Timely Resources Care Guide Series

Caregiving:

Assessing What is Needed:

A * P * I * E

What does your care receiver need? How can you make a plan for your loved one's care?

Here is information to help.

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INTRODUCTION

How do we know if an aging relative, friend, or someone else needs help?

As our population ages, more aging community and family members need help. Keeping a care receiver in their home or living independently is the first choice for the care receiver and for most family members. However, services have decreased in *availability* especially those offering sliding-scale fee structures or those that are administered through the states' agencies on aging. The care receiver may not have *access* to services where they live. Sometimes, the services are not *appropriate* for our care receiver's needs. We have also seen sharp increases in the cost of services which impacts *affordability*.

Care receivers and their needs vary. How old is the care receiver? Are there multiple health issues? Is the care receiver physically challenged and/or cognitively challenged? What is their financial situation? What are their environmental needs? Are there legal considerations? Is there a support system? So many things to think about!

Each situation must be evaluated and treated differently. Just as each of us in a unique individual, so are the circumstances of our lives. We need to consider feelings, the "wants" versus the "needs", and we need to be aware of the reality of our situations. Just because we hope for a desired outcome doesn't mean that it is going to happen.

We need to broaden our perspective to look at the bigger picture that represents our care receivers. This booklet will help you as you evaluate your care receiver and develop a plan to help them.

At the same time, we need to look at the caregiver(s). Just as you are evaluating your care receiver, apply many of the same questions to the caregiver(s). Are they still employed? Are there minors at home? Does the care receiver live with them? What can the caregiver do physically? How is the caregiver coping emotionally? How is the caregiver's health? Where does the caregiver live in proximity to the care receiver? Again – so many things to think about!

Hopefully, ***A*P*I*E*** will help you organize all those things that you need to consider. The abbreviation will help you remember the steps in the process of planning for someone's care. The booklet will go into deeper details about the components of ***A*P*I*E*** which are:

A * P * I * E
A = Assess
P = Plan
I = Intervene
E = Evaluate

Check out the Additional Information section of this booklet for more tips.

Altenheim Resource Services can help you with your questions. Get in touch with us for free and confidential consultation on service options and resources.

Check out our web page for more information or to contact us.
Go to: www.altenheimcommunity.com

HOW DO WE KNOW SOMEONE MAY NEED HELP?

Our Introduction to Caregiving

Sometimes a crisis brings us to the realization that we need to become involved with our family member. There may be a fall or some other health issue that lands our loved one in the hospital, and we get a call that we need to step up.

Maybe it's been a gradual process and we're just becoming aware that our family member is beginning to decline.

We may have started to help with small things but we see that more help is needed so we start adding chores to our plates.

We may be a long distance family who visits at Christmas, Easter, family birthday, or other special occasion and we see that things are in a general state of decline. Our loved one may not notice what we are seeing – or they may deny there are problems – but this is our wake-up call that says "HELP!".

There are many scenarios in which family members become aware of their loved one's increasing needs.

If you've not been faced with a crisis call but sense the need to check on your care receiver, there are indicators that your loved one may need help. Sometimes they ask for help, but often they are trying very hard to maintain their dignity and independence and won't say anything. What should you look for?

- A noticeable change in personal hygiene such as dirty clothing, body odors, urine stains
- A noticeable change in environmental cleanliness such as odors of rotten food, piled up garbage, dirty linens.
- The outside of the house is in a state of disrepair or neglect, the lawn needs care
- Out-dated food in the refrigerator
- Items stacking up in the home
- Difficulty handling finances: unpaid bills, shut-off notices, calls from credit agencies
- Mail piling up: unopened or not taken care of
- Changes in personality
- Lack of interest in family, friends, hobbies, or activities
- Memory loss or confusion
- Missed appointments and/or excuses for missed appointments or outings
- Significant weight loss or gain
- Falls or physical signs of injury such as bruises or scratches
- Calls of concern from friends, neighbors, or church family
- Is your loved one an Internet or TV shopper? Numerous packages and/or credit card charges are things to look for.

