Help at home for loved ones is just a phone call or email away.

Our staff can advise on hiring in-home help, qualifying for home-care programs and dealing with the everyday stresses of caregiving.

614-645-7250 | 800-589-7277 | COAAA@COAAA.ORG

Consultations are available via telephone, email, or in your home at no cost to you.

Call Today. We can help you help the ones you love.

Caregiver Bill of Rights

I have the right:

- To take care of myself. This is not an act of selfishness. It will give me the capability to take better care of my loved one(s).
- To seek help from others even though my loved one(s) may object. I recognize the limits of my own endurance and strength.
- To maintain facets of my own life that do not include the person I care for, just as I would if he or she were healthy. I know that I do everything that I reasonably can for this person and I have the right to do some things just for myself.
- To get angry, be depressed, and to express other difficult feeling occasionally.
- To reject any attempts by my loved one(s) (either conscious or unconscious) to manipulate me through guilt, and/or depression.
- To receive consideration, affection, forgiveness, and acceptance for what I do, from my loved one(s), for as long as I offer these qualities in return.
- To take pride in what I am accomplishing and to applaud the courage it has sometimes taken to meet the needs of my loved one(s).
- To protect my individuality and my right to make a life for myself that will sustain me in the time when my loved one(s) no longer need(s) my full-time help.
- To expect and demand that as new strides are made in finding resources to aid physically and mentally impaired persons in our country, similar strides will be made towards aiding and supporting caregivers.

~ Modified with permission from Today’s Caregiver Magazine (2006)
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**SECTION 1: CLARIFYING YOUR CONCERNS**

*Look over* the areas below and see which of them address the issues that you are currently concerned about regarding your older relative or friend. This exercise can help you know which part of this booklet may be relevant to your needs. Then go back to the appendix and consult those areas of greatest concern to you.

- **Social Concerns**
  
  Does your loved one have:
  
  - Ongoing contact with other people on a regular basis?
  - Any social life outside the immediate family?

- **Self-Care Concerns**
  
  Is your loved one able to:
  
  - Do grocery shopping independently?
  - Prepare his/her own reasonably nutritious meals?
  - Bathe and dress without help and look presentable?
  - Keep his/her home orderly and do housekeeping without assistance?
  - Handle emergency situations and know what to do to get help in a medical emergency at home?
  - Manage his/her own finances, pay bills and handle medical forms?
  - Manage without frequent falls/injuries?

- **Physical Condition Concerns**
  
  Does your loved one:
  
  - Have serious health problems?
  - Currently receive treatment for health problems?
  - Take medications (if so, how many and what kind?)
  - Take medications without being reminded?
  - Have a disability, making it difficult to get around in his/her own home?

- **Emotional/Mental Condition Concerns**
  
  Does your loved one:
  
  - Become very forgetful or confused about time and dates, where he/she is and what he/she should do?
  - Have frequent or unexpected mood changes for no apparent reason?
  - Complain about being bored and lonely?
  - Cry or seem sad a great deal of the time?
Section 2: Advance Care Planning

Section 2.1 What Is It?
- An organized approach to starting a discussion about a person’s:
  - Current State of Health
  - Goals and Values
  - Financial Resources Available
  - Legal Decision Makers
  - Preferences for Future Care, Treatment and Living Arrangements

- Not just a one-time event – it should be an ongoing process in families, as needs and situations change.

Section 2.2 Why Is It Important?
- People very often have strong preferences about these issues. However decisions about health care are often made in emergency situations with little time for discussion.
- If the family has not had these discussions before the emergency, misunderstandings can occur, mistakes can happen, and decisions contrary to a person’s wishes can be made.
- In addition, without planning there can be significant and unnecessary financial cost and a decrease in the older person’s quality of life.

Section 2.3 Why Do Families Delay Discussing These Issues?
- It is difficult and sometimes awkward to get these conversations started.
- It can be uncomfortable to talk about health, finances, disability, and death in families.
- Past relationships and conflicts sometimes interfere with honest communication.
- These discussions are easy to delay if people are healthy and there is no pressing need.

Section 2.4 Suggestions for Getting the Conversation Started
- Do your own advance planning. Then you can mention what you are doing in conversations with your relatives.
- Let them know why you are bringing the subject up. For example, “My goal is to support your independence as much as possible. If we talk about this now, we have a better chance of making sure you can receive the care you want, where you want it.”
- Prepare your questions in advance. For example: “What kinds of assistance would you accept if you were not able to do some things yourself?” or “How important is it to you to remain in this home?”
- Prepare information. Have appropriate documents on hand to show relatives. Some websites which can give you information and documents include:
  - www.conversationproject.org
  - www.proseniors.org
  - www.agingwithdignity.org
  - www.leadingageohio.org  (Some documents to download include “Choices Living Well at the End of Life, 6th Edition” and “Conversations that Light the Way”)
• Consider holding a family meeting so everyone can be involved.

• **Suggestions concerning family meetings:**
  - Don’t forget to include long-distance family/caregivers if possible.
  - Include adult 3rd and 4th generation family members if available. They often bring a productive dynamic to the discussion and a current knowledge of technology.
  - Set ground rules for the meeting so that only issues that apply to the current concerns are brought into the discussion (i.e. leaving out old arguments, past issues etc.)
  - Appoint a mediator who will move the discussion along. This can be someone from the family, a close friend or it can also be appropriate to hire someone who specializes in these issues.
  - Everyone should have a chance to share and listen to others.
  - Get all agreements with family members in writing.
  - Follow up soon after when there are joint decisions for action.

### SECTION 3:

**ACCESSING AGING SERVICES & INFORMATION**

**Section 3.1 What are Area Agencies on Aging and What Do They Do?**

• Established by the Federal Government in the Older Americans Act of 1965. Every part of the US and our territories are served by an AAA (over 670).

• Most states have multi-county regions served by an AAA. **Ohio has 12 regions which are pictured in the accompanying map on the next page (called Planning & Service Areas – PSA for short).** To see a more detailed map of the regions in Ohio, go to [www.ohioaging.org](http://www.ohioaging.org)

• **Area Agencies on Aging in Ohio: What Do They Do?**
  - **Fund** Community Based Services (under Title 3 of the Older Americans Act)
  - **Provide** Information, Assistance & Education to older adults, adults with disabilities and their families on a variety of issues like long term care services, housing, and health and wellness (call or check the website of any AAA to get connected to services and programs)
  - **Advocate** on behalf of older adults, adults with disabilities and their families
  - **Administer** many of the programs designed to allow those who are eligible for Medicaid and would be living in a nursing facility to receive care in the community.
Section 3.2 Where are they found in Ohio?
Locate your county in italics.

