

2019 CARE FORUM - A DONOR FUNDED INITIATIVE

SPONSORED BY AVENIDAS OF PALO ALTO

www.avenidas.org



Location of Care Forum Series | Avenidas Rose Kleiner Center
| 270 Escuela Ave, Mountain View | CA 94000

Avenidas of Palo Alto, a leader for decades to enhance the lives of caregivers and older adults launched this rich interactive experience for caregivers to gain distinctive insights into ways of learning, adapting and healing!

QUOTE BY AVENIDAS CEO - AMY ANDONIAN:

Avenidas of Palo Alto has been a leader for decades to enhance the lives of caregivers and older adults. We are so excited to launch this rich interactive experience for caregivers to gain distinctive insights into ways of learning, adapting and healing!

“There are only four kinds of people in the world. Those who have been caregivers. Those who are currently caregivers. Those who will be caregivers, and those who will need a caregiver.”

Former First Lady Rosalyn Carter

INTRODUCTION TO THE CARE FORUM SERIES

There are more than 35 million adults in the United States who are providing unpaid care to an adult age 50 or older. Thousands in the “Sandwich Generation” are grappling with childcare, eldercare and their own aging.

To address some of the challenges, Avenidas of Palo Alto, a leader in enhancing the lives of caregivers and older adults, launched a donor funded 2019 Care Forum. The Care Forum was designed by three local experts, Dr. Ellen Brown, Dr. Rita Ghatak, and Paula Wolfson, LCSW to offer a rich interactive experience for caregivers to gain distinctive insights into ways of learning, adapting and healing!

MEET THE EXPERTS: The Avenidas Care Forum is uniquely positioned to benefit family caregivers and their personal support teams. This series of 7 lectures will provide participants with insider information from a physician, a psychologist and a social worker who have dedicated their careers to helping family caregivers navigate complex levels of care transitions, minimize stress, cultivate resilience, and thrive!

Rita Ghatak, PhD, psychologist, was the CEO of Rose Kleiner’s eldercare company Older Adults Care management, after her research at Stanford. As the founder of the aging program at Stanford, and Aging 101, she focuses on caregiver research, education and care transitions. www.aging101.org.

Dr. Ellen Brown, a pioneer in developing the role of the hospice physician in the Bay area has provided care in the home to thousands of hospice patients in her 20 years at Pathways Hospice. She has trained countless Stanford Palliative Medicine and Geriatrics fellows. www.ellenbrownmd.com

Paula Wolfson, LCSW, Manager Avenidas Care Partners is an elder care consultant, caregiver advocate and thought leader in Santa Clara County aging services. Paula develops the content for the annual Avenidas Conference.



Avenidas Announces New CARE FORUM

Free monthly Caregiving Workshops for Families

FORUM SCHEDULE

| | |
|---------------------------|--|
| SAT APR 6 | Pro-Active Planning for Adult Children and Concerned Loved Ones 11am-2pm. Free lunch included. Dr. Ellen Brown & Dr. Rita Ghatak |
| SAT MAY 4 | From Chaos to Confidence: Navigating Home, ER, Hospital, Rehab 11am-2pm. Free lunch included. Dr. Rita Ghatak |
| SAT JUN 1 | Caregiving Conversations About Quality of Life and Treatment Options 11am-2pm. Free lunch included. Dr. Ellen Brown |
| SAT AUG 4 | The Emotional Work Inherent Within Caregiving 11am-2pm. Free lunch included. Paula Wolfson, LCSW, Manager of Avenidas of Care Partners |
| SAT OCT 12 | The Cost of Caregiving: Budgeting for Respite Resources 11am-2pm. Free lunch included. Kristina Lugo, Director Avenidas Rose Kleiner Center; Minda Cutcher, MBA, Director, Love and Order |
| SAT NOV 2 | Caregiver Health and Wellness Strategies 11am-2pm. Free lunch included. Dr. Ellen Brown & Dr. Rita Ghatak |
| SAT DEC 7 | Caregiver Empowerment and Advocacy: Your Voice, Your Vision 11am-2pm. Free lunch included. Paula Wolfson, LCSW |

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MEET OUR TOP EXPERTS



Rita Ghatak, PhD
www.aging101.org

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Dr. Ellen Brown is a pioneer in developing the role of the hospice physician in the Bay area has provided care in the home to thousands of hospice patients in her 20 years at Pathways Hospice. She has trained countless Stanford Palliative Medicine and Geriatrics fellows.

For more speakers, visit www.avenidas.org.

REGISTRATION & INFO

The Avenidas Care Forum is uniquely positioned to benefit you and your loved ones because our expert presenters have been on the front lines of elder-patient care services for years, and they understand the dire challenges experienced by family caregivers. They will provide insider information as to how family caregivers should navigate complex levels of care transitions, minimize stress, cultivate resilience, and thrive!

These free, public workshops are for families caring for loved ones. They will fill up fast. Reserve your space and lunch early.

To register, call: (650) 289-5400 or visit www.avenidas.org. If you have questions about the Care Forum call Paula Wolfson, Manager of Avenidas Care Partners, at (650) 289-5438.

These sessions will be held at the Avenidas Rose Kleiner Center, located at 270 Escuela Avenue in Mountain View, with plenty of free parking.

SESSION 1 | APRIL 2019

PROACTIVE PLANNING FOR ADULT CHILDREN Paula Wolfson, LCSW; Rita Ghatak, PhD, Ellen Brown, MD

TOOL KIT

The first Care Forum highlighted multiple areas that older adults, families and caregivers should look at before a crisis emerges. The concept of caregiving has changed, and family members are providing more hands-on care, managing legal, financial, and health care decision-making. The talk provided a robust list of all areas that should be looked at for optimal proactive planning, such as financial, legal, insurance concerns, different types of care options and benefits covered by Medicare, ways to promote better communication with doctors and other providers and good care coordination strategies.

The Care Forum experts recommended choosing a physician with expertise in aging, treatments and side effects of medications unique to the elderly and adequate emergency back-up. The following are important elements to keep in hand to facilitate communication with doctors as well as useful during a crisis.

1. Medical history, diagnoses, past illnesses, injuries.
2. hospitalizations, surgeries, latest lab tests.
3. Access to electronic health record (EHR).
4. Family history of physical/mental illness, eyeglasses, hearing aids, dentures.
5. Medications - past and current, over the counter and prescription, supplements.
6. Allergies and sensitivities to medications.
7. Daily habits – example: routines of eating, toileting, sleeping, exercise.
8. Difficulties in daily life: such as bathing, dressing, stairs, balancing checkbook.

GUIDE FOR CAREGIVERS

- Stay informed, educated, learn resources and plan pro-actively. Seek support from other caregivers. You are not alone!
- Cultivate communication skills to advocate, mediate, negotiate, for your care recipient's best interests and your own!
- Communicate effectively with doctors and other members of the healthcare team and ask them about resources, information and concerns. Be open to new ideas and technologies.
- Organize medical, financial, legal information so it's up to date and easy to find.
- Research on-line Validation Therapy for Dementia Communications techniques. Research Alzheimer's Association on-line library.
- Research on line national associations providing information and benefits to patients and their families with a disease such as cancer or diabetes.
- You do not need to solve everything. Accept what you cannot change. Avoid making rushed decisions during a crisis. Accept help.
- Take care of your own health so you are strong enough to take care of your loved one. Signs for being overwhelmed include lack of sleep and appetite, increased anxiety, inability to keep track of appointments and tasks, etc. Consult a health provider and join a caregiver support group.
- Give yourself credit for doing the best you can in one of the toughest jobs there is!

PROACTIVE PLANNING GUIDE

FINANCES: Create a list of all accounts, locations, advisors' contact information, all beneficiary designations up-to-date, track Social Security benefits and medical tax benefits. Know the monthly and yearly budget. Evaluate projected costs for private pay care. Streamline bill paying.

HOME CARE: Evaluate benefits of caregiver agencies vs private pay caregivers.

CARE COMMUNITIES: Learn about functioning, costs, legal details for independent, assisted, memory care and skilled nursing facilities.