GETTING ORGANIZED

*Learning about **A*P*I*E***

What do I need to consider? What's going on? What DON'T I know about?? As we have often heard: we don't know what we don't know!

OK – It's time to sit down, take a deep breath, and process the situation. Think about ***A*P*I*E***! No – not apple (like the cover photo) or cherry and not even coconut cream or key lime!

A*P*I*E is an acronym that will help you keep in mind the steps to follow when you are caring for someone and considering needs.

A = ASSESS

There are many things to consider when assessing a care receiver's situation and needs. The more informed you are about your care receiver's situation, the better you will be able to plan and arrange appropriate care.

P = PLAN

Now that you know about your care receiver and their needs, you can begin to make a plan. What is the problem(s)? What is the goal / desired outcome? Who can help make that happen?

I = INTERVENE

Make the calls. Ask the questions. Set up the service(s). Part of your caregiving job is to monitor the services. Stay in touch and stay informed about the service(s) your loved one is receiving.

E = EVALUATE

How are things going? Are the services appropriate? Is the service provider reliable? How is the care receiver reacting to the service(s)? Is the service achieving the desired outcome? You may want to do this every 6 months or after an event such as an illness, hospitalization, death of a family member, change in environment, or other significant life change, in which case you want to reassess at that time.

Read on to learn more about ***A*P*I*E***.

A = ASSESS: WHAT DO I NEED TO CONSIDER?

There are several areas to consider when assessing a care receiver's situation.

Looking at Strengths

It's important to focus on strengths and let our care receivers do as much as possible for themselves. It is also important to keep safety and security in mind.

Can your loved one:

- Obtain medications
- Take medications
- Make sound decisions
- Handle finances
- Pay bills
- Get where they need to go
- Navigate the environment when they are going out
- Get groceries
- Get other needed items
- Use the telephone
- Say "NO" if necessary (telemarketers, scammers, those who come to the door)
- Live alone safely
- Live alone with assistance safely

What can the care receiver do for themselves? What do they need help with? How much help do they need?

We need to know what areas present challenges but we also need to step back and allow care receivers to do what they can for themselves. It may be easier and quicker for us to do something but consider how we would feel. It may take a little longer to accomplish a task but that's OK. The care receiver may not do a task like we do. That's OK, too. Give your loved one the opportunity to be as independent as possible. Unused skills become lost skills.

The care receiver may be able to do things if parts are simplified. Think about modifying a task to accommodate decreasing abilities. (They may not be able to cook dinner but they can help prep the ingredients, mix, & stir.)

The ***Assessment*** is a "deep dive" into the care receiver's world. It's a comprehensive overview of the care receiver that includes the following. You may need to add questions based on your situation.

- What type of home?
  - House
  - House with acreage
  - Apartment
  - Condo, townhouse

- Who is in the home?
  - Live alone
  - Spouse
  - Dependent child
  - Granchilidren
  - Lives with adult children

- Is there a primary caregiver?
  - Is that caregiver effective?
  - Are they able to "do the job"?
  - Are they available?

- Immediate health needs
  - Are there acute issues that need attention now?
    - Skin breakdown, rashes, difficulty breathing, cuts that don't heal, foot and nail care, rapid decline in function, dental issues, sudden change in cognitive status
    - Do prescriptions need filled?
    - Do medical appointments need scheduled?

- Chronic health needs
  - Dementia
  - Arthritis
  - Diabetes
  - Neuropathy
  - Blood pressure issues
  - Cardiovascular issues
  - Bladder, kidney problems
  - Gynecological issues
  - Prostate issues
  - Mobility impairments
  - Other ongoing health issues

- Adaptive & safety equipment
  - Cane, Walker
  - Wheelchair / motorized wheel chair / power chair
  - Other
  - Grab bars in bathroom (tub, commode)
  - Non-skid strips in tub
  - Is an elevated commode seat needed?
  - Is lighting adequate throughout the house?