Council on Aging of Southwestern Ohio
(PSA 1)
175 Tri County Parkway
Cincinnati, OH 45246
800-252-0155 or 513-721-1025
(serving Butler, Clermont, Clinton, Hamilton and Warren counties)

Area Agency on Aging (PSA 2)
40 W. Second Street, Suite 400
Dayton, OH 45402
800-258-7277 or 937-341-3000
(serving Champaign, Clark, Darke, Greene, Logan, Miami, Montgomery, Preble and Shelby counties)
Area Agency on Aging 3, Inc. (PSA 3)  
200 East High Street, Suite 2A  
Lima, OH 45801  
800-653-7277 or 419-222-7723  
(serving Allen, Auglaize, Hancock, Hardin, Mercer, Putnam and Van Wert counties)

Area Office on Aging of Northwestern Ohio, Inc. (PSA 4)  
2155 Arlington Ave.  
Toledo, OH 43609-0624  
800-472-7277 or 419-382-0624  
(serving Defiance, Erie, Fulton, Henry, Lucas, Ottawa, Paulding, Sandusky, Williams and Wood counties)

Ohio District 5 Area Agency on Aging, Inc.  
2131 Park Ave. W.  
Ontario, OH 44906  
800-860-5799 or 419-524-4144  
(serving Ashland, Crawford, Huron, Knox, Marion, Morrow, Richland, Seneca and Wyandot counties)

Central Ohio Area Agency on Aging (PSA 6)  
3776 S. High St.  
Columbus, OH 43207  
800-589-7277 or 614-645-7250  
(serving Delaware, Fairfield, Fayette, Franklin, Licking, Madison, Pickaway and Union counties)

Area Agency on Aging, District 7, Inc.  
F32-URG, P.O. Box 500 (mail only)  
160 Dorsey Drive  
Rio Grande, OH 45674-0500  
800-582-7277 or 740-245-5306  
(serving Adams, Brown, Gallia, Highland, Jackson, Lawrence, Pike, Ross, Scioto and Vinton counties)

Buckeye Hills Area Agency on Aging (PSA 8)  
P.O. Box 370 (mail only)  
Reno, OH 45773-0370  
1400 Pike Street  
Marietta, OH 45750  
800-331-2644 or 740-373-6400  
(serving Athens, Hocking, Meigs, Monroe, Morgan, Noble, Perry and Washington counties)

Area Agency on Aging Region 9, Inc.  
1730 Southgate Parkway  
Cambridge, OH 43725  
800-945-4250 or 740-439-4478  
(serving Belmont, Carroll, Coshocton, Guernsey, Harrison, Holmes, Jefferson, Muskingum and Tuscarawas counties)

Western Reserve Area Agency on Aging (PSA 10A)  
925 Euclid Ave. #600  
Cleveland, OH 44115  
800-626-7277 or 216-621-8010  
(serving Lorain, Cuyahoga, Lake, Geauga, and Medina counties)

Direction Home, Area Agency on Aging Inc. (PSA 10B)  
1550 Corporate Woods Pkwy.  
Uniontown, OH 44685  
800-421-7277 or 330-896-9172  
(serving Portage, Stark, Summit and Wayne counties)

Area Agency on Aging 11, Inc.  
5555 Youngstown-Warren Road,  
2nd Floor Niles, Ohio 44446  
800-686-7367 or 330-505-2300  
(serving Ashtabula, Columbiana, Mahoning and Trumbull counties)
Section 3.3 How to Find what Assistance is Available

- **Eldercare Locator** – 800-766-1116 (www.eldercare.gov) Free information on services anywhere in the United States.

- **Free Long Term Care Assessment** –
  800-589-7277 (www.coaaa.org) *Free in home consultation* to help families make long term care choices. Can be provided anywhere in Ohio.

- Many counties and local communities have Senior Citizen Service Handbooks which list a wide variety of services. Check with your AAA to see if one is available for your community.

- **Websites to check:**
  - www.ohiobenefits.gov – go to this website to apply for all types of benefits in the state of Ohio.
  - www.medicare.gov – has several specialized areas to check for services in your area—Nursing Home Compare, Home Health Compare, Physician Compare, Kidney Dialysis Compare, Hospital Compare, and Hospice Compare.
  - www.ltc.ohio.gov – Long Term Care Consumer Guide offers information about nursing homes and assisted living facilities in Ohio. Includes resident satisfaction survey results.
  - www.ohiobenefitsbank.org – Free service that allows Ohioans to complete applications for state assistance programs, and file their Federal and State taxes. People can serve themselves by using a home or library computer or go to the site of a Benefits Bank Trained counselor. These sites are listed on the website or available by calling 800-648-1176.

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### Section 4: Long Term Care Options

Section 4.1 Types of Services Available in Most Communities

Many communities have numerous services for older adults who wish to receive care while living in their own home, apartment or condominium. The funding for these programs varies by each community. Some services charge a fee, some accept a donation, and some will bill long-term care insurance if the person has it and the service is covered. Individuals should inquire about financial assistance that may be available for a particular service. Some of these services include:

- Meal Programs – *Group dining at a community center or meals delivered to the home.*
- Transportation Service – *Rides to appointments, shopping, other activities.*
- Adult Day Health – *Supervision in a community center for all or part of a day. Individuals can receive their medications, personal care, meals, and therapies. Recreational activities and outings are planned according to the person’s interests and abilities.*
- Respite Care – *Provides a break for caregivers usually several hours but can also be for a longer time.*
• **Home Health Aide (or Personal Care Aide)** – *Provides personal care like bathing, dressing, feeding, some minor medical care and light housekeeping.*
• **In Home Therapy** – *Provides training in communication, movement or doing daily tasks.*
• **Companions** – *Provides conversation, supervision and some help with meals or tasks.*
• **Homemaker** – *Provides light housekeeping, laundry, cooking, errands.*
• **Chore Service** – *Provides minor repairs and handyman chores.*
• **Senior Center** – *Provides social activities, information and a range of services.*
• **Telephone Reassurance** – *Phone calls to check on the person’s well being*
• **Nursing Service** – *Provides medical care and medical monitoring.*
• **Emergency Response Systems** – *Provides a connection to emergency assistance if a person cannot get to a phone. Usually it is a button connected to a bracelet or necklace.*
• **Care Management/Care Coordination** – *Provides coordination of services coming into the home. Families involved in long distance caregiving find it especially helpful to hire someone to coordinate home care services.*
  - Some government funded home care programs (for example in Ohio: the PASSPORT program, Franklin Co. Senior Options, Delaware Co. In Home Services, Fairfield County Older Adult Alternatives, or Union County Senior Services) include a care manager to assist families in coordinating services (800-589-7277 or [www.coaaa.org](http://www.coaaa.org)).
  - Locate a private care manager by asking the National Association of Aging Life Care Professionals at 520-881-8008 ([www.aginglifecare.org](http://www.aginglifecare.org)).
• **Transitions Assistance** – *Sometimes older adults and families need assistance with downsizing and moving to a smaller residence. It is recommended that anyone who is hired to assist be insured against damage, breakage, and theft. Two websites which list professionals in this area are:*
  - National Association of Senior Move Managers [www.nasmm.org](http://www.nasmm.org)
  - National Association of Professional Organizers [www.napo.org](http://www.napo.org)