INSURANCE: Medicare/Medicaid, dental and vision insurance, Veteran's benefits, long-term care insurance; create lists of all insurance policies (life, health, long-term care, etc.), how to pay for costs not covered by Medicare, prescription plans, coordination of benefits between care providers and insurance companies.

LEGAL: Learn about medical, legal, capacity and competency standards. Review homeowners, auto and umbrella liability insurance, wills, trusts, health-care directive, durable powers of attorney for financial and health care decision-making, 'end of life treatment' options.

LIVING ARRANGEMENTS: Evaluate safety issues of current housing, cost of modifications, contingency plans for long term plans for illness and disability. Create networks of caregiver zip code buddies.

SAFETY: Reduce fall risks by removing cords, loose rugs, clutter. Create passage for mobility devices. Retain professionals for overall home and bathroom safety.

HEALTH PLANNING GUIDE

- Choose a physician familiar with expertise in aging, treatments and side effects of medications unique to the elderly, emergency back-up. Maintain contact information for all MD's.

KEY COMPONENTS OF HEALTH HISTORY

- Medical history, diagnoses, past illnesses, injuries, hospitalizations, surgeries, lab tests (EHR), family history of physical and mental illness, eyeglasses, hearing aids, dentures.
- Medications - past and current, over the counter and prescription, supplements, cannabis.
- Allergies and sensitivities to medications.
- Daily habits - eating, toileting, sleeping, exercise.
- Difficulties in daily life - bathing, dressing, stairs, balancing checkbook.

WARNING SIGNS FOR COGNITIVE DISORDERS

Memory problems, changes in mood or personality.

- Planning difficulties, difficulty with everyday tasks.
- Confusion with time or place, trouble understanding visual images or spatial relationship.
- New problems with words in speaking or writing, misplacing things.
- Decline in or poor judgement, withdrawal from work of social activities.
- Getting lost while driving in familiar places, frequent minor accidents, (when you begin to feel unsafe allowing this person to drive or you will not let children ride in the car).

TIPS FOR PRESERVING BRAIN HEALTH

- Exercise regularly
- Get enough sleep
- Manage your stress
- Nurture social contacts
- Continue to challenge your brain by learning new things
- Protect your head
- Improve your blood pressure, diabetes, cholesterol
- Curtail tobacco, alcohol use, stop substance abuse

SITES FOR RESOURCES

- American Association of Retired People - www.aarp.org. Resources for adults 50 and above.
- Alzheimer's Association - <https://alz.org>. Information, tips and support for Alzheimer's Disease.
- Avenidas Care Partners— www.avenidas.org. Information, resources, caregiver support.
- Family Caregiver Alliance - www.caregiver.org. Comprehensive on-line caregiver education, tips, articles.
- Farewell To Falls - <https://stanfordhealthcare.org/for-patients-visitors/farewell-to-falls.html>. Assists older adults with fall prevention tips.
- Eldercare Locator- <https://eldercare.acl.gov>. Find help in the community by entering zip code, OR city, state.
- KARA - <https://kara-grief.org/>. Grief counseling.
- National Council on Aging - <https://www.ncoa.org>. Tools to stay healthy, secure, and independent.
- Office of Disease Prevention and Health Promotion - www.healthfinder.gov. Information to stay healthy.

- Rehab Mart - <https://www.rehabmart.com>. Adaptive equipment for seniors.
- Senior Housing Referrals - www.seniorseasons.com – referrals for Assisted Living and Memory Care.
- VA - www.va.gov/GERIATRICS/Guide/LongTermCare/index.asp. Guide to long term services and support.

SESSION 2 | MAY 2019

FROM CHAOS TO CONFIDENCE: NAVIGATING ER, HOSPITAL AND HOME

Rita Ghatak, PhD

TOOL KIT

This session looks at the complexities of care as older adults and caregivers move from the home, Emergency Room, hospital, ICU to rehab settings and back to home. There are multiple reasons that caregivers experience chaos while navigating a loved one. Commonly these include not recognizing changes in older adults in a timely manner and not understanding some of the complexities of the health care system. This session further discusses checklists and warning signs as well as solutions.

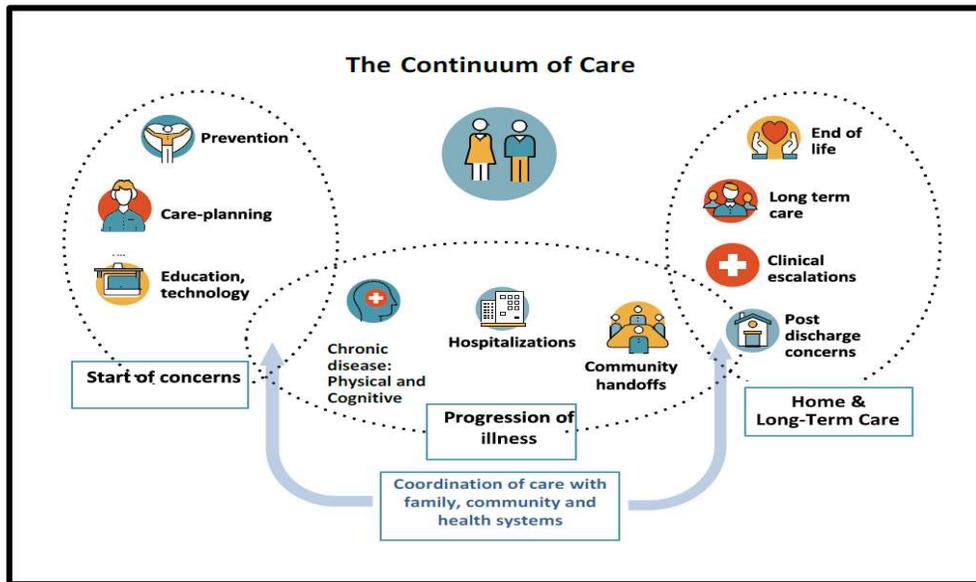


Figure showing 'Care through the Continuum'. Older adults with chronic illness and their caregivers can move through Phases 1, 2, and 3. (Ghatak, 2012)

Phase 1: The first phase may be a period of opportunity for caregivers. The time can be used for developing a road map for the future, building physical and psycho-social strength, learning about preventive practices, planning proactively, having family meetings, and creating care networks.

Phase 2: The second phase may be one where caregivers may face chaos as loved ones can be in and out of hospitals, ICU, rehab facilities, have progressive illness and frailty, and need help with discharge planning and aging in place.

Phase 3: The third phase may be one where caregivers can be overwhelmed with hard decisions.

FEW RISK FACTORS FOR OLDER ADULTS (National Institute on Aging)

- Age 75 or older.
- Moderate to severe deficits in 'Activities of Daily Living' (ADL's) - such as dressing, feeding, bathing, and 'Instrumental Activities of Daily Living' (IADL's) - such as making appointments, managing the home, finances, etc.
- An active behavioral and/or psychiatric health issue.

- Recent falls.
- Four or more active co-existing health conditions.
- Six or more prescribed medications.
- Two or more hospitalizations within the past 6 months, or a hospitalization within the past 30 days.
- Inadequate support system.
- Poor resources or unsafe living conditions.
- Low health literacy.
- Cognitive impairment.

WHAT IS INFORMED CONSENT?

Doctors will give you information about treatment or tests for you to decide whether you wish to undergo a treatment or tests. This process of understanding the risks and benefits of treatment is known as 'informed consent' and is based on patient autonomy: Few exceptions to the informed consent rule: an emergency in which medical care is needed immediately, incompetence in which someone is unable to give permission (or to refuse permission) for testing or treatment. HIPAA is the acronym of the 'Health Insurance Portability and Accountability Act' and includes privacy of health information, security of electronic records, administrative simplification, and insurance portability.

