THE FAMILY MEETING
July 2020

When a family member begins to decline, it may be a good idea to consider a family meeting. Siblings and any other family members who may be involved in the care or decision-making should participate.

Technology has enabled us to get together for meetings through Zoom, GotoMeeting, Skype, Facetime, and other applications. Many are free or low cost. In-person meetings can be held for those who are able to attend but those who can't be there in person can participate virtually. Becoming informed about care options, planning and early involvement can prove positive and meaningful.

Families need to respect the care receiver and their autonomy as they go through the care planning process, and involve them as much as possible. Their participation can help a family plan succeed or doom it to anxiety and difficulty.

You need to remember that this is not necessarily a "one and done" process. There will be health and life changes for care receivers and caregivers that will need to be addressed.

WHY HAVE A FAMILY MEETING?

- Concern about the care receiver's current physical and/or mental status
    - Decline in health
    - New diagnosis
    - Decline in cognitive function
    - Care receiver is exhibiting difficult behaviors
- Concern about the care receiver's current living arrangements
    - Steps in home, home not aging friendly
    - Bathroom on 2nd floor, laundry in basement
    - Home in need of repairs
    - Seasonal needs: lawn care, snow removal
    - Chores need done
    - Too much home
    - Housekeeping is too difficult
    - Cooking is challenging (operating appliances, forgets how to cook, turns on burners/stove and leaves
    - Affordability: utilities, taxes, upkeep, mortgage
    - Accessibility: hard to get to, service providers don't serve the area/have insufficient staff to serve the area, little or no transportation
- Concern about the care receiver's ability to do self-care
    - Clothes dirty
    - Body odor
    - Finger and toe nails need attention
    - Glasses need repair
    - Lost dentures, glasses, hearing aid repeatedly
- Changes in financial management abilities
    - Shut off notices in the mail
    - Overdrawn accounts
    - Strange withdrawals
    - Lots of purchases from QVC, Home Shopping, Amazon, etc
    - Inability to handle accounts (failure to respond to notices, changes in policies or financial institution regulations)
- Changes in caregiver status
    - Health change of caregiver / caregiver's partner / caregiver's children
    - Financial or employment change of caregiver or caregiver's partner

- Health care provider indicates that the care receiver needs a change in living arrangement
    - Functional decline indicates that care receiver needs supervision
    - Worsening health impacts long range prognosis/needs
    - New diagnosis impacts long range prognosis/needs
    - Recommended treatments will impact care receiver's ability to live alone
- Hospitalization admission / discharge requires change in care needs
    - Discharge recommendation is for more care (care receiver unable to do self-care at the time of discharge or long term)
    - Discharge recommendation is for new care (injections, eye drops, catheterization)
- Family discord about care receiver's status
    - Caregivers may think the care receiver is fine, manipulative, or possibly faking (especially with dementia)
    - Caregivers may think the care receiver needs more care or need relocated to a care facility
    - Caregivers may question the health care professionals' opinions
- Family discord
    - Sibling rivalry
    - Sibling jealousies
    - Those who hold on to grudges or hurts from childhood / adolescence
    - Some families just don't like each other
    - Blended families
    - "Seagull caregivers" – those who swoop in, make a mess, then swoop out leaving the mess behind.
    - History of abuse (physical, emotional, sexual)

PLANNING AND PREPARATION FOR A FAMILY MEETING

- Agree on who will facilitate / lead the meeting and consider an objective third party facilitate the meeting
- Assess and determine if the care receiver will participate in this meeting. Remember that unless the care receiver is unable to make his / her own decisions or has been adjudicated incompetent, the care receiver is the final decision-maker.
- Agree to logistics: time, place for those who can attend in-person or Skype, Zoom, etc for those who need to join remotely, length of meeting.
    - It is helpful to set a time limit. Too much information can be mind-numbing, and can create negative energy. (Think of some of those work meetings.)
- Acquire current financial (stocks, bonds, savings, checking, trusts, annuities, pension, alimony), insurance (medical, long term care, life) and legal information.
    - Where are accounts and how much is involved
        - Most services have a fee. Knowing available resources helps with planning
        - If nursing home care is being considered, assets will impact Medicaid availability
        - Do you need an estate planner and elderlaw attorney to help? There are specific regulations for Medicaid, and elderlaw attorneys are aware of laws governing expenditures and use of assets.
        - Is there gas and oil money? Leases? Royalties?
        - What about pension plans? What are the benefits?
    - Does the care receiver have a Medicare supplement or a Medicare Advantage Plan? What is the company? Is there a Part D plan? What is the company? Is there a long term care insurance policy? (That may help with in home care, assisted living, and/or nursing home care.) Is there a life insurance policy? What are the monthly costs of the insurances?
    - Does the care receiver have an attorney?
    - Does the care receiver have a Durable Power of Attorney? Medical Power of Attorney? Living Will? Will?
- Obtain current medical and/or psychiatric diagnoses, treatment plans, prognosis information from health care team.
- List primary care physician, specialists, therapists, and other health team members and contact information.
- Share current factual information and resources with participants before the meeting.