**Section 4.2 Independent Living Options for Older Adults**

Available in most communities. These can be apartment communities, condominium communities or communities of homes.

Some communities are subsidized and rent is less expensive for older adults who qualify based on income. Most offer a full apartment; not just a room. Many have waiting lists. For a full listing in Central Ohio, go to [www.coaaa.org](http://www.coaaa.org) and look under the topic “Resources,” then “Guides and Publications” and open the link to “Housing Guide.”

Some have transportation, social programs, noon meals, and emergency response systems available. This option is usually *not* appropriate for adults with significant confusion.
Section 4.3 Institutional Care Options

Section 4.3a Assisted Living

- In Ohio, the Department of Health licenses 600 Facilities as Residential Care Facilities, but they are commonly referred to as Assisted Living Facilities. For a full listing in Central Ohio, go to www.coaaa.org and look under the topic “Resources,” and open the link to “Long Term Care & Hospice Guide.”
- Assisted living units often include: a private bedroom, cooking area and bathroom, locking doors and individual temperature controls.
- Services may include: meals, housekeeping, personal care, routine nursing services (medicines, special diets, dressings), health monitoring and service coordination. Some assisted living facilities offer Memory Care Units.
- In Ohio, Assisted Living Facilities are private pay and some are now eligible for Medicaid when a resident spends down his/her assets (for a list of facilities that allow the Medicaid Waiver for Assisted Living, go to www.ltc.ohio.gov). There is great demand for this service and very few available openings in Ohio. Other states often provide financial assistance for assisted living facilities as well.
- Many assisted living facilities accept residents for short-term respite stays. They usually charge a per day rate for these stays.

Section 4.3b Extended Care or Nursing Facilities

- Known as nursing homes by the general public. They are available in most communities, and regulated in Ohio by the Ohio Department of Health. There are almost 1,000 in the state of Ohio.
- Fees for services can vary widely depending upon the type of care provided, the type of facility, and the economy of the local community. Many nursing facilities have Medicaid funding available for residents who spend down their available assets.
- It is suggested that families visit and evaluate several facilities before making a final decision for placement of a family member (see more information Chapter 4). For a full listing in Central Ohio, go to www.coaaa.org and look under the topic “Resources,” and open the link to “Long Term Care & Hospice Guide” or go to www.ltc.ohio.gov.
- Many nursing facilities accept residents for short term respite stays. Check with the facility for day rates and availability.

Section 4.3c Continuing Care Retirement Communities

- These communities usually contain a number of different living/assistance options. Often they require a large deposit and then monthly payments to live in the community. Residents can move between the various living options depending on their care needs. For a full listing in Central Ohio, go to www.coaaa.org and look under the topic “Resources,” and open the link to “Long Term Care & Hospice Guide.”
Section 4.3d What is “Level of Care” in Ohio?

- The words “Level of Care” refer to the types of care that the person requires and what type of professional would need to provide that care. The person’s “level of care” is usually what determines whether or not Medicare, Medicaid and Private Health Insurance will pay for the care.

In Ohio, there are 3 Levels of Care:

- **Skilled Level of Care** refers to medical needs that are specialized and result in rehabilitation. Often these needs are short term. Medicare and Medicaid both pay for skilled level of care needs.

- **Intermediate Level of Care** refers to medical needs that are routine in nature and do not result in rehabilitation. Most residents of extended care facilities nationally are intermediate level of care. Medicare does not pay for this but Medicaid does.

- **Protective Level of Care** refers to needs that are not medical in nature like transportation, meals, supervision, housekeeping etc. Neither Medicare nor Medicaid pay for this kind of care. This type of care used to be called “custodial”.

Section 5: Financial Realities

Section 5.1 Medicare

- Medicare is the federal health insurance program which covers:
  - People age 65 or older
  - People with End Stage Renal Disease or Amyotrophic Lateral Sclerosis (ALS)
  - Those who have been receiving Social Security Disability payments for 24 months or longer.
  - Everyone who pays into the Social Security System (FICA taxes) earns coverage for Medicare. Medicare pays only for Skilled Level of Care Needs (with the exception of Hospice Care).

**Medicare Part A is also called Hospital Insurance:**
Coverage is automatic and free for those paying into at least 10 years of Social Security. It includes hospital, post-hospital skilled rehabilitative care and hospice benefits.

**Medicare Part B is also called Medical Insurance**
- Coverage is voluntary. However, most beneficiaries buy coverage.
- In 2017 the monthly premium for most people ranges from $109.00-134.00. It covers Doctors, Lab/Diagnostic Services, Therapies, Some Durable Medical Equipment, Limited Ambulance and Home Health Care. It pays 80% after a yearly deductible of $183.00 (2017).
• In Ohio, providers cannot bill Medicare recipients more than the 20% that Medicare requires that they pay. This is called the Balance Billing Ban.

**Medicare Advantage Plans (Medicare Part C) are available to those with Medicare:**

• These operate like HMOs or PPOs (Health Maintenance Organizations orPreferred Provider Organizations). Those who choose this option agree to go only to those providers who participate in the plan. Usually they cover a city or a county. Most of these plans offer prescription drug coverage.

**Medicare Part D is also called Prescription Drug Coverage:**

• It is available to all Medicare Beneficiaries if they do not have coverage which is at least as comprehensive from another source. Some people qualify for the Limited Income Subsidy(LIS) which provides extra financial help in purchasing a plan. May also be called “Extra Help.”

• Go to [www.medicare.gov](http://www.medicare.gov) for cost comparisons. For questions, contact [www.coaaa.org](http://www.coaaa.org) or call 800-589-7277.