THE 3 D'S: DEMENTIA, DEPRESSION, DELIRIUM

DEMENTIA is gradual and a progressive decline in short term memory, communication, language, judgement, etc. Not everyone in the hospital knows the same basic facts about [memory loss](#), Alzheimer's disease, and related dementias. You may need to help teach hospital staff what approach works best with the person with Alzheimer's. Explain what can be triggers, what can be comforting, communication strategies, share with the team about the limitations and extent of impairment.

TIPS FOR HOME:

- Education re: disease and symptoms.
- Structured daily schedule with engagement and cognitive stimulation.
- Identification and elimination of modifiable triggers.
- Participation in leisure activities and socialization so patient can stay engaged.
- Encouraging exercise - walking, yoga, dancing.
- Sleep hygiene - limit daytime sleeping, treat sleep apnea, encourage healthy diet.
- Enforce safety, provide supervision, discuss driving hazards.
- Coordinate with patient's physicians to create medication regime, use medication management aids (pill organizers, dispensers, alarms, delivery systems).

DELIRIUM is a sudden change in mental status and is mostly reversible. Many factors can contribute to delirium, including hospitalization, acute illness, surgery, medications, infections, changes in medications. Studies have shown that dementia can be a risk factor for delirium.

- When delirium isn't recognized, it can delay an older person's recovery. Prolonged delirium can have a lasting impact on an older person's health and well-being.

- Common signs are confusion, sudden changes in personality or emotional state, decreased attention or concentration, periods of alertness that come and go throughout the day, etc. Tell the healthcare staff right away if you notice anything unusual.
- TIPS: Stay with the older person as much as possible, keep eyeglasses, hearing aids, and dentures on, help orient and make them remember where they are, make the person's surroundings more familiar, (family photos), encourage physical activity, games, and conversation.

DEPRESSION impacts thoughts, feelings, behavior and mood. Can leads to decreased function, impacts all aspects of life, and there is increased risk of self-harm. Important to notify the clinical team, provide history of medications and make sure the symptoms are differentiated from Delirium.

QUESTIONS FOR CAREGIVERS TO ASK DURING DISCHARGE FROM A HOSPITAL

DISCHARGE TO A SKILLED NURSING FACILITY (SNF): [Medicare Part A \(Hospital Insurance\)](#) covers [care](#) provided in a SNF for a limited time if the person has a [hospital-related medical condition](#), has Part A, has days left in their [Benefit period](#) to use, and a 3-day [qualifying hospital stay](#). It is important to note if the person is in the hospital under 'Observation' status. Observation is a way to keep someone in the hospital for a short time while doctors try to decide if he or she is sick enough to need inpatient treatment. Observation patients can sometimes be kept in the hospital for days, but these do not count towards the 3-day qualifying stay for a SNF. 'Long Term Care' insurance or Veteran's benefits may cover a SNF. Ask about all benefits and community resources before discharge.

DISCHARGE HOME: Patients and families are often told 'home care' may be covered once the person reaches home, but that may be skilled care such as physical, occupational, speech therapy or nursing care. Custodial care by an agency or private caregivers is typically private pay or may be covered by Long Term Care insurance or Veteran's Benefits. Adult Day Health care may take certain forms of health insurance. If person is discharged to Hospice, services can be provided at home or in a care facility or a SNF, health insurance pays for services of the hospice team visits (MD, social work and nurse) but not for room, board and custodial care such as bathing, dressing, feeding.

IF DISCHARGE IS TOO EARLY: If you do not agree that your loved one is ready for discharge, *you have the right to appeal the decision*. The first step is to talk with the physician and discharge planner and express reservations. If that isn't enough, you will need to contact Medicare, Medicaid, or your insurance company. The hospital will guide you to file an appeal. Formal appeals are handled through designated *Quality Improvement Organizations (QIO)*. If the QIO rules against you, you will be required to pay for the additional hospital care. The hospital will let you know the steps to take to get the case reviewed.

QUESTIONS ABOUT THE ILLNESS AND CARE NEEDED: These are related to - symptoms to watch for, care needed such as assistance with bathing, dressing, eating, diet restrictions, toileting, transfer (moving from bed to chair), mobility (includes walking), managing symptoms and training for that (e.g., pain or nausea), special equipment, coordinating the person's medical care, transportation, household chores, taking care of finances, etc..

QUESTIONS ABOUT BEING DISCHARGED TO THE HOME: Discuss with the hospital team if the home is safe, comfortable, with space for any extra equipment, the need for a ramp, handrails, grab bars, hospital bed, shower chair, commode, oxygen tank, and how to navigate stairs. Ask about who will order and bring the equipment, and will insurance, Medicare or Medicaid pay for them, (There are companies that will undertake minor home modifications).

QUESTIONS WHEN DISCHARGE IS TO A REHAB FACILITY OR NURSING HOME: How long is the stay, is the facility clean, does the facility have experience working with families of your culture/language? Always check online resources such as www.Medicare.gov for ratings. Ask about staff turnover, daily routine, diet, presence of social worker, safety, facilities/programs for dementia patients, means for families to interact with staff.

QUESTIONS ABOUT MEDICATIONS: Get a list of all medicines prescribed prescription and nonprescription, their side effects, interactions with other medications. Ask if insurance pays for the medications, are there less expensive alternatives? Does the pharmacy provide special services such as home delivery, online refills, or medication review and counseling?

QUESTIONS ABOUT FOLLOW-UP CARE: What health professionals will your loved one need to see? Have those appointments been made? What transportation arrangements need to be made? How will the primary care doctor (PCP)

learn about what happened in the hospital or rehab facility? Whom can you call with symptoms and treatment questions, 24 hours a day and on weekends?

QUESTIONS ABOUT YOUR NEEDS AS A CAREGIVER: Where can you find support groups?

QUICK DISCHARGE CHECKLIST

- Care coordination, family meetings
- Caregivers - private or agency, details for hiring
- Living options
- Medication management, supplies for care
- Follow-up with primary care physician/specialty care
- Emergency response systems
- Transportation support
- Home adaptive and safety devices
- Technology for support at home or monitoring of vitals
- Nutrition
- Mental health/pain management
- Hospice/palliative care/grief management
- Legal/financial planning

“LET’S GET THE CONVERSATION STARTED”! CRITICAL CONVERSATIONS FOR THE CAREGIVER DEALING WITH SERIOUS ILLNESS

Ellen Brown, MD

TOOL KIT

This session entails an overview why and how important conversations need to happen, when caregivers and loved ones are dealing with serious illness. The session looks at all the different ramifications of crucial conversations and important tips about how to start such conversations. The session also includes important resources and other materials that families and caregivers should consider. The importance of understanding the difference between Palliative Care and Hospice and quality of life options are discussed.

SECTION 1: THE NEED FOR CRUCIAL CONVERSATIONS

As a society, we tend to avoid discussions concerning end of life treatment options and death. Consequently, these conversations usually take place at the time of a health care crisis, between physicians and stressed family caregivers who may not know their loved one’s wishes.

We acknowledge that it can be difficult to initiate conversations on our deeply held values and thus our preferred end of life care options. Here is a compilation of helpful resources for beginning your conversation with loved ones on your values and what matters most.

WHY HAVE CONVERSATIONS?

- Goals of care conversations are associated with improved end of life care for patients.
- Lower risk of depression and anxiety in surviving members.
- Sharing your wishes for end of life care can bring you closer to the people you love.

MORE IMPORTANT QUESTIONS

- What matters to you?
- What are the important things in your life? What do you do you want to accomplish?

SECTION 2: NOT ONE THING THAT CAN WORK FOR EVERYONE, THERE ARE MULTIPLE TOOLS AVAILABLE TO GET THE CONVERSATION STARTED

1. PREPARE <https://prepareforyourcare.org>
2. The Conversation Project <https://theconversationproject.org>

Shared understanding of what matters most to you/your loved ones, makes it easier to make decisions when the time comes.

3. Go Wish cards <http://www.gowish.org>

Effective tool for people of all ages, levels of cognition, literacy. including people with limited literacy and limited English skills.

