skilled care needs.

Patient Discharge Meeting

- Patient's Baseline and Functional Status
- Disease Process and Impact
- Diagnosis and Prognosis
- Symptom Management
- Treatment
- Medication Regimen
- Rehab Potential
- Level of Care Needed
- Insurance
- Social and Family Supports
- Follow Up Care and Appointments
- Medical Equipment
- Transportation for Follow Up Care
- Compliance Coordination
- Skilled Care vs. Custodial Care
- Placement or Home Care?

Insurance Resources: Medicare

- Medicare is government health insurance for those of us 65 plus.
- We have paid into Social Security through paying our taxes and qualify for this benefit.
- You apply for Medicare through Social Security when you are 64 and a half years old. You may apply at your local county SS office or on-line.
- Medicare has 3 Parts; Part A is for hospitalization, Part B for outpatient care and Part D for drug prescription coverage.

Part A Medicare Coverage

- Medicare Part A is hospital insurance and covers under certain conditions; hospital room, meals, skilled nursing care, physical and occupational therapy, speech therapy, social work, medications, some medical supplies and transportation, dietary counseling.
- These must be ordered by the physician and necessary to meet health goals.

Hospital Discharge and Patient's Rights

- The discharge plan is determined by consultations between the patient, family and significant others, the MD, physical therapist, occupational and if necessary speech therapist and facilitated by a nurse case manager for skilled care services. The discharge is either for placement, rehabilitation, long term care or for home with skilled rehab services for in the home.
- Otherwise, a patient is discharged home with follow up instructions but no skilled care is ordered by the physician.
- If your loved one is in the hospital and you feel that their discharge is premature ask to see the Admission's Office rep or the nurse case manager and ask to file an Appeal regarding the Discharge.
- The hospital is responsible for providing you with a list of your patient's rights and the Medicare Appeal Process Instruction Sheet.
- Medicare will pay for the interim appeal process time.

Medicare Appeal

- If you decide to appeal the discharge first consult with the nurse case manager, physician or social worker regarding the process.

- Often just having a conversation may extend the discharge.

Medicare Appeals, Claims, Grievance

- Complete information is available at www.medicare.gov/claimsandappeals.
- A Medicare appeal is based on your right to question the date of discharge, denial of a prescription or denial of care.
- Medicare Claims are what your care providers file for payment.
- Medicare Complaints or grievance are what you file if you have a concern regarding the quality of service from your provider, hospital or nursing home.

Resources for Dementia Care

- Skilled Nursing Facilities-accepts insurance or private pay.
- Adult Day Health-respite care, may accept insurance.
- Alzheimer's Residence or Memory unit within a Residential Facility-Secured unit. Private Pay.
- Board and Care-family operated small group homes. Private Pay.
- Home Health Care-Skilled care
- Home Care-Non Medical, non skilled; provides only custodial care. Private Pay.
- Caregiver Support Groups-located at facilities or senior center, community groups. Usually ask for donations.

Relocation

- Relocating an older person who has dementia to a care facility may result in their being temporarily MORE confused and disoriented.
- If possible, decorate and design their new residence or room so that it feels familiar.
- The agency may or may not want to you stay for the first few hours or days to help with adjustment. Some advise you do NOT stay to help your loved one adjust to their staff. Other places may advise differently.

Geriatric Care Management

- GCM's are individuals or companies who help families coordinate care for a senior loved one.
- They may charge hourly or package rates and request that you sign a contract.
- They have either academic degrees such as Master's in Social Work or Counseling; are trained Marriage, Family Therapists or certified in Gerontology.
- Check their credentials.

Skilled Nursing Home Facilities

- 24 hour nursing staff, RNs with an MD as the Medical Director.
- State licensed, 95% Medicare or MediCal certified.
- Broad range of skilled care for rehab, PT, patients with IVs, tube feedings, wounds and infections.
- Staff may give meds and use restraints if ordered by MD.
- Medicare A will pay for a limited number of beneficiary days; private health insurance billed for co-pays.
- Review contract with Admission's and Business Office. You do not want any surprises.

Medicare Coverage: Skilled Placement

- Your costs in Medicare for placement in a skilled nursing facility;
- Days 1- 20 : $0
- Days 21-100: $148 per day
- Days 101 and beyond: all costs
- For breaks in care more than 30 days, you need a 3 day stay in the hospital to qualify for additional skilled nursing home care.