- Visual and hearing acuity
  - When was the last vision exam?
    - Does the care receiver wear glasses?
  - Are there vision changes or is there a decline?
  - Are there vision concerns?
    - Normal age-related changes
    - Cataracts
    - Glaucoma
    - Macular degeneration
  - Is hearing impairment a challenge?
    - Does care receiver need a hearing exam?
    - Does the care receiver have/wear hearing aids? Need hearing aids?

- Cognitive abilities
  - Diagnosis of dementia
  - Memory
  - Judgment
  - Orientation to time, place, people
  - Comprehension – written and spoken word
  - Communication abilities
  - Retrieval of information
  - Ability to recognize people

- Mental health issues
  - Is there a history of mental health issues? Has there been treatment?
  - Are there signs of depression?
  - Is there involvement with a therapist or behavioral health agency?

- Activities of daily living / instrumental activities of daily living – What can they do? Independent? Needs help? Totally dependent for assistance?
  - Bathing, dressing, grooming
  - Preparing meals and eating
  - Housekeeping
  - Shopping
  - Laundry
  - Managing finances
  - Managing medications
  - Using a telephone

- Environmental needs & neighborhood safety
  - Is the house aging-friendly?
    - Where are the bedrooms?
    - Where is the bathroom?
    - Are there steps? (Inside and outside)
    - Where is the laundry area?
    - Are there handrails? Are there grab bars?
    - Is the house in good condition? Are minor/major repairs needed?
    - Is lawn care needed?
    - Can the house be modified for changing needs?
    - Is the house equipped for physical challenges?

- Neighborhood safety
  - Is the home in a rural, suburban, or urban setting?
  - Is the home in a safe neighborhood?
  - How close are necessary services such as medical care, transportation, groceries?

- Transportation needs
  - Is the care receiver still driving? Should they be?
  - Is public transportation available? Are other transportation resources available?
  - Is there a need for a specialized vehicle?

- Support system
  - Family
    - Is there a family "leader"?
    - Who are family supports?
    - How stable is the family support system?
    - Is family support local? Available? Involved?
  - Other informal supports
    - Friends, neighbors, church family
    - Senior center peers, veteran peers, women's groups, men's groups, civic organizations
    - Postal carrier, newspaper carrier, garbage personnel
  - Health care personnel
    - Primary health care providers
    - Home health personnel (Physical/Speech/Occupational Therapists)
  - Support services (in home, home delivered meals, home health)

- Special affiliations such as Veteran status, United Mine Workers history, Masons
  - There may be additional benefits for the care receiver

- Income and assets
  - What is the care receiver's income? What are the sources of income?
  - Are there pensions? Other retirement benefits?
  - Is there alimony?
  - What are their assets? What are the sources of the assets?
    - Stocks, bonds, annuities?
    - Oil, gas, mineral leases or royalties?
    - Non-adjacent properties?

- Other financial
  - Income tax consideration
    - What will be needed to file taxes?
    - Save records on caregiving expenses
    - Is there Homestead Exemption consideration?

- Insurance coverage
  - What type of health insurance does the care receiver have?
  - Is there long term care insurance?
  - Is there life insurance?
  - Car insurance
  - House insurance
  - Where are the documents?

- Legal and Advanced Directives
  - Is there a will?
  - Is there a Durable Power of Attorney? Medical Power of Attorney? Living Will?
  - Is there a Deed on Death?
  - Where are the documents?

- Military Service
    - Branch of service
    - Service dates
    - Discharge status
    - Where are discharge papers? (DD-214)

- Social history
    - Is English the care receiver's first language? If not, what is the first language?
    - Where was the care receiver born?
    - What is the educational level?
    - Were there any traumatic events that could impact the care? (For example: a history of sexual abuse, serious accidents, violence, recent deaths in family)
    - Church affiliation

- Family history
    - How many marriages?
        - How did they end? Death of spouse? Divorce?
    - Children and contact information
        - Natural, adopted, blended family
    - Siblings and contact information

Additional notes on assessing the situation

Learn all you can about your care receiver. Here are some other areas that will be helpful. More 'personal' information can be helpful to those who are assisting the care receiver allowing them to personalize care.

