Timely Resources Care Guide:

WHEN PLACING A LOVED ONE

LONG TERM CARE BASICS
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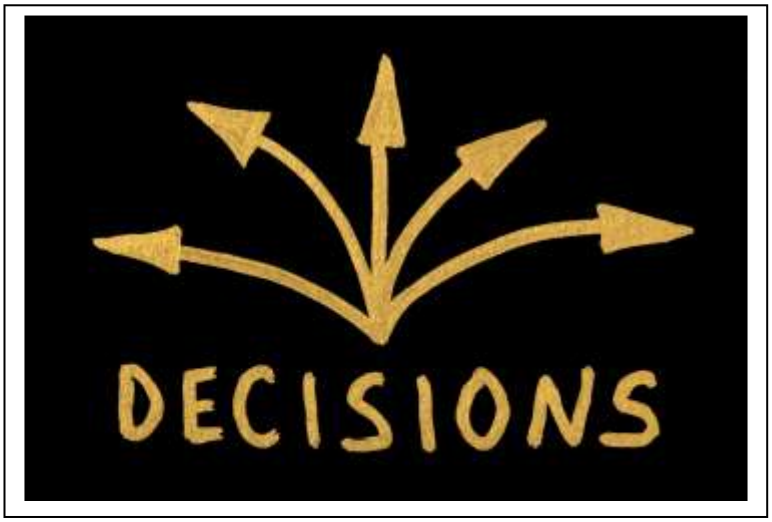
WHERE DO WE LOOK
HOW DO WE ADJUST TO THE CHANGE



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When Placing a Loved One

- *Helping* a loved one with placement decisions means we need to be informed.
- *Placing* someone in a facility also means we need to be informed.
- Placement is a difficult decision and there are some things we need to keep in mind.

There are basic considerations:

- *What basic information will help?*
  - What does long term care entail?
  - What are payment sources?
  - How can the caregiver stay involved?
- *Who is making the decision?*
  - Are you the helper or the decision-maker?
  - Are other family members involved? Are there siblings? Step-children?
  - Don't make promises you can't keep. (I will never put you in a nursing home.)
- *When do we make the decision?*
  - What guides us in deciding when someone needs more care than they will accept or that we can provide?
- *What do we look for in a facility?*
  - Survey results, Medicare ratings, word-of-mouth, location, and a personal visit can help us with decisions.
  - Are there special needs?
- *Where do we find information on facilities?*
  - There are several resources for locating appropriate placement.
- *How can we help the care receiver adjust to the change? How do we adjust to the change?*
  - Change is difficult. The care receiver is moving from their familiar environment and the caregiver is learning about the new responsibilities of providing care.

Remember the 4 A's of care

- What is *appropriate* for your loved one's care?
  - Can the facility provide what your loved one needs?
  - Are there issues that could impact the care?
- What is *available*?
  - Some facilities have waiting lists.
- What is *accessible*?
  - Can you and others get to the facility?
- What is *affordable*?
  - Finances and resources are always considerations with placement in long-term care.

LONG TERM CARE BASICS

Long-term care may be an assisted living facility or a nursing home. Assisted living is the level of care before nursing home care for those who do not need 24-hour nursing care.

Some facilities offer a continuum of care which means that independent housing through nursing care is offered. These may be in one facility, on a 'campus' setting or they may be spread out but have a corporate connection with the increasing levels of care. Other facilities offer only assisted living or nursing home care.

Assisted living may be an out-of-pocket expense or there may be assistance through a state program for those who qualify. Veterans' benefits or long term care insurance may be options to help cover costs.

Nursing home care may be an out-of-pocket expense until the resident qualifies for Medicaid medically and financially. Veterans' benefits or long term care insurance may be options to help cover costs. Most residents will need assistance from the state Medicaid program as their resources decline. Medicaid is a primary payer for many nursing home residents. Application for Medicaid is made in the county in which the care receiver is placed.

Long term care offers activities in-house and many facilities take residents to outside activities such as concerts.

The facility may have a resident council giving the residents the opportunity to discuss concerns.

Family meetings are held to discuss the individual resident's issues and / or well-being. If you have a complaint, talk to the Director of Nursing or Social Service staff. Learn what the facility's procedure is for grievances.

Some facilities offer support groups for family members.