Medicare and the US Budget

- Hospitalizations account for approximately 33% of the total Medicare expenditures.
- 1/5 of patients readmitted within 30 days results in a cost of 15 billion dollars.
- Readmissions due to premature discharge, untreated infections, poor communication, lack of follow up and medication non compliance.

Non-Skilled Custodial Care
What is it?

- Non-skilled care is for patients with functional decline or disabilities. They cannot feed, toilet, transfer, dress or wash themselves.
- They cannot take their own medications or negotiate a safe stay at home.
- They are at risk if residing alone.
- They may not be able to manage their own personal household and financial matters.
- **Health Care Insurance does not pay for this type of help. Long Term Care Insurance will pay for this. Check your policy if you have one.**

Residential Custodial Care for the Elderly

- RCFEs
- These include assisted living facilities, small group homes or Board and Cares.
- These are state licensed but not Medicare regulated.
- These are private pay facilities.
- Hospice staff may visit but the facility has mostly med techs and minimally trained staff for custodial care needs.
- Costs range and so do services. Check for references, visit facilities a few times. Have lawyer review contracts.
- If you are on a limited budget be sure you know what “add ons” are involved with their monthly fees; incontinence care, diapers, transportation fees?
- Do they use restraints, honor your AD or POLST and provide medication monitoring?

Tips for Facility Placement

- Tour facilities, review admission's criteria, payment plans, insurance coverage, staff and patient ratio.
- Ask for references from other families or residents.
- Participate in an activity if you can.
- Inquire at the Admissions Office what happens if the resident runs out of money?

Hiring Individual Caregivers or Using an Agency for Home Care?

- If you hire as a private pay employer you are responsible for filing taxes and accepting liability for your worker.
- Do not accept word of mouth referrals. Do a background and reference check.
- Full Caregiver agencies train, license and insure their workers.
- Referral agencies charge you for the referral fee and you are still the responsible employer.

End of Life Resources

- Hospice provides quality care during terminal phase of illness with individualized comfort care and pain medication.
- Will train family or caregivers.
- Care provided at home or in a facility.
- Goals include comfort, pain management, emotional support of patient, family, focus on spiritual care and patient's rights.

Advance Directives

- You have the right to give directives about your own health care.
- You have the right to select a health care agent who can make health care decisions for you if you are too sick to make them yourself.
- Start a family conversation about DNR status, tube feeding, dialysis, blood transfusions, surgery, funeral preferences and memorial services, wills.

POLST

- Physicians Orders for Life Sustaining Treatment
- This form is a set of orders signed by your physician so that it can be acted on immediately; it has the authority of a physician's order.
- The Advance Directive provides guidance to the medical team and to an agent acting as a patient representative.

Contact Information

• Avenidas Care Partners	650 289 5433
• Medicare	800 633 4227
• Social Security	800 772 1213
• California Patient's Rights	800 254 5166
• Disability Rights	800 776 5746
• Bay Area Legal Office	510 430 8033
• Family Caregiver Alliance	415 434 3388
• Alzheimer's Association	800 272 3900

Recommended Readings

- Current version of the *Diagnostic and Statistical Manual* - purchase at Stanford Bookstore or on-line.
- "*Passages in Caregiving-Turning Chaos Into Confidence*" by Gail Sheehy. Harper. 2011
- "*The 36 Hour Day*" Nancy L. Mace, M.A and Peter V. Rabins, M.D., M.P.H. Warner Books. Revised April 2001
- "*Person-Centered Dementia Care*", Dawn Brooker, Jessica Kingsley Publishers, London and Philadelphia, 2007

References

Data for this material was collected from the following resources:

- Caregiver census in the US, Family Caregiver Alliance, www.caregiver.org
- Diagnostic Criteria on Dementia from the DSM-IV, American Psychiatric Association, 2000
- Compassionate Communication Techniques, Alzheimer's Association, www.alz.org
- Tiffany Mikles Dementia Care Coaching, www.dementiacarecoaching.com
- Avenidas 10th Annual Caregiver Conference Resource Guide

Avenidas Care Partners

Contact Information

Paula Wolfson, LCSW, Manager
650 289 5438

Avenidas Care Partners
450 Bryant Street
Palo Alto, CA 94301
650 289 5433