- What is their daily routine?
    - Include meal times, shower times, other routine habits
- What are their likes? Dislikes?
    - Food
    - Entertainment (television, music, games)
    - People
    - What do they like to be called?
    - Do they like dogs? Cats?
    - What else will personalize the care?

Caregivers become case managers for their care receivers. They oversee the care receiver, they determine what services are appropriate and evaluate the outcome of the services. They are social directors, historians, advocates, and they try to be the voice of reason. Caregivers monitor services, daily activities, and health concerns. Caregivers help guide their care receivers and try to keep them safe and secure.

It seems like a lot of information to gather but the more you know about the care receiver, the better prepared you are to provide care.

P = PLAN: DEVELOPING A PLAN OF CARE

You don't have to be a "professional caregiver" to develop a plan of care. What you're doing is organizing your thoughts in regard to the care receiver's needs, the goal you hope to accomplish, what service or intervention can help, and who can help.

Where do you start? Perhaps you know your care receiver needs help but you're not sure what is needed. You are unsure of the terminology and what you can expect from services. You may not know what might be available to help. The following information will help with some of those concerns.

Developing a Plan of Care

What is a plan of care? It's a way of identifying a concern, deciding what you hope to accomplish, making note of what help is needed, and who / what agency can help.

You want to create a plan to address the issues of most concern

- Make a list and prioritize the needs
- Establish a goal for each need
- The next step is to determine who will fulfill those needs.
    - Are the tasks things that a family member can or is willing to do?
    - Do you need to look at an agency to provide assistance?
- Where do you find the services?
    - Do you need help in determining the options that are available?
        - Talk to a hospital social worker / discharge planner, your local senior center, your state aging office, or your local 211.
        - Contact Altenheim Resource Services for free consultation and information on services.
- Make the plan, work the plan
    - Contact the person or agencies who will provide or can offer the service
        - You can contact several and do some comparisons
    - Get information on regulations, costs, etc.
    - Arrange services

When developing a plan of care:

- Involve the care receiver in the decision-making process as much as possible but be aware of their capacity to make decisions. Also, most people want to remain in their homes and independent so the decision may be based on that desire as opposed to the reality of what it entails. Assess whether they can do that realistically and safely.
    - Identify areas of concern and areas where the care receiver needs help.
        - What are your care receiver's perceptions of their needs?
        - What are your perceptions of their needs?
    - Identify common goals that are realistic and workable. Talk about the need to work together to achieve the goal(s).
    - Offer reassurance BUT don't make promises that you are not able to keep!
        - It may be necessary to make hard decisions regarding a loved one's care and that may mean a move to another place, or the caregiver may need to assume control in financial and/or business areas that the care receiver cannot handle.
    - Be realistic with your abilities and limitations as well as your care receiver's abilities and limitations.
    - Assess strengths and weaknesses of the care receiver, the caregiver(s), the neighborhood, the services, and the support system.

- Create a plan that will involve those family members and supporters who can and are willing to help.
    - You may not be able to engage every family member in the care receiver's care. Some family members will not be involved no matter what you do. Others may not want to do one area of care but are willing to do another. (For example, someone may not want to do hands-on care but are willing to do financial assistance, grocery shopping, or another task.)
- Consider the programs that will be least expensive first. Utilize state programs with sliding scale fees or donation-based programs to maximize time and financial resources.
- Check on state programs, volunteer agencies, special groups (Veterans, UMWA, Masons/Eastern Star, etc) first when looking for assistance. There may be a program or benefit, or there may be a sliding-scale fee with some programs. Many states have Waiver programs to help with care for those who qualify medically and financially. Waiver programs vary from state-to-state.
- Consider the task and how to fulfill the need.
    - There may be different ways to address a need. For example, the care receiver may need meals. One option may be for the caregiver to provide meals. Other options include a local home-delivered meal program from the Senior Center (Meals on Wheels program), or a food delivery service such as Mom's Meals. If the care receiver also needs in-home assistance, the in-home care provider could prepare meals and clean up the kitchen.
- Are there special programs that may be helpful such as SNAP (Supplemental Nutrition Assistance Program), Energy Assistance, Extra Help for Park D of Medicare, Designated Special Needs Programs (Medicare), Medicare Savings Programs, Patient Assistance Programs for medications, special fund programs (such as a liquid nutrition program through a senior center), and others? Is there a Medicaid Waiver program for older adults, those with traumatic brain injury, special needs children, or others? Check with your state unit on aging or your Department of Human Services.
- If you determine that you need help from an agency, make some phone calls and compare services and prices. It's OK if you don't know the service name, just describe what you need.