**Open Enrollment for Medicare:**

• This period is now consolidated into one period for all parts of Traditional Medicare and Medicare Advantage Plans. It is **Oct. 15 - Dec. 7.**

**Medicare Summary Notice (MSN):**

• Medicare sends a statement to all recipients after it pays each claim. If there are several claims, Medicare consolidates them and sends one quarterly. Medicare beneficiaries can also access their claims online. Medicare recipients should **not** pay any bills until they receive this notice and then should **only** pay the amount that Medicare says to pay.

• Medicare does NOT pay for most long-term care services.

**Medicare Skilled Home Health Care Benefit:**

• Does not pay for private-duty nursing or non-medical services.

• Requires a doctor’s order for all covered services.

• Requires the individual to be homebound.

• Pays for home care typically on a very time-limited basis.

**Medicare Skilled Home Health Care Services Can Include:**

• Skilled nursing service or therapy (physical/occupational/speech)

• A home health aide and/or medical monitoring

• Some medical equipment like hospital beds or wheelchairs

• Patient/Caregiver teaching to use medical equipment, perform dressing changes, maintain functioning, and manage medications
Medicare Skilled Nursing Facility or Rehabilitative Services Benefit:

- Requires three consecutive midnights of ADMITTED hospital care prior to admission. Many hospitals are not admitting patients; instead they are keeping them in Observation Status. Check this because when you have a loved one in the hospital under Observation Status, Medicare will not cover rehabilitation services in a nursing facility.
- Pays for nursing facility care only as long as the patient requires skilled nursing care or therapy and makes progress towards recovery as a result.

Medicare Hospice Benefit

- Requires a terminal diagnosis of six months or less (can be renewed if death does not occur in a six-month period). Some illnesses like Alzheimer’s disease have a list of symptoms that count as a terminal diagnosis if they are present.
- Covers all care related to the terminal diagnosis. Concentrates on pain management and keeping the person as comfortable as possible.
- Does Not Cover active treatment of diseases and conditions.
- Can be provided in a variety of settings including a person’s home and extended care facilities.
- Can provide support to families for up to one year following the death of the individual.
- For more information on Hospice, visit Chapter 2 of this Manual.

To learn more on Medicare, go to www.medicare.gov or call 800-MEDICARE (633-4227) or contact the Central Ohio Area Agency on Aging at www.coaaa.org or 800-589-7277.

Section 5.2 Medicaid in Ohio

- Medicaid is a joint State/Federal assistance program for people who cannot afford healthcare. There are limits on the amount of income and assets you can have to be eligible for Medicaid.
- In Ohio, there are several types of Medicaid. Two of them are:
  - **Community Medicaid** – This type of Medicaid is available to someone who is aged, blind or disabled and has very limited income and assets. He/she must be living in the community. For a description of Community Medicaid, go to www.proseniors.org. Ohio is participating in the Medicaid Expansion Project which offers Medicaid Health Coverage to adults (age 18 - 64) at or below 138% of the Federal Poverty level. For more information visit www.medicaid.ohio.gov.
- **Institutional Medicaid** – Institutional Medicaid is used when a person needs to go live in a nursing facility due to a chronic illness. Often they spend down their assets and apply for Medicaid to cover their stay. For a description of Institutional Medicaid go to [www.proseniors.org](http://www.proseniors.org) or [www.medicaid.ohio.gov](http://www.medicaid.ohio.gov). Those on the Medicaid Home and Community Based Waiver programs fall into the Institutional Medicaid categories when looking at income and assets.

**Who is eligible for Institutional Medicaid?**

You must be a US citizen, lawful permanent resident whose date of entry is prior to August 22, 1996 or qualified alien and a resident of Ohio. In addition, you must be either blind, disabled or 65 or older, and in need of nursing facility services. The financial requirements for eligibility include a gross monthly income at or below $2,205 (2017) and countable resources (assets) not to exceed $2,000. You, or an authorized representative, may apply for Medicaid at the County Department of Job & Family Services in the county where the institutionalized individual lives. Medicaid eligibility may go back three months from the application date.

**Institutional Medicaid – INCOME RULES**

- In determining eligibility, only the income of the applicant is counted and may be used towards the cost of care.
- The community spouse and/or dependents may be allowed a portion of the institutionalized person’s income.
- Most trusts are not allowed. However, there are some exceptions depending on when, why and by whom the trust is created. Some trusts that are allowed include:
  - special needs trusts;
  - pooled trusts;
  - qualifying income trusts (QITs); and
  - supplemental services trusts.
- Trust rules are complicated and can have serious Medicaid consequences. You should consult an attorney experienced in Medicaid if you are thinking about setting up a trust.

**Institutional Medicaid – ASSET RULES**

- Medicaid will pay for intermediate nursing home care when an individual person’s countable assets have been reduced to $2,000.00
- If there is a spouse, ½ of the assets up to approximately $120,900 (2017), can be protected for the spouse living in the community. This amount changes yearly.
- Countable assets include cash, savings, checking accounts, certificates of deposit, IRAs, real estate property, mortgages, land contracts.
- The house is **not** counted as an asset for Medicaid eligibility as long as the person, his/her spouse or a dependent live in it. However, if the person is single and goes to live in a nursing facility, the house becomes countable and usually must be sold when the person has been in the institution for a period of time.
• Personal belongings, life insurance with a face value of no more than $1500 (2017) and irrevocable pre-paid burial contracts are not counted as assets for Medicaid.

• Assets transferred for less than fair market value within 60 months of application (5 years in 2017) for Medicaid may result in a penalty. The penalty is denial of Medicaid benefits for the period of time the assets would have paid for nursing home care.

Medicaid Waivers in Ohio for Home Based Care
• These are programs that fund services for an individual to remain at home instead of living in an institutionalized setting, such as a nursing home. Waivers use the institutional Medicaid income and asset rules.

• Services covered include medical care that would normally be covered in Community Medicaid as well as personal care, homemaker/chore services, adult day services, meals, transportation, emergency response systems and medical supplies.

• Ohio offers many different Medicaid waiver programs. For a detailed explanation of all of them go to the www.medicaid.ohio.gov website. From there go into the “For Ohioans” section and look under “Long Term Care.” PASSPORT is the Medicaid Waiver program for people age 60 and older in Ohio. Area Agencies on Aging conduct the free assessment for eligibility for PASSPORT.

• Parts of the state including Central Ohio are part of a demonstration called “MyCare Ohio” in which Managed Care Organizations assume responsibility for people who are eligible for BOTH Medicare and Medicaid. Many people in Central Ohio on Medicaid Waiver programs will be enrolled in MyCare Ohio from 2014-2019. For more information, see www.medicaid.ohio.gov.