- Request that participants prepare a list of concerns and suggestions on what might help.
- Ask participants to identify three values that they believe are most important to the care receiver.

GUIDELINES

- Make sure the care receiver is involved in the process and feels a sense of control over his/her destiny. (As they are able)
    - Give the care receiver the opportunity to express their wishes verbally or in writing.
- The focus is on the care receiver and the care receiver's health, safety, and well-being.
- Consideration needs to be given to caregivers' personal situations: health, family, finances, employment.
    - Work around limitations. What are alternatives?
- Be non-judgmental. Express and accept opinions freely.
- Be civil. No name-calling. No festering, personal old wounds.

PROCESS

- Share the lists of concerns, suggestions, and values prepared by participants.
- Help can be provided in several ways: physical, financial, emotional and social. Perhaps personal care isn't something that one family member can do but they are able and willing to grocery shop.
- Assess supports – informal and formal
    - Partner
    - Children
    - Friends
    - Church
    - Current services
- Discuss available resources with participants. Who offers in home care (non-medical)? Transportation?
    - Groceries and prescriptions can be delivered in most areas, or can be ordered on-line.
    - Home delivered meals through community meal programs, restaurant delivery through UberEats, Door Dash or restaurant delivery, or mail-order meal kits are options for food.
- Keep in mind:
    - Availability of services
    - accessibility to services
    - appropriateness of services
    - affordability of services
    - The service may be available but can the care receiver get to the service / can the service get to the care receiver? Is the service appropriate or does the care receiver need a little more or a little less? There may be services that are free or offered on a sliding scale but most have a fee. Is the cost affordable?
- Discuss the options based on actual need, feasibility of implementation, compatibility of values, and the level of acceptability to your care receiver.
    - Your care receiver may want a NURSE to bathe her but does she need someone with those qualifications? Nurses are much more expensive and unless there are extenuating health issues, that level of qualification is not needed.
    - Is the option workable? Affordable?
    - Look at your lists of core values. How do options align with those values?
    - The options may look good to the family team but the care receiver adamantly refuses to consider them.
- Don't make promises you can't keep!
    - Many caregivers make a promise such as "I'll never put you in a nursing home" only to discover that the care becomes too intense, life circumstances change, caregiver's health changes, or any number of things occur that make that promise unfeasible. Don't make the promise in the first place!
- Focus on the actions that best serve your care receiver's needs, safety, well-being, and values.
- Brain-storm! Write down additional ideas as the group suggests.
- Agree to specific actions. Record what individuals have agreed to do and give everyone a copy of the information.

- Set a date for the next meeting to evaluate the plan. Depending on the complexity of the situation, you may need to have an additional meeting.
    - In this case, the first meeting could focus on identifying the needs and desires of the care receiver, and exploring options for assistance.
    - The second meeting could finalize plans and implement the plans.
- Recognize that the situation will certainly change over time and plans will need to be modified.

Acronym to guide caregivers: A – P – I - E

Assess – Look at the whole situations. Finances, home safety, neighborhood, health – physical and mental, strengths and weaknesses of the care receiver, and pros and cons of the situation. Identify the problems or concerns.

Plan – What services or assistance can be provided to address the identified problems or concerns. Frequency of assistance?

Intervene – Implement the plan. Arrange for services and/or get family assistance lined up.

Evaluate – You may want to give this a little time to see how it is going. What worked? What didn't? Do you need to increase or decrease service?

Care planning for the care receiver
Following these guides may help the family develop a plan:

Identify the problem(s) or concern(s)

Establish a goal – what do you hope to accomplish?

What service / intervention will help you accomplish that goal?

Who will be the service provider(s)? (Agency or family member)

Frequency? Length of service?

Sources: American Society on Aging, "A Survival Guide for Caregiving", Jo Horne, 1998; Ann Koegler, MA, LSW, Altenheim Resource Services, Wheeling WV.