There are some realities that may be difficult to consider:

- Can you – the caregiver - provide the care that the care receiver needs?

- Are the outside services adequate for the care receiver's needs?

- Is it too difficult and/or too expensive for your loved one to remain at home?
    - Cost of in-home assistance
    - Cost of home modification and/or adaptive equipment

- Do you think they need more assistance than can be provided in the home?

- How – and where – can your care receiver achieve the highest level of independence possible that is safe and meets their needs?

A Plan of Care is NOT a "one and done". You will be re-evaluating the plan on an on-going basis. You will want to do a deeper look at regular intervals, and you will need to re-evaluate if there is a trigger (a health crisis, a new health concern, a hospitalization, a change of environment, a change of caregivers, family changes such as death or divorce, or other life-altering event).

When thinking about services, consider the following

- Appropriate / Adequate
    - Do the services meet your care receiver's needs?
    - Do they help to keep your loved one independent and safe?
- Affordable
    - What are the costs?
    - Are there subsidized programs such as meal programs or state in-home programs?
        - There may be income and asset guidelines as well as medical guidelines
- Accessible
    - Can the care receiver get to the service or does the service area include your care receiver's area?
- Available
    - Is what you want available in your area?
        - With the broad marketing range of the media, services that are advertised are not always available in your area.

I = INTERVENE: MAKING IT HAPPEN

This is the phase where you get your list of concerns and needs and prioritize them. Then, determine what the goals are, determine what you can put in place to help, determine who can help, and then make the calls.

Perhaps the least difficult way of doing this is to take out your list of concerns and needs. Let's say you identified Nutrition as a concern. What's the goal? What service or intervention can help? Who can help with the issue? Who might you call? There may be several options or there may be limited or no options.

You will consider who can help (available services or family members), costs, and scheduling.

For Example:

I. Concern: Nutrition
Goal: Make sure care receiver gets a nutritious meal daily

What might help: Family helps with meal prep
In home agency caregiver assists with meals (if care receiver is receiving in home agency assistance)
Home delivered meal program

Who might help: Family
In home agency (if care receiver is receiving in home agency assistance)
Senior center, other agency, Church program

Plan: Contact Aunt Sophie and Cousin Mary Ann to see if they can help
Contact in home service agency about in home caregiver preparing meals (schedule can be arranged during scheduled service time)
Call Senior Center or other agency about regulations and suggested donations home delivered meals

II. Concern: Assistance with light housekeeping and personal care
Goal: Make sure environment is clean and care receiver has bathing supervision

What might help: Family
Senior center for light housekeeping program, supervision during bathing
In home agency for light housekeeping, supervision during bathing
Paid cleaning service

Who might help: Family
Senior center in-home department
In home agency staff
Paid cleaning service staff

You might use one or any combination of the interventions. Sometimes it is necessary to combine services. For example, a paid cleaning service may do a broader monthly cleaning, and the agencies provide services weekly or bi-weekly to maintain the environment. A family member may be able to help on weekends but added services are needed during the week. What will work for your situation?

E = EVALUATE: DID THE INTERVENTION WORK?

You want to determine how effective the Intervention has been.

It may take a little time for your care receiver to acclimate to the assistance. You may get some push back.

- Encourage (or even make a deal with your care receiver) to TRY the assistance or service for a designated amount of time.
- You may also encourage the care receiver to try the service to help you – the caregiver.
- A trusted friend, family member, or pastor may also encourage the care receiver to accept the help.
- The fact is that perhaps with assistance, the care receiver can maintain their independence longer and age where they are most comfortable.