4. WHEN YOU SIMPLY CAN'T HAVE THE CONVERSATION - The Letter Project - <https://med.stanford.edu/letter/what-matters-letter.html>

ADVANCE DIRECTIVES

- Advance directives are only as good as the conversations around them.
- Forms are the symbols of the conversations behind them.

1. **DPAHC** - Durable power of attorney for health care.

Appoint a decision maker or proxy to speak for you if you can't speak for yourself.

2. **LIVING WILL / FIVE WISHES - Five Wishes** <https://fivewishes.org>

Helps you imagine your vision of a good death

- My wish for how comfortable I'd like to be...
- My wish for how I want other people to treat me....
- My wish for what I want my loved ones to know....

3. **HEALTH DIRECTIVE FOR DEMENTIA** www.dementia-directive.org

SECTION 3: POLST - https://capolst.org/wp-content/uploads/2017/09/POLST_2017_Final.pdf

A doctor's order, signed by a doctor, nurse practitioner or physician's assistant and the patient or proxy.

NO WRONG ANSWER. WHAT IS CONSISTENT WITH YOUR VALUES?

1. Attempt Resuscitation/CPR or Do Not Attempt Resuscitation (Allow Natural Death)

2. WHAT TYPE OF MEDICAL INTERVENTION DO YOU WANT?

- Full Treatment: with the primary goal of doing everything possible to prolong life. This includes CPR, intubation, ventilators, dialysis, intensive care units.
- Selective Treatment: with the goal of treating medical conditions while avoiding burdensome measures. No CPR, but IV antibiotics, IV fluids, hospitalization utilized.
- Comfort focused treatment: Primary goal is maximizing comfort. Relieve pain and suffering with medication by any route necessary. Use oxygen if for comfort.

SECTION 4: CRUCIAL CONVERSATIONS WITH HEALTH PROVIDERS

- Talking to your doctor about your goals and what matters.
- Many doctors don't know how to have these conversations.

HELPFUL TIPS WHEN MEETING WITH DOCTOR

- "I want a realistic picture, so I can plan ". Take notes.
- Bring a friend or relative, ask follow-up questions.
- If they are using medical jargon, ask them to say it more simply so you can understand.

KNOW THE TRAJECTORY OF AN ILLNESS

- What can you expect (if the disease follows its usual course)?
- Can you give me a rough estimate of how much time I have left (years, months, weeks or days)?
- How will you feel?
- How will treatments affect your quality of life?

SECTION 5: DISCUSSION OF HOSPICE AND PALLIATIVE CARE

PALLIATIVE CARE

- Extra level of support, focusing on relieving suffering and improving quality of life for those who are coping with serious illness.
- Other names: supportive care, pre-hospice, pain management.

- You can still be receiving curative treatment.
- A team of MDs, nurses, counselors and social workers, provide medical, emotional and social support needed to cope with the burdens of serious illness.
- Works with your health care team.
- Experts at managing pain, shortness of breath, nausea and fatigue.
- People who receive palliative care:
 1. Spend less time in the hospital
 2. Have less pain and suffering
 3. Enroll in hospice earlier

HOSPICE CARE

A specialized type of palliative care available to people with an incurable illness and a life expectancy of less than 6 months. Focus on caring, not curing. Doesn't hasten death but focuses on living well until you die. Motto: Hope for the best but prepare for the worst. Care provided by a team of MD, nurse, social worker, chaplain, personal aide and volunteer. Treats emotional and spiritual pain in addition to physical pain Addresses emotional needs of caregivers

MYTHS OF HOSPICE

- Hospice is a place or building - NOT in the US. It is a type of care that goes to where you live.
- Hospice is care for the last hours of life - benefit meant for those who have up to 6 months.
- Signing up for hospice is like signing your death warrant - 15% of people "graduate" from hospice.
- Hospice is expensive - It is covered by Medicare and Medical and private insurance, but there are gaps.
- Hospice covers around the clock care - Major shortcoming. Hands-on bedside care needs to be provided by family, friends or private aides.
- Hospices push morphine and hasten death - no evidence that hospice shortens life.

SOURCES FOR TOOL KIT

- AARP - www.aarp.org/caregiving. Information of current reports and research
- Family Caregiver Alliance - www.caregiver.org. Comprehensive caregiver education, tips, articles.
- National Council on Aging - <https://www.ncoa.org>. Tools to stay healthy, secure and independent.
 - National Institute on Aging - <https://www.nia.nih.gov> Research and health information.
- National Alliance for Caregiving - www.caregiving.org/research/. Current research trends on caregiving.
 - Medicare - <https://www.medicare.gov/> Information for hospital discharge.
- Office of Disease Prevention and Health Promotion - www.healthfinder.gov. Information to stay healthy.

SESSION 4 | AUGUST 2019

THE EMOTIONAL WORK WITHIN CAREGIVING

Paula Wolfson, LCSW

TOOL KIT

This session provides an overview regarding caregiving and the multiple emotions caregivers experience. Caregivers are at risk for physical and emotional setbacks. The session provides ways of cultivating essential emotional skills, boundaries, resilience, coping with triggers, and when to seek professional medical and mental health support

SECTION 1: CAREGIVING IS RISKY BUSINESS

- A. **BEHAVIORAL RISK STUDIES:** Older family caregivers are considered an “at risk” sub-group of elder Americans: one’s health is at risk due to prolonged years of exposure to multiple stressors such as family conflict, navigating loved one’s prolonged years of cognitive and physical decline, while managing complex, challenging legal, financial and health care matters. (Center for Disease Control 2016 Data).

Findings:

- Increased self-report of caregiver social isolation, lack of sleep, poor self-care.
 - Increased self-report of caregiver depression, anxiety, complicated grief: increased use of psychoactive medications.
 - Increased rates of caregivers diagnosed with high blood pressure, reduced immune function. increased risk of coronary heart disease (CHD) for women.
- B. **COMPASSION:** means the desire to alleviate and take on the suffering of others. This is potentially risky business if the caregiver feels constantly overwhelmed and depleted of energy.
- **SIGNS OF COMPASSION FATIGUE** - Emotional and mental exhaustion, stagnation, frustration, apathy, decreased social interactions with others, reduced sense of personal accomplishment, emotional reactivity and verbal outbursts, depersonalization and disconnects in our thinking and behaviors. CG becomes depleted of energy, sense of self, purpose, self-isolates may neglect, self and possibly CR.

SECTION 2. EMOTIONS PROVIDE MESSAGES

- It is how we respond to them that is either helpful or harmful.
- Mind over mood techniques allow us to use reason, investigation, common sense before responding to our triggers.
- Triggers may cause us to become emotionally reactive: rather than use reason we fall into the pattern of responding to assumptive or “hot thoughts-emotionally charged” which in turn impact moods, behaviors, shuts down positive communications.

TIPS AND DEFINITIONS:

Emotional intelligence informs us of our values, boundaries: when we feel safe and or at risk.

- Use your emotions wisely for making wise and reasonable choices during tense situations.
- Anger: arises when a boundary has been crossed. Anger helps you understand your values, beliefs and allows you set personal guidelines. Anger can also help you set healthy detachment, avoid enmeshment, protect yourself and others. Anger side effects: shortness of breath, knot in the throat, complexion changes, excessive alcohol and drug consumption, increased smoking, lack of patience, desire to strike out. May need to count to 10, walk away, seek support.
- Guilt and shame arise to help us try not hurt, embarrass, dehumanize self and one another.
- Fear orients us to surroundings, situations and others who present danger, high risks, possible hazards. Fear grounds us in a present moment of crisis and change. Helps us take decisive action.

- Anxiety helps us identify unresolved feelings about past events, concern for future and worry about present tasks. Anxiety may cause us to spiral into depression if not addressed properly. Anxiety side effects: muscles ache, head-ache, feel jumpy, cannot be still, talk too much and say nothing-imagine rocking in a chair fast and going nowhere.
- Panic arises when you feel a threat to your survival. Panic side effects: Chest pains, pressure, sweat, dizzy, panic attack may feel like a heart attack.
- Sadness helps you release that which is no longer, mourn, honor and let go, move forward.
- Grief acknowledges when you have lost a loved one: a person, a pet, a prized possession (wedding ring), a time in your life (high school) and or an experience that you cannot get back (your youth).
- Happiness (joy, hope, love), keep you connected to others, community, feel affirmed, have purpose, and invested in the present and the future. Allows for play, relaxation, open-hearted connections, renewal of hope, feelings of contentment, life satisfaction.