Medicare Savings Programs – What Are They?
For individuals on Medicare with limited income and assets:

• Qualified Medicare Beneficiary(QMB): Pays Part B premiums, deductibles and copayments.

• Specified Low Income Medicare Beneficiary(SLMB): Pays Medicare Part B premiums.

• Qualified Individual(QI): Pays Medicare Part B premiums.

All of these qualify a person for Extra Help with Medicare prescription drug coverage (Part D). Apply for these at Ohio Department of Job and Family Service, or the Ohio Benefit Bank. For more information on these programs and detailed eligibility levels, go to the Ohio Dept. of Insurance’s website at www.insurance.ohio.gov and download the flyer called “Ohio Medicare Savings Programs”.

Medicaid Estate Recovery
• Federal law allows Ohio Medicaid to make a legal claim against the estate when the individual and spouse have died, there are no surviving children under age 21, and no surviving disabled children.

• Estate recovery may be deferred or waived by the state if it is found to create undue hardship (i.e. a family-owned business or a farm that is the survivor’s sole source of income).
The amount of Medicaid’s claim includes the total amount of all payments made on the person’s behalf for long term care and medical expenses. It does not apply to those who hold deeds to the home or people covered by Medicare Savings Programs.

**Medicaid Estate Planning**

It is critical to obtain accurate legal advice regarding Medicaid estate planning early in planning for long-term care. Annual nursing home costs average $85,000. Many people deplete their savings and rely on Medicaid for long-term care with either PASSPORT in their home or in a nursing facility. Medicaid services and programs vary from state to state and are complex. Rules and financial limits can change yearly.

**Section 5.3 Insurance Options – Medicare Supplemental & Long Term Care**

- Medicare Supplemental or Medigap Policies are standardized and tend to cover Medicare’s co-payments and deductibles. The Ohio Dept. of Insurance’s Ohio Senior Health Insurance Information Program (OSHIIP) publishes an excellent guide to these policies called “Ohio Shopper’s Guide to Medicare Supplemental Insurance.”
- Long Term Care Insurance may be available and often covers many types of extended care and in-home care expenses. Consumers should be very careful when purchasing these policies as they are not regulated or standardized in Ohio. See OSHIIP’s publication “Ohio Shopper’s Guide to Long Term Care Insurance” for a detailed description of these policies and their availability in Ohio.
- These are both available for free by calling 800-686-1578 or by going to the OSHIIP website at [www.insurance.ohio.gov](http://www.insurance.ohio.gov).

**Section 5.4 Other Sources of Assistance**

- In most communities, money from the Federal Older Americans Act (Title III) and the Social Services Block Grant (SSBG Title XX), and United Way fund some in-home services. Many of these suggest a small donation for services.
- Also in Ohio, many counties have passed Senior Services Levies which provide in-home care on a sliding fee basis. In Central Ohio, the counties that have senior services levies are Delaware, Fairfield, Franklin, Licking, Madison, Pickaway and Union Counties. For a list of counties statewide with levies and more information on Senior Service Levies in Ohio, go to [www.aging.ohio.gov](http://www.aging.ohio.gov).

**Section 6: Legal Issues in Ohio**

**Section 6.1 What is Elder Law?**

Elder law attorneys focus on the legal needs of older adults. Most attorneys do not have special expertise in all areas of law. When an attorney indicates he/she practices elder law, it is important to find out the types of legal matters the attorney has expertise in handling.
Legal issues which might be part of an elder law practice include:

- Medicaid
- Estate planning
- Administration and management of trusts
- Planning for long term care needs and decision making (Advance Directives)
- Medicare claims and appeals
- Social Security disability claims and appeals
- Conservatorships and guardianships
- Nursing home rights
- Elder abuse and fraud recovery
- Age discrimination

A Certified Elder Law Attorney is a designation indicating an attorney has enhanced knowledge, skills and experience in elder law. To use this designation, attorneys must meet special rules and regulations and pass an examination demonstrating enhanced skills in elder law. For more information please visit the following websites: National Academy of Elder Law Attorneys (www.naela.org) and National Elder Law Foundation (www.nelf.org).

Pro Seniors, Inc. offers a free legal hotline for older Ohioans. When you call Pro Seniors, a volunteer attorney will arrange a time to call you back and provide a free half hour consultation. Although Pro Seniors provides ongoing legal assistance to individuals who live in the Cincinnati area, they can offer you information about other organizations throughout Ohio that provide legal assistance. The toll-free number for Pro Seniors is 800-488-6070. The website, www.proseniors.org has fact sheets on a wide-range of important legal topics.

Section 6.2 Legal Documents in Ohio

Section 6.2a Durable Powers of Attorney (Health Care & Financial)

Health Care and Financial Powers of Attorney are different legal instruments.

- The **Health Care Power of Attorney** grants someone authority over your health care decisions only.
- The **Financial Power of Attorney** grants someone authority over your financial affairs only.

Typically, they are used when you are unable to make your own decisions. You can grant them to two different persons or both to the same person. You grant them when you are healthy and you can revoke them at any time. They cannot be changed or revoked by anyone else but you. You do not need a lawyer to complete these documents. However, they do need to be witnessed and notarized in Ohio. They end at your death. For more information, or to download blank documents, go to www.proseniors.org or www.leadingageohio.org.
Section 6.2b Living Will

- A legal document that specifies your wishes to doctors regarding the use of life-sustaining treatments if you should become terminally ill or permanently unconscious. You do not need a lawyer to complete this document.

- It becomes effective only when you are unable to communicate your wishes and are permanently unconscious or terminally ill. You can change or revoke it at any time but it cannot be changed or revoked by anyone but you.

- **The Patient Self Determination Act** from 1991 requires all health institutions to ask all patients if they have a living will or other form of advance directive. They also need to provide all patients information in writing about advance directives and their right to refuse certain treatments.

Section 6.2c Do not Resuscitate Order (DNR)

An order issued by a physician which says that a person does not want Cardiopulmonary Resuscitation (CPR) administered to him/her. Ohio’s DNR order relieves emergency medical services (EMS) personnel and other medical professional and facilities of their duty to resuscitate a person if that person has one. For more information, go to [www.proseniors.org](http://www.proseniors.org) or [www.leadingageohio.org](http://www.leadingageohio.org).

Section 6.2d Guardianship

- Under Ohio law, if you are mentally impaired to the point that you cannot take proper care of yourself, your property or those for whom you are legally responsible, you may be determined incompetent and have a guardian appointed.

