

Prepare to Care

Caregiving Communication: It is Never too Soon to have a Conversation about Caregiving

Introduction/Background

Prepare to Care: A Resource Guide for Families, is a workbook published by AARP that provides families with the necessary tools to think about and start conversations about caregiving for



older family members. The workbook highlights five simple steps and provides checklists and resources to help families take better care of loved ones. Because the majority of people fall into a caregiving role due to crisis, faculty in The University of Kentucky Family Consumer Sciences Cooperative Extension Service and College of Social Work partnered with Kentucky AARP to further translate and disseminate AARP's caregiver preparation program to help Kentuckians prepare for caregiving before a crisis. As a result of this partnership, an FCS facilitator guide and evaluation for the existing *AARP Prepare to Care* program was developed so that FCS agents throughout Kentucky could more easily teach and evaluate this program in their communities. In addition, four Extension publications were created for participants to further highlight the importance of planning for caregiving, making sense of legal and financial issues and self-care. This general publication briefly summarizes the AARP program, *Prepare to Care*, and highlights the five steps AARP recommends families to take.

Prepare to Care

Despite the joys that can be associated with caregiving it is also very real that caregivers experience strain and burden. When families plan ahead for later life care needs, less stress will likely be experienced because individuals have time to prepare for the caregiving role and are relieved from the burden of being the sole decision maker as a result. While discussing the future needs of aging family members may not completely shield families from negative outcomes, AARP advocates for families to discuss caregiving prior to illness and dependency. Having such conversations may improve difficulties often faced by both caregivers and care recipients. Families who do not plan ahead are at greater risk for making caregiving decisions during a crisis when stress and pressure is usually high.

According to AARP, to help prepare for caregiving, families must:

- Start the Conversation
- Form a Team
- Assess Needs
- Make a Plan
- Take Action

This publication, based on information from the AARP's "Prepare to Care" resource guide, highlights the importance of and steps for starting a conversation about caregiving.

Do Not Wait for a Crisis—Start the Conversation

Rather than wait for a crisis—a fall, an illness, disability or serious diagnosis, the AARP recommends that families have conversations with each other about care and financial preferences, values and wishes. Such communication is important because it alleviates assumptions and may lessen caregiver stress and burden. When family members know what their loved one wants in regard to caregiving and end-of-life care decisions, they are not left wondering or arguing about what is in their loved one's best interest. For the person who will be receiving the care, the planning provides peace of mind that they will be taken care of, their wishes will be respected and the family caregivers will be less stressed and burdened because they are not left guessing, assuming or wondering what their loved one would want.

How to Bring Up Caregiving

It may never seem like a good time to bring up a conversation about caregiving/end-of-life. Family members may feel uncomfortable because it is a sensitive topic that many people choose to avoid or they may fear that a loved one might not trust their intention. AARP has found that more times than not, the initiation of a caregiving

conversation provides a sense of relief for both caregivers and loved ones. Furthermore, it has been found that loved ones often “keep meaning” to bring it up as well. If feeling leery, AARP suggests using stories seen on the news or social media as an ice breaker. They also suggest the following subtle ways to start the conversation:

- “I’m starting to think about estate planning, do you have any advice?”
- “I just read an article on gathering all your important papers. Sometime can you show me where yours are and what you’d like, just in case?”
- “As time goes on, do you think you want to stay in this house? It may be difficult with all of these stairs.”

The conversation will likely not happen overnight, but once that door has been opened, it can get easier to re-visit the conversation and even include additional family members. AARP suggests that each family should ideally have a spokesperson who helps to keep the conversation moving and ensures that everyone is on the same page and understands decisions. Some loved ones will resist. They might be too private or have a difficult time admitting that they need help. If conversations do not go well at first, do not give up. Keep trying. Starting the conversation small—with even just a minor detail of a caregiving concern, can help get the foot in the door to start the conversation. If a loved one continues to resist, it might be appropriate to call a trusted health care provider or significant member in the community, such as church leader, to help bring up future care needs.

Include Your Loved One

Every conversation and plan should not only include your loved one, but it should revolve around your loved one’s preferences, wishes and values. Even loved ones living with cognitive decline or impairment should be included as much as possible. As a family member, these wishes may differ from your wishes or even beliefs. AARP suggests that prior to the initial conversation, family members should analyze their own feelings about having the conversation and the expected and/or anticipated outcome of the conversation. Family members should also discuss among themselves who they think is the best person to lead the conversation. This spokesperson or “point” person is often a family member who lives close by, has a close relationship with their loved one or may just have a more commanding personality.