CULTIVATING ESSENTIAL EMOTIONAL SKILLS

EMPATHY: Empathy is an “emotional” skill, forms the foundation for positive-regard, patience, open mindedness, kind-hearted relationships, forgiveness. Author and researcher Karla McClaren, M.Ed states empathy is composed several aspects which impact our behaviors and thoughts.

- Emotional awareness: before empathy kicks in you need to sense that a feeling / emotion is occurring and or a response is expected of you. Empathy relies on one’s ability to detect, understand and share emotions. Empathy is an emotional skill.
- Empathic accuracy: the ability to accurately understand your feelings and others so that you can make appropriate responses. This is always a challenge as cultural norms vary regarding discussions of death, aging, illness, treatment, sex, abuse, etc. Some cultures avoid intimate discussion to “save face”, topics taboo, inappropriate, vulgar, insulting.
- Emotional contagion and regulation: Necessary to have self-awareness and insight, so that in the presence of strong and powerful emotions you can take control rather than be overpowered by strong feelings, especially if they are dangerous to your safety or that of someone else. We might think of this as “impulse control.”
- Perspective taking: Put yourself in the other persons’ “shoes.” Understand others’ wants, needs, capacity for coping. Requires open-mind, open hearted approaches and humility.
- Perceptive engagement: Allows you to gage complex interactions, situations, and respond respectfully to your own and the other person’s needs. “Sometimes the most empathic action may be to do nothing at all, just listen, give people their privacy, space.”

BOUNDARIES

- Preserve our sense of self, values, integrity, self-respect.
- Setting a firm boundary re: use of your time, money, emotional energy is not saying “I don’t care about you.” Instead one is declaring, “I need to make myself the priority in this moment.”
- Our boundaries change with situations.
- Sustaining a safe, personal boundary is very much like a consistent “declutter” practice: declutter your life of situations, relationships which drain and deplete you, do not sustain you and cause more harm than good to your spirit and soul.

THRESHOLDS

- Mark sacred personal time, transitions, traditions helps you renew your energy, sense of self, values.
- through rituals, time alone or with others, meditation, journaling, lighting candles, praying, chanting, walks outside, being in nature. Possibly having your first “caregiver show?”

RESILIENCE

- Resilience-is one’s ability or capacity to overcome stressful situations, and “roll with the punches” to bounce back from crisis, conflict, change without lasting emotional difficulties.

- Resilient people have a strong inner sense of control and focus, can proactively plan, control impulses, use mind over mood, persevere (ability to learn from one's mistakes).
- Characteristics of those with resilience include having perspective, optimism, humor, faith or spirituality. Those with resilience find purpose and meaning in life: experience adversity as an opportunity for personal growth.

SECTION 3. COPING WITH TRIGGERS | COMMON CAREGIVER TRIGGER POINTS

- Loss of free time: may stop working, less time seeing friends, limited time for travel, hobby and passions.
- Loss of loved one's companionship, loss of intimacy.
- Social isolation
- Family roles change, conflict, role reversals, conflict over decision-making, taking away car keys, money, daily tasks, placement, end of life care
- Untreated, undiagnosed mental health disorders in family become prominent due to stress
- Coping with a care recipient's prolonged dying phase
- Caregiver's health declines before that of care recipient
- Coordinating events related to loved one's death

COMMON CARE RECIPIENT TRIGGER POINTS

- Loss of capacity, chronic pain, autonomy, cannot feed, bathe, dress, incontinence care
- Multiple sensory loss involving vision, hearing, mobility, balance
- Home Safety, Hiring Home Care, Modifying Home
- Home care, managing work force in home, strangers in the house
- Cultural communications clashes with care providers
- Safety issues at home, modifying home for safety features, alarms
- Navigating complex legal, medical and financial systems-resistance
- Frequent medical interventions: ER, hospital, rehab, SNF, placement memory care
- Discharge planning sessions and hand-offs between providers
- Designating legal decision-makers, managing elder care estate plans, Wills, Trust, Advanced Directives, POLSTS
- Financial stressors - maintaining budget, high costs of custodial care, arranging for fiduciary services, selling family home to pay for assisted and or memory care

COGNITIVE BEHAVIOR TECHNIQUES FOR EMOTIONAL REGULATION: MIND OVER MOOD

- Mind over Mood-Techniques: change how you feel by changing how you think.
- Track dysfunctional patterns of thought which influence moods and behaviors: these are described as "assumptive" or "hot" thoughts: evolve from emotional reactivity to triggers, not evidence based.
- Goal - reduce reactive thinking patterns, maximize reasonable responses to triggers and stay calm.
- Assumptive or hot thoughts include the following patterns of thinking:
- Going global: making generalized statements: "You are completely unreliable!"
- Alternative response: "I was hoping you were going to take him to the doctor. Why are you not available? I thought it was your turn."
- Jumping to conclusions: "You took my money?"
- Alternative Response: "Has anyone seen my wallet?"
- Discounting the positive: "Oh, his sister always sends a card and flowers: so, she does not have to visit him at the memory care place."
- Alternative: "I think his sister might be heartbroken he has dementia. How can we help her? He misses seeing her."
- Using "Should" rather than "I" statements. "You should call more often!"
- Alternative: "I miss you, please call us more often, I need support."
- Personalizing events as if everything is your fault: "I should not have said that."
- Alternative: "May I help you? Are you upset?"
- Shaming and blaming others: "His sister is so clueless about dementia caregiving."
- Alternative: "I will call his sister and offer suggestions how to plan activities for her visits with Don."

SECTION 4. WHEN TO SEEK PROFESSIONAL MEDICAL AND MENTAL HEALTH SUPPORT

- Extreme Compassion Fatigue: Tells us we are almost depleted of energy to function well and to think clearly. Emotional outbursts, frustration, anger, dark moods, fatigued.

- Compassion- Fatigue Body Talk: exhausted, cannot think clearly, drained.
- Complicated Grief: Lasts many months into a year, several components. Disbelief in the death of the loved one. Intense sorrow, bitterness, anger. Blaming oneself for the death. Avoiding others. Life feels meaningless. Loss of identity and purpose. Wishing to die. Complicated Grief Body Talk: Emotional numbness. Loss of appetite, oversleeping, isolation, crying. Mood is intensely sad. Cannot move forward on one's own. Requires medical and mental health support, intervention.
- Suicidal ideation: arises when something difficult in your life (bullying, financial stress, interpersonal strife, depression) needs to end but NOT your physical life. The question is what idea or behavior needs to end or be transformed? If in crisis call suicide hot line 1 800 273 8255. Go to nearest emergency room. Share feelings with supportive friend who will take you to your health providers, urgent care.

ASSISTANCE REPORTING ELDER ABUSE

Elder abuse can be emotional, physical, financial and or neglect, indulging self-neglect resulting in "failure to thrive". Call Adult Protective Services (call in telephone lines are listed by counties) to report elder abuse and neglect. You only need to have a suspicion of neglect or abuse. APS staff will evaluate your call and send out investigators if they determine follow up is needed with welfare calls.