The resident is permitted to leave the facility for special events, occasions, or visits. Talk to the facility for the regulations that apply. Ask about bed-hold rules for longer absences.

It is permissable to move to a different facility. There may be waiting lists for transferred residents. If transferring to a different state, Medicaid rules may be different. Look into what is involved so you're prepared.

Moving someone with dementia can result in an adjustment period since they are no longer in a familiar environment. There may be some changes with the care receiver while they adjust to their new home. Talk to the staff about how they can support your care receiver during this transition.

Your role as a caregiver has changed but you are still a caregiver. The facility is now responsible for the day-to-day care but you will still have the roles of advocate, historian, social liaison, and support person. Your involvement can make a great deal of difference.

Learn about long term care options. Be prepared to discuss this with your care receiver and/or those involved in the decision.

- What type of care is provided in assisted living? Nursing homes?
- Is there financial assistance in my state for assisted living?
- What are the Medicaid regulations for nursing home Medicaid in my state?
- What are my choices of facilities?

The following information surely does not cover every detail and concern of long term care placement. Every situation, every caregiver, every care receiver, and every family is unique but hopefully there will be a lot of information that will offer some guidelines as you move along this part of your life.

Don’t hesitate to ask for help.

Resources for more information:
Basic Needs | ACL Administration for Community Living or https://acl.gov/ltc/basic-needs

MAKING THE DECISION: WHO IS MAKING THE DECISION

Who is involved in the decision?

Can the care receiver make the decision? Do they have the capacity to make the decision? If you have questions as to their ability to decide about their care, consult their primary care provider.

If the care receiver cannot make the decision, who will be the decision-maker or who will be involved? There may be other children or the care receiver may have siblings or other interested family members. These 'others' may be allies or they may oppose your loved one's decisions and/or your decisions. They may be helpers or they may be the 'seagull' caregivers. (They swoop in, make a mess, and then fly away.) They may have agendas: control, inheritance, resentment for old hurts, promises made to the care receiver, or made by the care receiver. They may have the ear of the care receiver and attempt to influence their decisions. They may have the best interests of the care receiver at heart or they may be self-serving. Think about a family meeting to determine family members' roles.

Can my loved one make the decision for themselves?

If your loved one has the capacity to make the decision for placement, he/she will be instrumental in the process. Hopefully, you have had the discussion about what happens if long term care is needed but if not, you need to have a serious talk about the situation.

- Talk to your loved one. What's a good time?
- Discuss their needs, their hopes, and their expectations regarding their long term care.
- Discuss your / other family members' abilities to provide assistance and support.
- Enlist the support of the care receiver's physician. What level of care does the care receiver need: assisted living, intermediate?
- Take your loved one to visit homes, if possible. Do they have friends or relatives in care homes? What are their opinions / their caregivers' opinions of the facility?

What if my loved one cannot make the decision for themselves?

If your loved one doesn't have the capacity to make the decision to be placed, you / the caregiver / agent for MPOA will need to have the authority to make the decision for them. Hopefully, there is a designated agent to act as Medical Power of Attorney. If not, it may be necessary to go through the court process to be appointed guardian and/or conservator.

- If your loved one is resistant, try enlisting the assistance of the care receiver's primary care provider.
- Try to visit facilities and determine the appropriateness.
    - Do they have a memory care program?
    - Is there a place to walk that is safe?
    - Is there a wander alert system?
    - Are there other special needs or considerations?
- Does the care receiver have issues with behaviors? A special care unit may be needed

Regardless of whom the decision-maker(s) is/are, the following information needs to be considered and gathered.

- Are advance directives in place? Powers of attorney, living will, will?
- Was the care receiver in the military?
- Do they have long term care insurance, life insurance, trusts?
- What is the financial picture? Checking, savings, bonds, stocks, IRAs, 401Ks, gas/oil/mineral leases or royalties, etc, and in whose name are they held? Information on Social Security amounts, pensions, alimony payments, rents, etc.
- What are the resources (house, other property, boats, etc)? In whose name are they held?
- Do you need to consult an elder law attorney for guidance on estate and/or Medicaid planning?
    - Make sure the attorney you see is an elder law attorney and that they are familiar with Medicaid law and regulations. Google those in which you're interested for any reviews or comments.
    - At this time, there is a 5-year look-back for transfers of assets per Medicaid regulations. Other programs may have similar look-back regulations. Ask.
- Is there a safe deposit box? Where is it?
- Is there additional property? Where is it?
- If it's a blended family, make sure you know who all the children are. Were any promises made to any of the children? (If Medicaid is involved, state regulations will take precedence over "promises".
- Who are ex-partners (legal)?

