

**2019 AVENIDAS CARE FORUM
CAREGIVER TOOL KIT
SESSION 7 - CAREGIVER ADVOCACY AND EMPOWERMENT: YOUR VOICE! YOUR VISION!
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WELCOME CAREGIVERS!

This Avenidas Care Forum, the final lecture of our series, 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 of today's forum is to help caregivers clarify their vision of one's role, voice concerns in a productive manner and overall strengthen one's advocacy skills.

Discussion 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 pro-actively 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 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

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