COMMUNITY RESOURCES

- APS Santa Clara County: 800 414 2002, San Mateo - 800-675 8437.
- National Alliance Mental Health-Support, Education, Advocacy, Referrals for Therapists
- Santa Clara County - 408 453 0400.
- Check your health plans for access to mental health support: psychiatrists, psychologists, social workers, palliative care and hospice teams, health care navigators.
- Private Pay therapists are listed online by certification, area of expertise. Sample: Google Search: "Psychologist specializing in grief, loss and or depression among older adults."
- Linda Nastari, LCSW, 408-358 5414-San Jose office
- Nina Poletica, MFT, 650-269 1695-Palo Alto office
- Mental Health Clinics
- Stanford Outpatient Psychiatry
- University of Palo Alto, Los Altos location
- KARA – Palo Alto, Grief

CAREGIVER SUPPORT GROUPS

- Alzheimer's Association- Google alz.org - Caregiver support groups
- Avenidas www.avenidas.org | Caregiver Support Groups (Call Paula for an intake interview at 650-289 5438).
- Monday Caregiver Group (Location: Palo Alto Sunrise Assisted Care Community on Sheridan Street)
- Wednesday Caregiver Group - Avenidas, 450 Byrant Street, Palo Alto
- Rose Kleiner Center Caregiver Support Group - 270 Escuela Ave, Mt. View

ARTICLES

- Family Caregiver Alliance-<https://www.caregiver.org>
- "Emotional Side of Caregiving," Donna Schempp, LCSW, 2014
- "Dementia, Caregiving and Controlling Frustration-The Stresses of Caregiving."
- "Caring for Someone with Incontinence: Emotional and Social Issues"
- American Cancer Society - www.cancer.org
- "Seeking Help and Support - Grief and Loss"
- "What is Compassion?" <https://greatergood.berkeley.edu/topic/compassion/definition>
- The American Institute of Stress - www.stress.org
- "What is Compassion Fatigue?" - American Psychological Association
- "Controlling Your Anger Before It Controls You" - <https://www.apa.org/topics/anger/control>

BOOKS

- The Art of Empathy, Karla McLaren
- Mind over Mood -Change How You Feel by Changing the Way You Think, Dennis Greenberger, PhD, Christine A. Padesky, PhD
- The Four Agreements” (by Don Miguel Ruiz
- Caregivers Path to Compassionate Decision-Making” Viki Kind, MA
- What I Know for Sure, Oprah Winfrey
- The Four Agreements, Don Miguel Ruiz
- The Giving Tree, Shel Silverstein

REFERENCE MATERIALS

- Caregiver Adjustment Scale, Caregiver Stress Survey
- Emotional Regulation: Mind Over Mood Techniques
- Emotional Intelligence, Empathy, Resilience, Coping with Grief
- Sample Self- Care Plan
- Professional Mental Health and Caregiver Support Resources.

SAMPLE SELF CARE PLAN

1. Personal Support Team-speak to a friend each day
2. Professional Support Team-ask for help when needed
3. Time Management for Respite Each Day, Week, Month, Year
4. Set a Daily Intention
5. Go Outside Each Day, Need Sunshine
6. Identify caregiver trigger points, coping strategies
7. Track assumptive and hot thoughts: find alternative responses, practice, role play.
8. Acknowledge accomplishments
9. Develop Thresholds
10. Set Boundaries, say no
11. Declutter: let go of people, objects, commitments which do not enhance your well-being, but drain your energy.
12. Join caregiver support group

SESSION 5 | OCTOBER 2019

THE COST OF CAREGIVING

Minda Cutcher, MBA

TOOL KIT

This session provides an overview of the costs associated with caregiving. The session provides valuable resources and a sample cost of care. Caregivers will also learn about critical documents to locate and save.

1. **Take care of yourself and your personal finances**
2. **Plan for the worst, hope for the best**
3. **Research and collect Costs of care:**
4. **Create a Budget:**
5. **Explore opportunities to INCREASE income**
6. **REDUCE expenses**

RESOURCES

- Adult Protective Services
 - Santa Clara County: 408-975-4900
 - San Mateo County: 800-675-8437
- Local Police (Fraud Protection Unit)
- District Attorney's Office (Elder Abuse Unit)
 - Santa Clara County: (408) 792-2652
- Veteran's Enhanced Pension Benefits
 - <http://www.vba.va.gov>
- Western States Pension Assistance Project
 - 866-413-4911
- California Advocates for Nursing Home Reform
 - <http://www.canhr.org/>
- Assist Guide Information Services
 - <http://www.agis.com>
- Caring.com
 - 800-973-1540
 - <https://www.caring.com/>
- National Academy of Elder Law Attorneys
 - <http://www.naela.org/>
 - Aging Lifecare Association - <http://www.aginglifecare.org/>

SAMPLE COSTS OF CARE

Care Management

- \$90-\$275/hour

Adult Day Care

- \$70-\$150/day

Skilled Nursing Care

- \$200-\$800/day

24x7 In Home (non-medical) Care

- \$400+/day

Medical in Home Care

- \$25-\$45/hour

Health Insurance Premiums

- \$0-\$400+/mo

CRITICAL DOCUMENTS TO LOCATE AND SAVE

Financial

- Life Insurance Policies
- Location of/Keys to Safe Deposit Boxes
- Tax Returns
- Real Estate Transactions
- Bank and Investment Account Statements

Legal

- Trust
 - Will
 - DPOA, Health Care Directive
- Social Security Correspondence
- Military Service Discharge Papers
- Death Certificates
- Funeral Pre-Planning Information

Health

- Medicare Card
- Supplemental Insurance Card(s)
- Copies of LTC Insurance Policies
- Formulary

SESSION 6 | NOVEMBER 2019

HOW TO THRIVE AS YOU AGE: CAREGIVER HEALTH

Rita Ghatak, PhD, Ellen Brown, MD

TOOL KIT

This session offers an overview of tips to help caregivers thrive as they age, evidence-based health screening tools, avoidance of over screening, tips for physical and brain health. The session also provides important strategies for maintaining physical and health.

SECTION 1: SCREENING GUIDELINES

Source: US Preventive Services Task Force:

GENERAL SCREENING: Height, weight, BMI, blood pressure, personal history, social risk factors.

SENSORY SCREENING: Eye Exams: every 2-4 years (ages 40-54): every 1-3 years (ages 55-64).

Individual factors: History of diabetes, African Americans, have earlier incidence of glaucoma.

Hearing assessments if needed.

BREAST CANCER SCREENING: Women aged 40-49 years old: talk to your doctor. An individual decision based on risk factors.

Women aged 50-74 years old: biennial screening (every 2 years) with mammography.

Women 75 years and older: insufficient evidence to recommend routine screening.

CERVICAL CANCER SCREENING: Women aged 30-65: every 3 years with cervical cytology or every 5 years with hrHPV testing or combined.

Women older than 65: USPSTF recommends against screening, if have been adequately screened before and not high risk for cervical cancer.

COLORECTAL CANCER SCREENING: Not one recommended way, too few getting screened.

Ages 50-74: Annual stool-based tests (e.g. FIT) performed at home (no bowel prep necessary) OR direct visualization with a colonoscopy every 10 years.

Ages 75-86: Talk to your MD; an individual decision taking into account overall health and prior screening.

Ages 86 and older: NOT recommended.

DEPRESSION: Should be screened as it is too often missed. Screening tools are available. Therapies include medications, counseling, other.

PROSTATE CANCER SCREENING:

Talk to your doctor: An individual decision for PSA testing in men age 55-69. Depends on risk factors, consider benefits/harms from testing, values and preferences.

Men older than 70: Recommend against screening.

LUNG CANCER SCREENING: Adults age 55-80 with a 30-pack year smoking history who currently smoke or quit in the past 15 years: recommended annual screening with low dose CT scan.

Not recommended to screen for asymptomatic individuals with no history of smoking.

OSTEOPOROSIS SCREENING: Women age 65 and older: bone density testing recommended to prevent osteoporotic fractures.

Women younger than 65 at increased risk for osteoporotic fractures: bone density testing (Central DXA) recommended (measures bone density of hip and lumbar spine).

ASPIRIN USE TO PREVENT CARDIOVASCULAR DISEASE, COLORECTAL CANCER:

Adults 50-59, who have greater than 10% 10-year cardiovascular risk, are not at increased risk of bleeding, and have a life expectancy of greater than 10 years: recommended to take low dose aspirin (81mg), for primary prevention of cardiovascular disease and colorectal cancer, benefit is not seen until 10 years of use.