Resources for more information:
Family Caregiver Checklist: A Discussion Guide for Family Caregivers

WHEN TO MAKE THE DECISION

So – how do I know if it's the right time?

- Your care receiver
- What signs should I look for?
- Is there something else that can help to keep them home?
- How am I – the caregiver – holding up?

Your care receiver

This is probably the most heart-wrenching decision. Knowing when the time is right involves many factors.

- Your loved one

Does your loved one have dementia?

Many people with dementia do not have health issues that would necessitate long term care but other issues such as decline in functional abilities, nutritional issues, frequent falls, or medication administration issues make living independently unfeasible. The need to place someone with dementia may be marked by behaviors that are dangerous to the person or dangerous to others such as wandering, aggressive or violent behaviors, or sundowning.

Is your loved one mentally well but physically impaired or declining?

There are times when our loved ones are mentally healthy but their physical health is not conducive to their living alone safely. They may be unable to do the basics of independent living such as meal preparation, personal care, or medications, and they may be unable to manage a home or apartment without a lot of help.

What signs should I look for?

Safety concerns may also be factors in your decision to pursue placement.

- Frequent falls
- Memory loss that impacts their safety
- Is the environment safe? Are there stairs? Are the bedroom and bathroom easily accessible?
- Is the neighborhood safe? Can home repairs be done? Can regular maintenance such as grass cutting be done?
- Are they vulnerable to exploitation and being scammed or have they been scammed?

Other factors may include:

- Declining health and frequent hospitalizations or doctor visits may also be factors in the decision to place a loved one.
- Are there nutritional problems? Can the care receiver cook or get food?
    - Is there outdated food in the refrigerator?
- Can the care receiver call for help or use the phone?
- Are bills piling up or are there shut-off notices?

Is there something else that can be done to keep my care receiver at home?

But – wait! I feel guilty. Maybe I haven't done enough. Can I do something else? Maybe. What services or help have you tried? How much help do you need? What financial resources are available?

In home (non-medical) services are available in most areas. There is a broad fee range, and services cost more in larger areas. Services usually can be provided 24/7 but the cost may be prohibitive.

- Many senior centers / senior service agencies have state programs that can offer in home assistance and may be less expensive, at a sliding scale rate, or free. Hours available may be limited.
- Medicaid Waiver programs may be available for those who qualify financially and medically for Medicaid.
- Fees for in-home assistance are often an out-of-pocket expense or there may be assistance through the Veteran's Administration for veterans or widows of veterans who qualify. (Contact your local Veteran's office for details.)
- A long term care insurance policy may also pay for some benefits. (Check policy for terms.)

Some services such as home delivered meal programs or senior center transportation programs may be on a suggested donation basis.

Transportation services may be available through senior centers, in home service agencies, or specialized transportation services. Transports for those who are non-ambulatory can be challenging to find. Home delivered meal programs or services can help with food. Other services may be available to help keep your care receiver independent.

Hospice services are for those at end-of-life and can be provided in the home or in a facility. Medicare and most insurances cover hospice care.

How am I – the Caregiver – holding up?

Are you (the caregiver) facing increasing challenges in providing care to your loved one?
It is critical that we as caregivers KNOW and NO our limits. Caregiving is hard. It's hard physically, emotionally, and often financially. We need to KNOW when we have reached out limit.

- Is the physical care becoming too difficult for our abilities?
- Are we lashing out at loved ones or the care receiver?
- Are we depressed? Crying? Experiencing sleep disturbance? Change in appetite?
- What is the financial situation? Have we cut back hours or quit work altogether?
- Have we reached the "end of our rope"?

Just as important is our need to NO our limits. We can't do what we did before we were caregivers. We may not be able to celebrate holidays with the old family traditions. We may not be able to go to lunch with our friends or dinners with our partners. We have to be able to say NO when an activity puts undue hardship on us and on our care receivers.