There are times that the paid caregiver and the care receiver just don't connect. Talk to the agency supervisor about a change of personnel. (Be prepared for staff shortages within agencies so alternatives may be limited.)

If there is a change in the care receiver or if there is another event such as a new medical concern or a hospitalization, you will need to step back, look at the services being provided, and determine what, if any, changes need to be made.

What do I look at?

- Is the Intervention helping with the identified concern and is the hoped-for goal being achieved?
- Are there new concerns that need addressed by the agency's in-home provider? Does the service plan need revised?
- Have there been issues from the care receiver or the provider about the service?
- Is the agency responsive and easy to work with?
- How is the quality of the service?
- Is the service affordable?

While you are evaluating the Intervention, you need to also evaluate the care receiver.

- Have there been changes in the care receiver's health?
    - Worsening of chronic conditions
    - New diagnoses
- Are services still affordable?

OK – Now you've been through the process. You will need to constantly re-evaluate your care receiver. Changes occur with health, finances, the home, and so much more. As they say – the only constant is change!

Make changes in your Plan of Care as your care receiver's situation changes. Being prepared doesn't change the situation but it can help you – the caregiver – navigate the caregiving journey with a little less difficulty.

ADDITIONAL INFORMATION

Family Involvement

It can be helpful to have a "family meeting". In-person gatherings are preferred but technology enables anyone who wants to participate the opportunity to do so. FaceTime, Zoom or other platforms, all allow family members to 'gather' to discuss the care receiver's needs.

Who do you include? The care receiver's children, other family involved in the care, agents for Powers of Attorney (if different), and friends who may be willing to assist / be involved. Some families are blended so step- or half-siblings may be involved in the care receiver's network.

Involving the care receiver is an individual decision. Hopefully, you will have been able to discuss your concerns with your loved one but in many families that doesn't happen or it's not successful. Also, cognitive impairment may limit the care receiver's ability to comprehend and process the situation which can result in fear and misunderstanding….and resistance.

Some families find it helpful to meet and discuss the situation then present their concerns to their family member. This also allows families to air differences and work on conflict resolution without the presence of the care receiver. It also allows families to find out where family members stand in regard to the care of the loved one.

Here are some ideas for discussion:

1. Who are the agents for Medical Power of Attorney and Durable Power of Attorney?
2. Who will act as the "on-site" caregiver?
3. Identify concerns and needs
4. What can they do by themselves? What do they need help with? What can they no longer do?
5. Can services be provided to meet those needs?
6. Should they live alone?
7. Identify who can help / will help with the concerns and needs
8. Who can help with financial arrangements/oversight?
9. Who can help with services oversight (if not the "on-site" caregiver)?
10. Who can help with continuity of medical care? (Appointments, prescriptions, etc)
11. Are there issues with family members such as substance abuse, mental health issues, health issues, financial issues, long distance involvement, other, that might impact the care and well-being of the care receiver?
12. Offering different scenarios may help others to understand some of the situations that could occur and give them an opportunity to gauge their reactions. Here are some examples:

    What will we do if the care receiver experiences:

    a. Sleep problems
    b. Loss of bladder control
    c. Loss of bowel control
    d. Appetite changes
    e. Mood fluctuations
    f. Behavioral problems, outbursts, aggression
    g. Memory problems
    h. Excessive fatigue
    i. Falls

Family meetings can take place on a regularly scheduled basis so everyone knows what is happening. Additional meetings can be scheduled as needed.

The Support Network

The care receiver's support network is an important part of their lives and can include any number of people from all walks of life. Our loved ones have had their own lives for a long time. So many people have crossed their paths! Explore their connections. Involving friends for socialization can help prevent isolation and keep the care receiver involved in their community.

Our care receiver's support network can also provide help and/or insight into the care receiver's needs/situation. They can help with friendly visits, phone calls, or a note in the mail. They may be able to go to lunch or go to another social outing. Don't underestimate the value of these relationships and activities.

The support network may include the primary health care provider, interested family members, geriatric social worker or case manager, attorney, financial advisor, neighbors, old friends, new friends, the church family, the meal delivery person. Make a list of the care receiver's social / support network.

