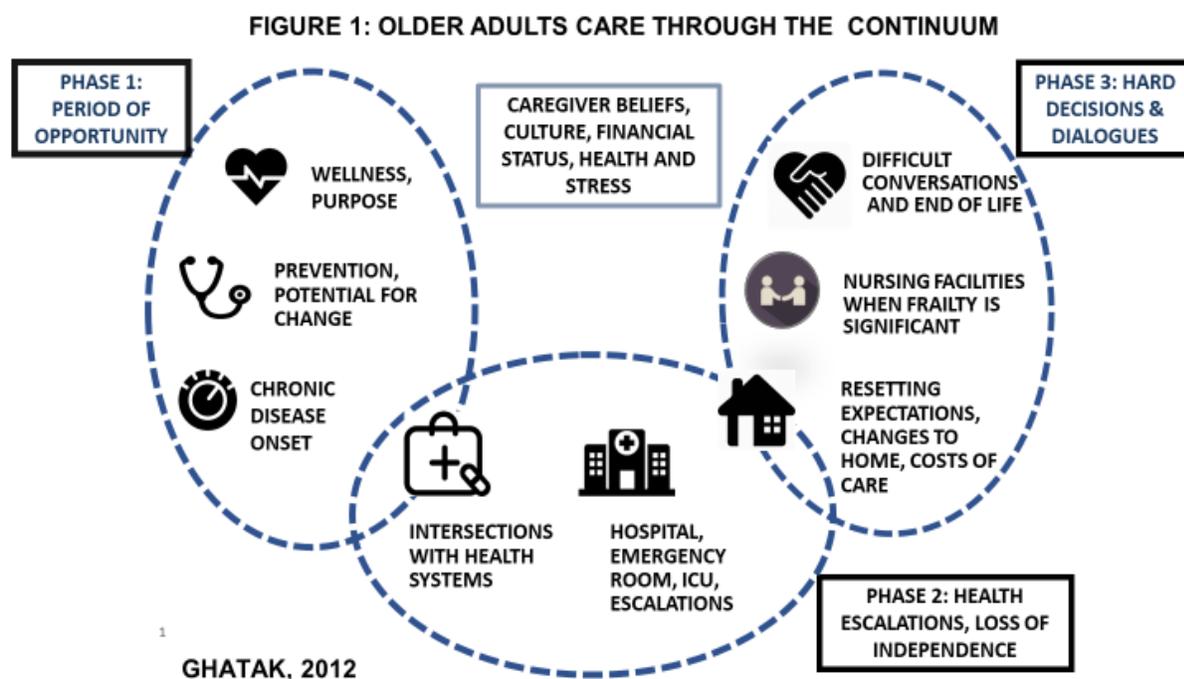


AVENIDAS CARE FORUM CAREGIVER TOOL KIT
SESSION 2 - FROM CHAOS TO CONFIDENCE: NAVIGATING HOME, ER, HOSPITAL, REHAB
MAY 4, 2019
www.avenidas.org

WELCOME CAREGIVERS!

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 to help family caregivers navigate complex levels of care transitions, minimize stress, cultivate resilience, and thrive!

Figure 1: showing 'The Continuum of Care' for older adults. Older adults with chronic illness and their caregivers can move through Phases 1, 2, and 3.



PHASE 1

PHASE 2

PHASE 3

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.

SOME 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, infections, surgery, medications or 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: 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

CARE FORUM FACULTY

ELLEN BROWN, MD
Palliative Care Consultant
Former Medical Director - Pathways Hospice
ellen@ellenbrownmd.com – www.ellenbrownmd.com

RITA GHATAK, PHD
Founder - Aging 101
Founder and Former Director - Aging Adult Services at Stanford
Associate Director – Optimal Aging Center
rghatak@aging101.org – www.aging101.org

PAULA WOLFSON, LCSW
Manager - Avenidas Care Partners
pwolfson@avenidas.org – www.avenidas.org

CARE FORUM FACILITATORS

KRISTINA LUGO, LCSW
Director, Social Service, Rose Kleiner Center

SUSAN LAM, RN
Outreach, Rose Kleiner Center

SUE ALVEY, MA, COUNSELING
Director Social Services, Rosener House

THOMAS KINGERY, BSW
Case Manager, Avenidas Care Partners

LINDA NASTARI, LCSW
Private Practice Therapist

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.