You have tried additional services. Perhaps the services weren't adequate for your care receiver's needs. Perhaps other assistance was needed that couldn't be provided. Perhaps you can't afford the additional assistance. Perhaps you just can't give anymore. Perhaps it's time to look for an alternative.

Resources for more information

Placement is a difficult decision. We become so enmeshed with the caregiving and the care receiver that we may not realize how much the caregiving is impacting our physical, mental, and spiritual health.

Ask a trusted friend for an objective opinion of the situation.

There are several tools that can help you assess the situation. Use a check list that assesses areas where assistance is needed and how much. This can give you a more objective view of the situation. The following documents can be found on our webpage at www.altenheimcommunity.com.

- “A Discussion Guide: What Does the Care Receiver Need?”
- “Daily Task Appraisal”
- “Should My Loved One Live Alone?”

WHAT TO LOOK FOR IN A FACILITY

There are different levels of care for care receivers. You have tried in-home services, and other community services to support your loved one but these interventions are no longer enough.

Assisted living is the first rung on the facility care ladder. Assisted living offers assistance with activities of daily living such as meals, medication administration, personal care assistance (bathing, dressing, grooming), and activities. Most facilities have registered nurses and licensed practical nurses for medical needs and supervision, and nursing assistants or aides to help with day-to-day activities.

Nursing home care offers more intense medical care when assisted living is not an option.
If your loved one has dementia and displays behavioral problems which could be problematic to other residents or staff, it may be necessary to consider a secure unit.

Talk to your care receiver's primary care provider about the appropriate level of care.

Some facilities are part of a continuing care community or a continuing care facility. Care is arranged in levels of increasing need offering independent, assisted and long term care as part of the care structure.

You can find survey results at the facility, and you can look for nursing home survey results on the Medicare website (www.medicare.gov) under Nursing Home Compare.

How will the care be paid for?

If your care receiver needs assisted living, payment may be an out-of-pocket expense. Medicare does not pay for assisted living. Some state's Medicaid programs will help with the cost for this level of care. The Aid & Attendance Program for Veterans and Widows of Veterans may help with assisted living for those who qualify. Some long term care insurance policies will pay on assisted living.

Intermediate care in a nursing facility is private pay, Medicaid, and possibly Veteran's or long term care insurance assistance. Medicare does not pay for long term stays in nursing homes. Medicare covers short-term skilled services only. When the care receiver no longer meets the criteria for skilled care, they will be discharged home or to a long term care bed in a facility. Medicaid has financial and medical guidelines that a nursing home resident or prospective resident must meet.

Other considerations

- When someone is being admitted to a nursing home, a Pre-Admission Screen (PAS) is required. The health care professional completes the form which determines a patient's need for the nursing home level of care.
- There are asset limits for Medicaid
- States have different Medicaid regulations
- Estate Recovery is a consideration in all states. The state's Medicaid program can put a lien on the estate (if there is one) to recoup Medicaid money spent for care.

WHERE TO LOOK: HOW DO I FIND A FACILITY

Information on long term care facilities is available from various sources. You may want to contact:

- Altenheim Resource & Referral Services
- Hospital social workers or discharge planners
- Area Agencies on Aging
- State survey agencies such as Office of Health Facility Licensure & Certification in WV, Ohio Department of Health, PA Department of Health
- Check out the facility comparison tool on the Medicare website: www.Medicare.gov
- Ask friends or family members who have had loved ones in assisted living or nursing homes
- Your church friends and pastor/priest/rabbi

When you have narrowed down your search, visit the homes in which you are interested. Ask to see their state survey results. Talk to staff. Talk to residents. Ask about staff turnover. Ask about staff to patient ratios.

When you visit, use your senses. Consider the following:

- What do you see? What does the facility look like?
    - Is it clean?
    - What is in the halls?
    - Do you see activities?
    - Do you see smiles on the faces of the staff and residents?
- What do you hear?
    - Do you hear laughter?
    - Do you hear unanswered call bells?
    - Do you hear cries of pain?
    - Do you hear respect for the residents?
- What do you smell?
    - Do you smell lunch or dinner?
    - Do you smell urine or feces?
    - Do you smell pleasant cleaner aromas?
- Can you taste any of the resident meals?
    - Ask if you can have lunch at the facility. If this cannot be accommodated, ask for a menu.
        - Do residents have choices?
        - Do they have help filling out the menu?
        - Are there special diets?
- Touch, human contact is so important to our well-being.
    - Are residents hugged? Shown signs of affection or connection by the staff?