- Talk to the primary health care provider about your care receiver's physical and cognitive needs. You may run into issues with HIPAA laws. If that happens, consider sending a letter to the health care provider introducing yourself and expressing your concerns.

- Involve family members in a meeting to discuss needs and to delegate tasks, and to find out who is going to provide any help. (You will also find out who may not provide assistance. You can't force family members to be involved, and it's best to know who you can count on.)
    - Make a list of interested and available family, friends, neighbors, and other supports and what they may be able to do. Include telephone numbers, email addresses, and physical addresses.
    - Keep family members informed about the status of your care receiver on a regular basis. Include those who are not actively supportive.

What Does the Care Receiver Need? A Primer on Assistance

Here is some information on some commonly needed services. There are several others as well.

There are a variety of services that can help. Some are provided in the home, some are provided in the community, and some are provided in facilities such as assisted living facilities or nursing and rehab facilities.

- What are some options?
  - In home (non-medical) assistance
    - General tasks: Helps with basic supervision, light housekeeping, personal care, may provide transportation, most often will NOT administer medications
    - States have programs to assist through Senior Centers
      - There may be "no fee" or a "sliding scale fee" structure
      - Service time may be limited and there may be waiting lists
      - Hours may be limited to weekdays with no evening or weekend coverage
    - Agencies providing in-home assistance may be for-profit or non-profit
      - Fees start at roughly $25 / hour and go up
      - Most agencies require a minimum block of time
      - Hours may depend on availability of staff but may be able to provide 24/7 coverage
      - Medicare does not cover this level of assistance
    - States also have Waiver programs for those meeting program requirements for eligibility.
  - Nutrition
    - Home-delivered meal programs from Senior Centers are donation-based
    - Mom's Meals and other commercial food deliveries offer menu options for a fee but work with some state agencies to provide meals
    - There are also congregate meal sites at senior centers and churches for those who want the socialization and activities.
  - Transportation
    - Transportation services may be provided by the county senior center, volunteer agencies, medical facilities, and public sources such as buses and cabs
    - Catchment area may be limited
    - Fees may be donation-based or have set fees
    - Paratransit services may be available from public transit services for those with challenges. Area may be limited.
      - There are wheelchair accessible transportation services
      - Cost may not be covered by any insurance
    - Transportation can be a challenge to locate
  - Home Health
    - Physical, occupational, speech therapy
    - Need referral from primary health care provider
    - Covered by insurance when medical criteria is met
  - Legal Services
    - Attorney
    - Legal Aid
  - Financial
    - Accountant, financial institution
  - Downsizing
    - Smaller home, townhouse, condominium
    - Apartment
      - Fair market or subsidized

- Higher level of care
  - Assisted living
    - May be an out-of-pocket expense
    - Some states offer some coverage for assisted living
    - Veterans benefits or long term care insurance may help pay costs
  - Nursing home
    - Must meet medical criteria for admission
    - Must meet financial criteria for Medicaid assistance
- Hospice care
  - For those who are at end-of-life
  - Usually prognosis of 6 months
  - Can be provided in the home or in higher levels of care

Some areas of service are more challenging

Are services available to the care receiver?

Services are often less difficult to arrange in an urban or suburban area as opposed to rural areas.
There is usually a wider choice of services and service providers in larger cities and the surrounding areas.

- Transportation, especially long distance transports
  - Specialized transportation is limited
  - Not many providers
  - Expensive
- In-home assistance
  - Extended hours may be limited through agencies due to staffing
  - State programs may have limited slots available
- Adult Day Services
  - Available in some areas, not in others
- Chores / lawn care
  - Depends on your area
  - Often there is limited availability for chore services
- Home repairs
  - There are grant and low-interest load programs for low income families & seniors who meet eligibility criteria through USDA
  - Limited availability of inexpensive assistance in many areas

This will give you an idea of some of the services that may be available to the care receiver and some services that may be more challenging to arrange. Remember, not all services are available in all areas; you may need to think about alternative options; just because it's advertised in your area doesn't mean the business is available in your area; and, prices vary.