- A guardian may be appointed over the person or the estate or both. A guardian of the person is responsible for the physical care of the person. A guardian of the estate is responsible for the person’s finances.

- The county probate court appoints and manages all guardianships in Ohio. To obtain information or application forms, contact your county probate court.

- In 2015, Ohio modified some of its court rules on guardianship and now it has both booklets and courses for guardians in Ohio. For information on these and to download information, go to [www.supremecourt.ohio.gov](http://www.supremecourt.ohio.gov) and go into the Adult Guardianship Section.

Section 6.2e Wills

- A will is a formal document that lets you provide for the distribution of your estate when you die. An estate consists of real estate property (e.g., land), personal property (e.g., stocks, bank accounts, cars) and intangible property (e.g., claims, interests, rights) that you own at death.

- Ohio law permits anyone 18 or older, with sound mind and memory and not under restraint, to make a will.
• Your will must be in writing. It may be handwritten or typed. You must date and sign the will on the last page in front of two competent witnesses, who see you sign the will and hear you acknowledge that the will is yours. The witnesses must be at least 18 years of age. The witnesses must sign the will and they can also testify that you were of sound mind and memory and not under restraint.

• In your will, you will name an “Executor,” which is a person who has responsibility for representing you after your death and distributing your goods between those listed in your will.

• Keep the original in a safe place where it may be found easily after your death. Tell your executor where a copy can be found or give a copy to him/her.

• A will does not take effect until your death. You can change or revoke the will at any time before your death. When you revoke a will, it means that the will has been canceled and is no longer valid.

• A will from another state is valid if it was made according to the laws of the state in which it was made.

• Probate is the court procedure that must be followed in order to distribute property which the deceased person owned at death. The probate process generally takes from 3-18 months depending on the complexity of the person’s estate. Having a will does not allow someone to bypass the probate process but it may make it smoother and less time-consuming. Some of the person’s property can be structured in such a way that it avoids the probate process.

SECTION 7: AFTER A DEATH: PLANNING AND RESOURCES

Section 7.1 When Someone Dies Checklist

Used with Permission from the Funeral Consumers Alliance of Central Ohio (FCACO); 614-263-4632 and www.funeralsohio.org. More specific questions should be referred to an attorney.

1. When Death Occurs

• Unexpected death (at home or elsewhere): Call 911. The body may be temporarily held at the morgue.

• Death at home: If the person has been under medical care recently but not in a hospice program, call the police (911), who will determine if the coroner needs to be notified.

• Death in a Hospice Program: Call the hospice nurse for instructions.
• Death in a hospice facility, hospital or nursing home: A doctor will be called to pronounce death.
• In all cases, someone will need to provide the contact information for final disposition of the body (the name and number of the funeral home or name and number of the person in charge of the home funeral).

2. Decision Making
• The first step in making the transition less stressful is to be sure that family members know who has been designated to make necessary decisions. A trusted family member, executor or designated agent should know the combination to a safe or location of the key to a safety deposit box.
• Contact those who will have responsibilities (e.g. “Designated Representative for Disposition of Bodily Remains,” family members, funeral director, clergy, executor/administrator of estate; attorney; accountant)
• Keep a written list of decisions and actions completed.

3. Information Needed for an Ohio Death Certificate
Typically, a funeral director handles this form, but the family must supply the personal information:
• Person’s Legal Name and Sex
• Social Security Number
• Dates of Military Service, Branch of Service and Type of Separation
• Marital Status and Name of Surviving Spouse (Including Maiden Name)
• Person’s Education and Ethnic Origin
• Usual Occupation
• Father’s Name and Mother’s Maiden Name
• Informant’s Name, Relationship and Address
• Method and Place of Body Disposition; Cemetery Section, Lot And Grave Number If Applicable.

4. Disposition of the Body
Preferences regarding a funeral: Honor the preferences of the deceased person. In the case of direct cremation, decisions regarding a memorial service can be delayed. For a typical funeral, someone will have to make decisions regarding selection of a casket and other services. By federal law, the funeral home must provide a General Price List, and you should receive an itemized contract of your choices. Read this carefully before signing (See Section 7.2 for a more detailed discussion of this issue).

5. Social Security and Benefit Issues
Social Security is notified electronically after the death certificate is filed with the Department of Health (Vital Statistics). Other important contacts include pension administrators, creditors and potential heirs. Tasks include determining income sources and expenses, arranging for payment of outstanding medical and other bills, closing
financial accounts, closing club memberships and subscriptions, notifying the post office and arranging for forwarding of mail. The probate process may take many months to complete particularly if there are significant assets.

Social Security Lump Sum Death Payment

• A surviving spouse or dependent child may receive a special lump-sum death payment of $255 (2017) if they meet certain requirements. Generally, the lump-sum is paid to the surviving spouse who was living in the same household with the worker when he or she died. If they were living apart, the surviving spouse can still receive the lump-sum if, during the month the worker died, he or she:
  - Was already receiving benefits on the worker’s record; or
  - Became eligible for benefits upon the worker’s death.
  - If there’s no eligible surviving spouse, the lump-sum can be paid to the worker’s dependent child (or children).

• Survivors must apply for this payment within two years of the date of death. For more information about this lump-sum payment, contact your local Social Security office (www.ssa.gov) or call 800-772-1213.

Social Security Survivor’s Benefits

• These may be available to a surviving spouse who meets certain requirements as well as dependent children at the time of the person’s death.

• The amount of the benefit is determined by the worker’s length of service and amount of payments into the system.

• Surviving family members who think they may be eligible for benefits should contact their local Social Security office, www.ssa.gov, or call 800-772-1213.

Section 7.2 Funeral Arrangements

Section 7.2a General Guidelines

• Shop around in advance. Compare prices from at least two funeral homes. Remember that you can supply your own casket or urn.

• Ask for a price list. The law requires funeral homes to give you written price lists for products and services.

• Resist pressure to buy goods and services you don’t really want or need.

• Avoid emotional overspending. It’s not necessary to have the fanciest casket or the most elaborate funeral to properly honor a loved one.

• Recognize your rights. Laws regarding funerals and burials vary from state to state. It’s a smart move to know which goods or services the law requires you to purchase and which are optional.
• **Apply the same smart shopping techniques you use for other major purchases.** You can cut costs by limiting the viewing to one day or one hour before the funeral, and by dressing your loved one in a favorite outfit instead of costly burial clothing.

• **Plan ahead.** It allows you to comparison shop without time constraints, creates an opportunity for family discussion, and lifts some of the burden from your family.