Next Steps

In addition to knowing a loved one's preferences, wishes and values, it is also important to gather necessary information, such as the details of their finances and health. This information can help you plan as much as possible ahead of time. To obtain this information, it is important to be respectful and make your intentions known. To help with this part of the conversation, has created a "Goals and Needs Checklist" to help families sort out home, health, financial and legal needs. The Goals and Needs Checklist is attached to this publication.

Identifying goals and needs can also help families form the caregiving team. This team may include other family members or it may even include friends, colleagues or people from the neighborhood or church. Some families may even pay for additional services to be a part of the team. The important key to a caregiving team is remembering that each person is a participating member based on their strengths or the specific role that they can play. For example, a brother who lives 3 hours away may be a team member because he best understands financial management and long term care insurance and he can help with that. Meanwhile another sibling is good at running errands or repairing things at the house, while a sister who lives down the street from the aging parent serves as the primary caregiver because she is most available and able to provide daily physical and emotional care. A supportive team will deepen and strengthen the caregiving process and help families better deal with issues as they develop.

For more information on caregiving preparation, contact your local Extension Agent or AARP (888) OUR-AARP chapter.

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The AARP Goals & Needs Checklist is being used with permission from the KY AARP

GOALS & NEEDS CHECKLIST

Use this list to start the conversation about what is most important to your loved ones and what strengths they bring to bear.

Goals

- _____ To remain healthy and active
- _____ To stay/move near family
- _____ To remain in my own home for as long as possible
- _____ To stay active with religious or community groups
- _____ To maintain hobbies
- _____ To be around people
- _____ To move to a residence with support services
- _____ Other

Strengths

- _____ Great negotiator
- _____ Adequate savings
- _____ Low-maintenance single story home
- _____ Large network of friends
- _____ Close relations with family
- _____ Other

Needs

First determine if there is an immediate need under each area. If there is not a pressing issue, prioritize the tasks to be addressed and develop a timeline.

GENERAL NEEDS ASSESSMENT

(One for each individual who will need care)

Area of Need	Types of Possible Tasks	Point Person
Home Maintenance and Living Situation	<ul style="list-style-type: none"> _____ Pay rent/mortgage _____ Home repairs _____ Ongoing maintenance _____ Safety concerns _____ Grocery shopping & meal preparation _____ Lawn care _____ Pet care _____ Housekeeping _____ Research alternative living arrangements _____ Other: _____ 	<hr/> <hr/> <hr/> <hr/> <hr/> <hr/> <hr/> <hr/> <hr/> <hr/> <hr/>
Financial Affairs	<ul style="list-style-type: none"> _____ Paying bills _____ Keeping track of financial records _____ Managing assets _____ Applying and supervising public benefits programs 	<hr/> <hr/> <hr/> <hr/>
Transportation Needs	<ul style="list-style-type: none"> _____ Driving decisions _____ Coordinating rides _____ Locating transportation services 	<hr/> <hr/> <hr/> <hr/>
Personal Care	<ul style="list-style-type: none"> _____ Organization of family and professional care providers _____ Help with daily grooming and dressing _____ Rides to hair stylist _____ Clothes shopping 	<hr/> <hr/> <hr/> <hr/>

GENERAL NEEDS ASSESSMENT (One for each individual who will need care)

Area of Need	Types of Possible Tasks	Point Person
Health Care	<ul style="list-style-type: none"> ----- Determine medical or emotional problems ----- Make, accompany, drive or make alternate logistic arrangements for doctor's appointments ----- Submit medical insurance and bills ----- Explain medical decisions ----- Medication management (fill prescriptions, fill pill boxes, give reminders, and dispense medications) ----- Perform medical tasks (wound care, injections, and catheter) 	<hr/> <hr/> <hr/> <hr/> <hr/> <hr/> <hr/> <hr/>
Communications	<ul style="list-style-type: none"> ----- Keeping family caregiving team informed ----- Coordinating team visits ----- Daily check in 	<hr/> <hr/> <hr/> <hr/>
Socialization	<ul style="list-style-type: none"> ----- Sending greeting and thank you notes ----- Arranging for visitors ----- Arranging outings 	<hr/> <hr/> <hr/> <hr/>
Adaptive Devices	<ul style="list-style-type: none"> ----- Ordering, maintaining, and paying for adaptive devices (e.g., wheelchair, walker, etc.) ----- Training on how to use devices ----- Other: <ul style="list-style-type: none"> ----- 	<hr/> <hr/> <hr/> <hr/>

PERSONAL INFORMATION CHECKLIST
 (One for each individual who will need care)