Adults ages 60-69, who have greater than a 10% 10-year cardiovascular risk, not at increased risk of bleeding, and a life expectancy of greater than 10 years: it is an individual decision.

Adults younger than 50: There is insufficient evidence to assess benefit and harms.

Adults older than 70: There is insufficient evidence to assess benefit and harms.

The tools to assess cardiovascular risk include age, ethnicity, sex, blood pressure, smoking history, lipid levels, and history of diabetes and whether or not on treatment for diabetes.

STATINS FOR PRIMARY PREVENTION OF CARDIOVASCULAR DISEASE:

Adults ages 40-75 with no history of cardiovascular disease and one or more cardiovascular risk factors (high lipids, hypertension, smoking or diabetes), and a calculated 10-year cardiovascular event risk of 10% or greater: recommend low to moderate dose statin.

Adults older than 75, if no history of myocardial infarction or stroke, recommend no statin use.

TOBACCO AND ALCOHOL USE. Ask and screen. Refer to counseling if inappropriate ETOH use.

ABNORMAL GLUCOSE SCREENING:

Adults aged 40-70 (overweight or obese) and no symptoms of diabetes: screen for abnormal glucose levels as part of the cardiovascular risk assessment. If there is a family history of diabetes, history of gestational diabetes, or of a certain ethnicity that has a higher risk of diabetes, may screen earlier.

Offer or refer patients with abnormal glucose values to behavioral counseling, with recommendations for a healthy diet and increased physical activity.

SCREENING FOR ABDOMINAL AORTIC ANEURYSM

Men ages 65-75, who have ever smoked: recommended one-time screening with an ultrasound.

Men ages 65-75 who have never smoked: discuss with your doctor, net benefit is small.

NOT recommended in women.

SECTION 2

HEALTHY BRAIN:

WARNING SIGNS OF COGNITIVE CONCERN

- Challenges in planning or solving problems
- Memory loss that disrupts daily life
- Difficulty completing familiar tasks at home, work
- Confusion with time, place
- Trouble understanding visual images and spatial relationships
- New problems with words in speaking or writing
- Misplacing things and losing the ability to retrace steps

- Decreased or poor judgement
- Withdrawal from work and/or social activities
- Changes in mood and/or personality

LANDMARK STUDY:

Prevention of Cognitive Decline in Healthy Older Adults. A large population-based study in Finland looked at effect of a multi-domain intervention on cognitive performance and 5 different domains. Below are lifestyle changes the research suggests may assist your brain to age optimally. <https://www.beingpatient.com/finger-study/>

Findings:

- Significant intervention effects were found on overall cognition, including executive functioning and processing speed.
- Beneficial effects were found on BMI, dietary habits, and physical activity.
- No noted significant effects on memory, although post-hoc analyses showed an effect on more complex memory tasks.
- Very few side-effects were reported.

MANAGE VASCULAR DISEASE:

Vascular disease is any abnormal condition of the blood vessels (arteries and veins). High blood pressure is a risk factor.

PHYSICAL ACTIVITY (PA): Why it Matters to the Brain

Findings:

- PA is the most effective preventive strategy in preventing & reducing disability & preserving independence.
- Increase in size of hippocampus by 2%, post 1-year exercise intervention.
- Sarcopenia is the decline of skeletal muscle tissue with age. The beneficial impact of resistance or endurance training on muscle mass and function suggest that the response to exercise is good.
- During exercise: 82% added at least one new social contact, and 60% cultivated multiple new relationships.

The goal is: Get at least 150 mins of exercise each week.

BOTTOM LINE: Physical Activity is the best thing you can do to keep your brain healthy.

DIET: The Mediterranean-DASH Intervention for Neurodegenerative Delay (MIND) diet

Findings: DASH stands for 'Dietary Approaches to Stop Hypertension'.

- MIND Diet offers significant protection against Alzheimer's Disease (AD). Lowered AD risk: with MIND diet - 53%.
- With moderate compliance: MIND diet shows lowered AD risk - 35%
- Those with rigorous adherence to the MIND diet were about 35% less likely to perform poorly on tests of brain function.

BOTTOM LINE: Modifying your diet can help to reduce AD risk.

SLEEP: A Vital Component of Brain Health: Healthy Sleep Behaviors

- Avoid long naps, stick to a schedule.
- Spend time in the sunlight, get moving.

- Restrict what you eat and drink.
- Banish electronics, try a warm bath.
- Wear warm socks.
- No difficult discussions before bed.

BOTTOM LINE: Aging doesn't mean you can't get a full night of quality sleep.

SOCIALIZING: Why Other People Matter So Much

Social Connectedness is the measure of the meaningful, close and constructive relationships with others.

Findings:

- An active & socially engaged lifestyle is related to improved cognitive function aging.
- More social support showed better general cognitive abilities.
- Less social support had slower processing speed.
- Higher social engagement associated with larger total brain and grey matter volumes.

BOTTOM LINE: It is important to stay socially connected as we age!

SECTION 3: STRATEGIES

1. RESILIENCE

The World Health Organization has made resilience a priority in its Health 2020 campaign. Resilience is the ability to withstand, recover, and sometimes grow when faced with adversity; an active process of enduring and successfully coping. Resilience is bouncing back after a crisis, adjusting to a “new normal.” Growing research shows higher levels of resilience are directly related to better outcomes of managing chronic disease and chronic pain; improved emotional and physical health; better relationships; and a better ability to handle the myriad challenges, big and small, that life brings our way.

<https://www.resilientoption.com/>

2. CUSTOMIZED AND DETAILED CARE PLANNING

Caring for yourself (or others) needs planning. No matter the chronic condition or disease you are managing, creating a care plan is important. Here is an example of tips when you are first faced with any chronic condition.

- Get a medical assessment, diagnosis, educate yourself and family.
- Determine the multifactorial health needs.
- Make current and future care decisions.
- Consult professionals for integrated care, safety, living.
- Build a home caregiving plan
- Look at finances, review legal documents, safety-proof home
- Connect with others, take care of yourself, stress management, spirituality

3. BUILDING SMART GOALS

Designed as a tool to assist individuals improve the chances of success in achieving a goal.

S- Specific, M- Measurable, A-Achievable, R-Realistic, T-Timely

Example:

- **Specific:** I want to add physical activity to my life to improve my health. Last time I was at the doctors she noted that my blood pressure was borderline. I can add physical activity by joining a Golden Zumba class at the YMCA.
- **Measurable:** By my next physical in six months, I will have a lower blood pressure, be able to bend down and pick something up off the floor and be able to walk up a flight of stairs without shortness of breath.
- **Achievable:** I can do this by attending a class twice a week for the next 6 months. I will ask my friend Suzy to go with me so we can encourage each other and hold each other accountable.
- **Realistic:** Since I am a member of the Y, I know who to talk to, and I have taken other classes with the instructor. I am cleared by my doctor to exercise.
- **Timely:** I will start with 2 classes a week for the 1st month and move to 3 classes a week by the 3rd thru 6th month.

SESSION 6 | DECEMBER 2019

CAREGIVER ADVOCACY AND EMPOWERMENT: YOUR VOICE! YOUR VISION!

Paula Wolfson, LCSW

TOOL KIT

This session will provide strategies, resources and guidelines to help family caregivers (CG) navigate complex health, legal, financial systems and mediate communications challenges with care recipient (CR) health providers, legal and financial advisors, care facility staff and others. The goal is to help caregivers clarify their vision of one's role, voice concerns in a productive manner and overall strengthen one's advocacy skills.