### Section 7.2b Planning Tips

• You can make arrangements directly with a funeral establishment or through a funeral planning or memorial society – a nonprofit organization that provides information about funerals and disposition but doesn’t offer funeral services. If you choose to contact such a group, recognize that while some funeral homes may include the word “society” in their names, they are **not** nonprofit organizations.

• Put your preferences in writing, give copies to family members and your attorney, and keep a copy in a handy place. **Don’t** designate your preferences in your will, because a will often is not found or read until after the funeral. And avoid putting the only copy of your preferences in a safe deposit box. That’s because your family may have to make arrangements on a weekend or holiday, before the box can be opened.

### Section 7.2c Prepaying for a Funeral

• Millions of Americans have entered into **contracts to prearrange their funerals and prepay some or all of the expenses involved.** But protections vary widely from state to state, and some state laws offer little or no effective protection. If you’re thinking about prepaying for funeral goods and services, it’s important to consider these issues before putting down any money:

  - What are you paying for? Are you buying only merchandise, like a casket and vault, or are you purchasing funeral services as well?
  - What happens to the money you’ve prepaid? States have different requirements for handling funds paid for prearranged funeral services.
  - What happens to the interest income on money that is prepaid and put into a trust account?
  - Are you protected if the firm you dealt with goes out of business?
  - Can you cancel the contract and get a full refund if you change your mind?
  - What happens if you move to a different area or die while away from home? Some prepaid funeral plans can be transferred, but often at an added cost.

• Put your preferences in writing, and give out copies to family.

• Be sure to tell your family about the plans you’ve made; let them know where the documents are filed. If your family isn’t aware that you’ve made plans, your wishes may not be carried out. And if family members don’t know that you’ve prepaid the funeral costs, they could end up paying for the same arrangements. You may wish to consult an attorney about the best way to ensure that your wishes are followed.
Section 7.2d The Funeral Rule

- The Funeral Rule, enforced by the Federal Trade Commission, requires funeral directors to give you itemized prices in person and, if you ask, over the phone. The Rule also requires funeral directors to give you other information about their goods and services. Many funeral providers offer various “packages” of commonly selected goods and services that make up a funeral. But when you arrange for a funeral, you have the right to buy individual goods and services. According to the Funeral Rule:
  - You have the right to choose the funeral goods and services you want (with some exceptions).
  - The funeral provider must state this right in writing on the general price list.
  - If state or local law requires you to buy any particular item, the funeral provider must disclose it on the price list, with a reference to the specific law.
  - The funeral provider may not refuse, or charge a fee, to handle a casket you bought elsewhere.
  - A funeral provider that offers cremations must make alternative containers available.

7.2e Common Kinds of Funerals

Every family is different, and not everyone wants the same type of funeral. Funeral practices are influenced by religious and cultural traditions, costs and personal preferences. These factors help determine whether the funeral will be elaborate or simple, public or private, religious or secular, and where it will be held. They also influence whether the body will be present at the funeral, if there will be a viewing or visitation, and if so, whether the casket will be open or closed, and whether the remains will be buried or cremated.

- **“Traditional,” Full-Service Funeral**
  This type of funeral, often referred to by funeral providers as a “traditional” funeral, usually includes a viewing or visitation and formal funeral service, use of a hearse to transport the body to the funeral site and cemetery, and burial, entombment or cremation of the remains. It is generally the most expensive type of funeral.

- **Direct burial**
  The body is buried shortly after death, usually in a simple container. No viewing or visitation is involved, so no embalming is necessary. A memorial service may be held at the graveside or later. Direct burial usually costs less than the “traditional,” full-service funeral. Costs include the funeral home’s basic services fee, as well as transportation and care of the body, the purchase of a casket or burial container and a cemetery plot or crypt.
• **Direct cremation**
  The body is cremated shortly after death, without embalming. The cremated remains are placed in an urn or other container. No viewing or visitation is involved, although a memorial service may be held, with or without the cremated remains present. The remains can be kept in the home, buried or placed in a crypt or niche in a cemetery, or buried or scattered in a favorite spot.

**Section 7.2f Funeral Costs**

• **Basic services fee for the funeral director and staff**
  The Funeral Rule allows funeral providers to charge a basic services fee that customers cannot decline to pay. The basic services fee includes services that are common to all funerals, regardless of the specific arrangement.

• **Charges for other services and merchandise**
  These are costs for optional goods and services such as transporting the remains; embalming and other preparation; use of the funeral home for the viewing, ceremony or memorial service; use of equipment and staff for a graveside service; use of a hearse or limousine; a casket, outer burial container or alternate container; and cremation or interment.

• **Cash advances**
  These are fees charged by the funeral home for goods and services it buys from outside vendors on your behalf, including flowers, obituary notices, pallbearers, officiating clergy, and organists and soloists.

**Section 7.2g Other Funeral Services and Products**

• **Embalming**
  Many funeral homes require embalming if you’re planning a viewing or visitation. But embalming generally is not necessary or legally required if the body is buried or cremated shortly after death. Eliminating this service can save you hundreds of dollars. Under the Funeral Rule, a funeral provider:
  - May not provide embalming services without permission.
  - May not falsely state that embalming is required by law.
  - Must disclose in writing that embalming is not required by law, except in certain special cases.

• **Caskets**
  - When you visit a funeral home or showroom to shop for a casket, the Funeral Rule requires the funeral director to show you a list of caskets the company sells, with descriptions and prices, before showing you the caskets. Industry studies show that the average casket shopper buys one of the first three models shown, generally the middle-priced of the three.
Traditionally, caskets have been sold only by funeral homes. But with increasing frequency, showrooms and websites operated by “third-party” dealers are selling caskets. You can buy a casket from one of these dealers and have it shipped directly to the funeral home. The Funeral Rule requires funeral homes to agree to use a casket you bought elsewhere without charging you a fee for using it.

- **Veterans Funeral and Burial Benefits:** consult Section 8.7 of this booklet for information regarding this issue.

### Section 7.3 Cemetery Arrangements

#### Cemetery Sites

- When you are purchasing a cemetery plot, consider the location of the cemetery and whether it meets the requirements of your family’s religion. Other considerations include what, if any, restrictions the cemetery places on burial vaults purchased elsewhere, the type of monuments or memorials it allows, and whether flowers or other remembrances may be placed on graves.