HOW DO WE ADJUST TO THE CHANGE

So – what happens with life after caregiving at home? We may feel depressed. We may feel like we failed our care receiver. We may feel like we have lost our purpose. We may feel a sense of relief – and a sense of guilt for feeling relief. There is such a mixture of emotions.

Guilt is not unnatural for caregivers who have placed loved ones. We think we should have done more. We should have waited. We should have tried more services. We shouldn't feel relief at no longer being the primary caregiver.

A few things are important to remember.

One is that you are giving up being the "everything: the cook, financial manager, personal care aid, transportation coordinator, scheduler, shopper, and many other positions. You no longer have to sleep with one eye and one ear open, always being on alert for the call or being afraid of the catastrophic event that will signal a crisis. You are turning over your role as primary caregiver to the facility, and that facility has departments and shifts of workers doing what you did as a primary caregiver!

Another thing to keep in mind is that we are still caregivers. Our role has changed but we are still caregivers.

- We become the liaison for care. The primary care is the responsibility of the facility but they will come to us for care decisions, and reports of changes.
- We become "overseers" of our loved one's care. Person-centered care is the facility's focus on offering care that addresses the individual. Meals, shower times, and other care items that *can* be personalized are tailored to your loved one's preferences. (Please note that not all aspects of care can be personalized.)
- We are the historians for the facility. We 'introduce' our care receiver to the new caregivers at the facility, providing information on who our care receiver is.
- We are the social contacts and facilitators. We let family members know where our loved one is, how they are doing, we encourage contact, we keep our loved one connected with their faith family.
- We are stabilizers for our family member. We try to help our loved ones when they are sad, feeling alone, feeling helpless. We cannot fix them. We cannot make them better or independent nor can we take them "back" to a time when they were young and vibrant. We have to understand and accept our limitations.

Our care receivers may also be having difficulty with the adjustment. They may 'want to go home'. They may have problems with eating – lack of appetite, refusing meals. They may refuse to participate in activities.

Many facilities ask family not to visit for a few weeks to allow for adjustments. Don't think that the facility doesn't want you involved! They do. The more the family is involved, the less difficult the placement.

This is the time for you – the caregiver – to adjust, too. You need to renew yourself. You need to find that there is life beyond the home phase of the caregiving journey.

- Get reacquainted with friends. Start slow if you need to. Make a few phone calls to friends and catch up. Go out to lunch.
- Meditate, do yoga, journal how you feel.

- Exercise, walk, go back to the gym.
- Perhaps a support group or counseling will help if you need support.
- Take time to do some of the things that you haven’t been able to do.

Give yourself time to adjust!

Resources for more information:
Getting to Know You…Information on Care Receivers
Making Family Part of the Caregiving Team

To sum it up

The decision to place is emotionally difficult. The realization that our loved one is declining and can't be fixed is hard to accept. It's hard for our loved ones to accept, too. The realization that we can no longer provide care is hard to accept. The realization that we need care is hard to accept. What is the best option for our loved one's care and well-being, and for our well-being? How can we help our loved ones adjust? How can we adjust?

Those in assisted living or a nursing home are in their new home. Just as they lived in their own home or apartment, this is where they live now.

Placement is difficult for everyone. The care receiver probably doesn't want to go to a facility. Most of us don't want to have to leave our home. But – the reality is that most of us will need long term care sometime in our life.

Get prepared and have information available.

- Have the talk with your family. Write down your wishes.
- Prepare documentation: living will, medical power of attorney, durable power of attorney, will.
- Keep a log of where important papers are kept. Insurance policies (life, long term care, auto, home); deeds or titles (home, car, other property); stocks, bonds; Medicare, Medicare Supplement, Part D cards; account information (checking, savings, credit union); birth certificates; marriage licenses; divorce decrees; and any other documents that would be needed.
- Where are keys (car, house, safe deposit box)?
- Who are important people? (Minister, accountant, attorney, funeral home, landlord, and others)

Reach out for help and information. There are several resources.