Outline

- 1) Creating your "Caregiver Bill of Rights" to acknowledge one's rights for respect, respite and self-care.
- 2) Navigating difficult conversations during early phase of a disease with care recipient and family to proactively plan and complete legal documents so that designated decision makers can act when necessary, and everyone is clear on the care recipient's end of life treatment options and goals.
- 3) Petitioning courts for guardianship and conservator, if CR is deemed lacking capacity and has not previously designated legal decision-makers.
- 4) Navigating Medicare protocols to appeal physicians' order to stop treatment or discharge a patient from a service, file a grievance concerning quality of care, conditions of facilities, mediate issues related to patient's rights, informed consent, privacy and unprofessional staff behavior.
- 5) Navigating issues related to delivery of private pay non-skilled services from custodial care providers (staff in home care agency, board and care, assisted living, memory care facilities): these are regulated by state license boards, county business affairs offices, long term care ombudsman office (staffed by volunteers.)
- 6) Access county social services to help qualified care recipient' obtain Medical, case-management, transportation, food stamps, other benefits.
- 7) Review article on Caregiver Advocacy to change elder care policies; article contains templates for letters to express concerns to political representatives.

Caregiver Bill of Rights (CBR):

Respect, Respite, Knowledge, Support

See Hand-Out

General Tips for Caregiver Advocacy Work

Order a Caregiver ID tag from Med Alert.

If you are found down, this alert will inform paramedics you have a frail loved one at home in need of care.

- Be able to articulate your loved ones' values, wishes and preferences for treatment options. Stay informed. Become a literate consumer of health, legal and financial services and products.

- Take notes during all appointments, keep a record of professional contacts.
- Review complicated contracts, care facility admissions agreements with your attorney.
- Prevent and minimize health care crisis by following up on appointments, maintain medication compliance, health care screenings, seeking help in a timely manner.
- Express gratitude for the good will and work of others, say thank-you to CR, family and friends for their cooperation and support, send letters of appreciation to service providers.

Informed Consent:

Access to medical information is critical for caregivers.

Most hospitals, clinics, health care providers, such as Kaiser and the Palo Alto Medical Foundation, have protocols and procedures for care recipients to assign informed consent to their caregivers and trusted loved ones. Care recipient must sign form in person at the medical records office to designate informed consent status to caregivers and families.

Care recipient's or their caregivers should submit to health provider's medical secretary (or records office,) copies CR's Advanced Directives and Durable Powers of Attorney forms.

- Once you have informed consent you have access to medical information including: 1) care recipients medical history and exam or test results, 2) diagnosis and prognosis, 2) nature and purpose of intervention or treatment, including surgeries, medications, referrals to other health services, 3) burdens, risks, expected benefits, including forgoing treatment.
- Emergency Medical Interventions and Decision-Making Protocols: When a decision must be made urgently, and the patient or the legal decision-maker is not able to participate, and the patient's wishes are not known, physicians initiate treatment in such situations keep the patient or the legal decision-making informed as soon as possible for on-going consents. Most hospitals have available to patients and their loved ones the option to call for an emergency meeting of the Hospital Ethics Committee to assist medical staff, patients and families resolve complicated treatment decisions.

Medicare Policies and Patient Rights

- www.medicare.gov/claims-and-appeals,
- www.medicare.gov/coverage/skilled-nursing-facility-care.html

Medicare Criteria and Mandates

Skilled care providers have mandated Medicare policies and protocols which direct the provision and physician's orders for designating a skilled care diagnosis, treatment options, duration of treatment and costs of health care services.

Calling 911 and navigating medical crisis, emergency room protocols.

When calling 911 try to stay calm, know your exact location and number you are calling from, let the dispatch operator ask their questions, answer clearly, let them guide the conversation, follow their directions, depending upon the type of emergency they may dispatch you to a different call center. If there is time be prepared to provide ambulance or paramedic transport team with emergency contact information, patient's relevant health history, medication list, insurance coverage. Once at the ER, introduce self to intake clerk, follow instructions and if needed, speak with the ER social worker. They support family caregivers and help advocate for the patient.

Emergency Room Observation Stay Status.

Not every patient is admitted to the hospital from the emergency room: some patients are placed on an Observation Stay. This means that the patient's initial condition does not yet meet with criteria for a hospital admission. Patients on Observation Stay are generally charged the Medicare Part B co-pay rates for services. And discharged home with medications, follow up regimen and directives from physician.

Medicare Appeals:

Patient or legal decision maker initiates this process to have Medicare audit a health providers decision to stop a treatment, drug coverage or discharge a patient from skilled care. This triggers an audit of the patient's medical records usually within 72 hours. And may result either in continued care or... not and thus patient might be billed for directly for the care if it is determined unnecessary.

Medicare Payment and Claims:

Providers file reimbursement claims to Medicare for services delivered. If you receive a payment due notice but assumed it was paid by Medicare contact the provider and ask if their billing office submitted the claim in a timely manner. May take phone work, persistence to resolve these matters. Often, the problem is due to work delays.

Medicare Grievance or Complaint:

- α. Patient or caregiver files a grievance about the quality of care under a Medicare provider, poor performance outcomes, delay in treatment, injury to patient, condition of facility, and unprofessional staff behaviors.

Navigating Non-Skilled Care Providers

- Home Care Agencies
- Board and Care Homes
- Assisted and Memory Care Units
- Certified Care Managers

Best practices for the primary family caregiver: Keep a Record on Service Provisions

- Keep a daily record of dates of services, track communications, incidents. Note patterns, bad players. Know the location, address of the agency or provider, names of staff and their responsibilities.
- First, discuss concerns with unit managers, agency owners or director.
- Describe incident, consequences. Note bad players, poor compliance. Share positive feed-back as well to cultivate productive discussions.
- List strategies for enhancing services, be clear about your goals, boundaries and limitations. Assess the staff member's abilities to understand your concerns and if needed, go up the chain of command.

Submitting A Grievance Letter

- Address letter to provider, supervisor or director and CC to relevant parties, such as care recipient's physician, attorney, and key players in the situation.
- Document in the body of the letter who you are, your goal in writing the letter, note date and time of incidents, involved staff, and state the facts of the situation as it unfolded.
- Do not make assumptions or negative statements about the involved parties.
- State your concerns, what was observed, impact, consequences and request to discuss matters in person.
- If needed contact the county agencies listed below for assistance or seek legal advice.
- Contact for help the Long-Term Care Ombudsman Office listed by County.
- Consumer Protection Unit Santa Clara County District Attorney's Office - 408 792 2880 (locate by county)

Navigating County Social Services

The mission of county social services agency is to help low-income qualifying elders receive these services: MediCal coverage for health care, including medical, mental and dental health care, case management, In-Home Support care, housing and transportation assistance, food stamps, access to senior nutrition sites and recreational activities at senior centers.

To obtain resources and guidance, family caregivers and care recipient may contact Santa Clara County Elder Assistance programs by calling 877 962 3633.

Main office located at 1867 Senter Road, San Jose, CA 95112.

For assistance in North Santa Clara County, contact Avenidas Care Partners

Case Manager, Information and Assistance call 650 289 54338

Elder Care Consult, Caregiver Group Support call 650 289 543

Review Articles and Hand-Outs

- Hospital Discharge Protocols
- Psychiatric Treatment and Involuntary Holds-Patient Rights
- Kaiser, PAMF directives for filing grievances
- Caregiver Advocacy article and templates for writing letters to political representatives
- Review Alzheimer's Association Advocacy efforts on behalf of family caregivers and care recipients.
- Review Dr. Ayati's testimony on "The Challenges of Aging in America" presented 2018 to the Senate Select Committee on Aging, Washing D.C Adult Protective Services-See Hand Out

Resources

Santa Clara County Adult Protective Services - 1 800 414 2002

San Mateo County Adult Protective Services - 1 800 675 8437

County Agencies

- SALA- Senior Adults Legal Assistance-408 295 5991
- Bay Area Legal Aid-408 850 7066 SALA
- Project Sentinel Mediation Services - 408 720 9888-Mediate Housing Issues

Social Security

- Social Security www.socialsecurity.gov :comprehensive information provided about SS and Disability benefits, application process, Medicare, nursing home ratings surveys located by zip codes.
Call 188 722 1213 to speak with representatives.
- Second Opinion Geriatric Clinic
Dr. Mehrdad Ayati, Geriatric Center, 851 Fremont Ave, Suite 103, Los Altos, CA 94024
O: 650-808-0180 - FAX: 650-666-8215

CARE FORUM FACULTY

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www.ellenbrownmd.com

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