NAME

X	Personal Information	Where is it kept? Contact Name <small>(attach copy of documents)</small>
	Social Security Card	
	Birth Certificate	
	Marriage Certificate	
	Death Certificate (for Deceased Spouse)	
	Divorce Papers	
	Military Records Branch of Service VA ID#: Discharge Papers:	
	Driver's License/Organ Donor Card	
	Passport/Citizenship Papers	
	Address Books (names and addresses of friends and colleagues)	
	Lists of church & community memberships and contact information	
	Information on waiting lists or contracts with retirement communities or nursing homes	
	Information on funeral arrangements	
	Pet Care: Vet, Sitter, Walker	
	Beautician/Barber	
	Lawyer	
	Other	
	Passwords	

HOME MAINTENANCE CHECKLIST

X Home Item

Where is it kept? Contact Name
(attach copy of documents)

Mortgage Company Name:

Amount due:

Rental Management Company:

Amount due:

Rental/Real Estate Agent:

Gas/Electric/Water Company:

Cable/Internet/Telephone:

Homeowners Insurance Agent:

Insurance Policy #:

Homeowners Premium:

Garbage Service Garbage Pickup Day is:

M T W Th F (circle)

Home Services:

- Handy person
- Lawncare
- Appliances

Passwords

Computer(s) password clue(s)

Phone messages password clue

HEALTH CHECKLIST

PHARMACY Name

PHONE #

LOCATION

PHARMACY Name

PHONE #

LOCATION

DOCTOR Name

PHONE #

ADDRESS

DOCTOR Name

PHONE #

ADDRESS

DOCTOR Name

PHONE #

ADDRESS

DOCTOR Name

PHONE #

ADDRESS

DENTIST Name

PHONE #

ADDRESS

HOME CARE AGENCY

PHONE #

ADDRESS

HEALTH CHECKLIST (continued)

X	Item	Where is it kept? Contact Name
	Medicare Original or Medicare Advantage (company name): ID Number:	
	Medicare Prescription Drug Coverage (company name): ID Number: <i>(does not apply to an Advantage plan with drug coverage)</i>	
	Other Health Insurance Policy (Medigap): Company: Premium: Payment schedule:	
	Veteran's Health System: ID #:	
	Do Not Resuscitate (DNR) Order:	
	POLST form-if available in your state	
	Living Will	
	Durable Power of Attorney for Health Care	

MEDICATION CHART

Prescription Name	Strength	Dosage	Warnings/Instructions

TRANSPORTATION CHECKLIST

NAME

X	Item	Notes	Where is it kept?
	Auto(s):	Make(s):	
	Auto Loan Information:	Model(s):	
	Title for Car(s):		
	Auto Insurance Company:		
	Recreational Vehicles: Title: Insurance:		

FINANCIAL CHECKLIST

X	Item	Where is it kept? Contact Name
	Bank Records (checking/savings accounts) Pin number clues — online banking and accounts with passwords and clues	
	Trusts	
	Will	
	Durable Power of Attorney for Finances	
	Any rental agreements or business contracts	
	Complete list of assets & debts	
	List of routine household bills	
	Federal & State Tax Returns (past 3-5 years): Tax Preparer:	
	Records of any personal loans made to others:	
	Financial Planner or Broker:	
	Life Insurance Policy or Policies:	
	Disability Insurance (long- and short-term):	
	Long-Term Care Insurance:	
	Safe Deposit Box(es):	Location(s): Number(s): Keys:

PUBLIC BENEFITS CHECKLIST

Your loved one may have or be eligible for help with paying for food, heating bills, property taxes and more. Use **AARP BenefitsQuickLINK**, www.aarp.org/quicklink, to find out about programs in your state.

X	Item		
	Food Assistance, (i.e., SNAP/FNS)	<input type="checkbox"/> YES	<input type="checkbox"/> NO
	Low Income Home Energy Assistance (LIHEAP)	<input type="checkbox"/> YES	<input type="checkbox"/> NO
	Supplemental Security Income (SSI)	<input type="checkbox"/> YES	<input type="checkbox"/> NO
	Property Tax Assistance	<input type="checkbox"/> YES	<input type="checkbox"/> NO
	Extra Help Paying for Medicare Part D (prescription drug coverage)	<input type="checkbox"/> YES	<input type="checkbox"/> NO
	Medicare Parts A, B and D Premium Support	<input type="checkbox"/> YES	<input type="checkbox"/> NO
	Medicaid (help with long-term care and medical care) Number & Identification Card	<input type="checkbox"/> YES	<input type="checkbox"/> NO
	Transportation Assistance	<input type="checkbox"/> YES	<input type="checkbox"/> NO