Exploring In-Home (non-medical) Services

If you need help from an agency, call them and do some comparisons. Most have websites and you can get an idea of the agency and their services but please don't depend on the accuracy of the site. Services, hours, owners, and locations can change and you want up-to-date information.

Many agencies offer in-home (non-medical) services. These services provide basic supervision, light housekeeping, personal care assistance, and some agencies offer transportation to their client/care receivers. Don't hesitate to talk to several agencies about the care receiver and their service needs, and the agency's ability to provide that care. Take notes. Make comparisons.

Here are some questions that you may want to ask. You may think of others.

- What is the hourly cost of care?
- Are there minimum blocks of service time?
- What is the billing cycle?
- Are there price differences for different levels of care, holiday hours, or other factors that may change the hourly rate? Are there price cuts for larger blocks of time?
- How is the worker's time determined? Are there sign-in sheets? Telephone check-ins?
- Is there a nurse supervisor?
- Who develops the agency's plan of care?
- How are workers screened?
- Do workers receive on-going training?
- Do workers receive specialized training for dementia or end-of-life care?
- Are your workers certified? How?
- Are your workers bonded and insured?
- What if your worker cannot make it to their scheduled time with the client/care receiver? Is another worker provided?
- Can your workers provide transportation? How are arrangements made? How are the charges assessed?
- What if there is an incident with the care receiver? (Examples: fall, elopement)
- What if there is an incident with the worker? (Examples: unethical behavior, abuse, theft)
- What if the client/care receiver and your worker just do not get along?
- What does your worker do if the care receiver tells them to "get out", "go home", or won't let them in?
- What does your worker do if the care receiver becomes aggressive?
- What would trigger a dismissal from your services?

Having Information Close at Hand

When we become caregivers, we become (in many cases) Keepers of the Information. We need to know where names and numbers are for important contacts. We need insurance cards. We need to know where documents are kept that offer the authority for agents to make medical and/or financial decisions.

The hospital that your care receiver uses may have the Medical Power of Attorney and Living Will on file.

Keep a notebook or an electronic file to track important information. There are also fireproof fireboxes for important information and documents.

- Copies of Durable Power of Attorney
- Copies of Medical Power of Attorney and Living Will
- Copies of Will
- Insurance cards
- Insurance policies
- Banking / financial institution, accountants, other financial consultant contact information, safe deposit box information
- Military service information and discharge information
- List of important contacts
- List of emergency contacts with phone numbers
- List of medications, dosages, amounts, and pharmacy information
- Information on funeral arrangements
- Information on services including agency names, contact names and numbers, and service descriptions, hours, days of service

Resources for Information

We know that help is needed but where do we start?

There are many options for getting information for assistance. Here are a few resources to consider.

Altenheim Resource Services (a division of Altenheim Retirement Community)
1387 National Road, Wheeling WV
www.altenheimcommunity.com
304 243-0996
Free, confidential information on resources and services. No eligibility requirements.
Empowering older adults, caregivers, and their advocates through information, education, and support.

Ideas for additional resources follow. As states offer different programs, ask about your particular needs and what program might help. Many states offer similar programs but have different names.

General resources
State Units on Aging
Area Agencies on Aging
County Senior Centers
Aging & Disability Resource Centers / No Wrong Door programs
Hospital social workers / discharge planners
State Health Insurance Information Programs
211 Information

West Virginia
Bureau of Senior Services
Family Resource Networks
Mission WV (grandparents raising grandchildren / Relatives as Parents / Kinship Care)
Legal Aid WV (grandparents raising grandchildren / Relatives as Parents / Kinship Care)
WV Senior Legal Aid (issues specific to older adults)
West Virginia Department of Human Services (Medicaid, Medicaid Waiver programs)
WVU Centers for Excellence in Disabilities
Bridging Resources WV

Ohio
Ohio Department on Aging
Area Agency on Aging (Caregiver programs, Passport – Medicaid Waiver program, Assisted Living Waiver)
Department of Job & Family Services
Ohio Justice Foundation (legal aid)
Ohio Legal Help