- **Cost** is another consideration. Cemetery plots can be expensive, especially in metropolitan areas. Most, but not all, cemeteries require you to purchase a grave liner, which will cost several hundred dollars. Note that there are charges – usually hundreds of dollars – to open a grave for interment and additional charges to fill it in. Perpetual care on a cemetery plot sometimes is included in the purchase price; but it’s important to clarify that point before you buy the site or service. If it’s not included, there will be a separate fee for maintenance of the grounds.

If you plan to bury your loved one’s cremated remains in a mausoleum or columbarium, you can expect to purchase a crypt and pay opening and closing fees, as well as charges for grounds care and other services. The FTC’s *Funeral Rule* does not cover cemeteries and mausoleums unless they sell both funeral goods and funeral services, so be cautious in making your purchase to ensure that you receive all pertinent price and other information, and that you’re being dealt with fairly.

#### Burial Vaults or Grave Liners

- Burial vaults or grave liners, also known as burial containers, are commonly used in “traditional,” full-service funerals. The vault or liner is placed in the ground before burial, and the casket is lowered into it at burial. The purpose is to prevent the ground from caving in as the casket deteriorates over time. A grave liner is made of reinforced concrete and will satisfy any cemetery requirement. Grave liners cover only the top and sides of the casket. A burial vault is more substantial and expensive than a grave liner. It surrounds the casket in concrete or another material and may be sold with a warranty of protective strength.

- **State laws do not require a vault or liner, and funeral providers may not tell you otherwise.** However, keep in mind that many cemeteries require some type of outer
burial container to prevent the grave from sinking in the future. Neither grave liners nor burial vaults are designed to prevent the eventual decomposition of human remains.

7.4 Organ & Tissue Donation

• **How to Donate**
The Ohio Donor Registry was established in July 2002. It provides Ohioans the opportunity to give legal consent to be an organ, eye and tissue donor at the time of death. An individual may sign up anytime online at [www.donatelifeohio.org](http://www.donatelifeohio.org) or, by saying “yes” when receiving or renewing their driver license or state ID at the Bureau of Motor Vehicles. Forms can also be completed and mailed in to the registry. Download the forms at the website listed above or request they be mailed to you by calling 800-525-5667.

• **Donation Process**
  - Federal law requires hospitals to contact an organ, eye, or tissue recovery organization in the event of a death or expected brain death. The recovery organization determines the suitability of the potential donation based on the medical history of the donor. In most cases, an organ donor must have been declared brain dead and must be maintained on a ventilator. Special circumstances occasionally allow for organ donation following cardiac death. Eye and tissue donation can occur after brain death or cardiac death.
  - Once a donor is cleared, the recovery agency verifies whether the potential donor has registered with the Ohio Donor Registry. If the potential donor is not registered, the option of donation is discussed with the potential donor’s family. After obtaining consent through the registry (first-person consent) or by the donor’s family, all costs associated with the donation are covered by the organ and tissue recovery organization.
  - After organ, eye, or tissue recovery, the donor’s body is released to the funeral home of the family’s choice, or to the coroner or medical examiner, depending on the circumstances. The recovery organization will advise the donor’s family of the outcome of the donation. Identities of the donor and recipient are not shared between families. However, the recovery organization can attempt to facilitate communication if mutually agreed upon.

• **For More Information:**
In Central Ohio, contact Lifeline of Ohio at either [www.donatelifeohio.org](http://www.donatelifeohio.org) or 800-525-5667.

Section 7.5 Anatomical Gift Programs

Many of the schools of medicine in Ohio will accept a person’s body as a gift to be used in research and teaching. The particular aspects of these programs, i.e., application process, cost, time frame, return of person’s cremains do vary by school. Please contact the individual school to receive details of their program. The seven schools of medicine that accept anatomical gifts are listed below:
Section 7.6 Indigent Burial/Cremation

Until July 1, 2001, the State of Ohio took primary responsibility for burial expenses when someone died without resources. **Currently the burial or cremation is the responsibility of the township or municipal authority in which the person had legal residence at the time of his/her death** (Section 9.15 of the Ohio Revised Code).

The local authority is also responsible for providing a stone or concrete marker on which the person’s name and age, if known and date of death shall be inscribed. The local authority is not relieved of its duty to bury or cremate an indigent person if he/she is claimed by family members.

Unfortunately, there are no uniform statewide standards for local communities to follow in determining who is defined as indigent, how families may apply for assistance or what amount/type of assistance is given. Some local communities have very well defined application and assistance programs and others do not. **Check with the township or city of a person’s residence at the time of death to see what may be available and under what conditions.**
Section 8: Resources and Services for Veterans

Section 8.1 Benefits and Services Available
The Dept. of Veterans Affairs (VA) provides a wide range of benefits including, Disability, Education and Training, Vocational Rehabilitation and Employment, Home Loan Guaranty, Dependent and Survivor Benefits, Medical Treatment, Life Insurance and Burial Benefits.

The website [www.va.gov](http://www.va.gov) provides many documents and information regarding these benefits as well as many printable documents. See also [www.vetsfirst.org](http://www.vetsfirst.org) and [www.veteranaid.org](http://www.veteranaid.org).

Section 8.2 Eligibility for VA Benefits
You may be eligible for VA benefits if you are a:
- Veteran of any branch of the US Armed Services or a Veteran’s dependent
- Surviving spouse, child or parent of a deceased Veteran
- Uniformed service member
- Present or former reservist or National Guard member

Section 8.3 How to Apply for VA Benefits
- The VA has several ways to apply for benefits depending on the veteran’s category and status.
- The Pre-Discharge Program: Joint VA and Department of Defense (DoD) program that affords service members the opportunity to file claims for disability compensation up to 180 days prior to separation or retirement from active duty or full time National Guard or Reserve duty (Titles 10 and 32).
- The VONAPP (Veterans On Line Application): The VONAPP web site is an official VA web site that enables service members, veterans and their beneficiaries, and other designated individuals to apply for benefits using the Internet ([www.vabenefits.vba.va.gov](http://www.vabenefits.vba.va.gov)).
- Apply at Local & Regional Offices: VA regional offices can assist veterans in filing the appropriate VA forms. Contact the Ohio Dept. of Veterans Services at [www.dvs.ohio.gov](http://www.dvs.ohio.gov) or call at 614-644-0898 / 888-387-6446.
- In addition, many VSOs (Veteran Service Organizations) can assist veterans as well by answering general questions and even petitioning on their behalf for services they believe the veteran is qualified to receive.
Section 8.4 Pensions for Veterans


1. Who Is Eligible for a Veterans Disability Pension?
A veteran aged 65 or older or permanently and totally disabled from a non-service connected disability that is not the result of his or her willful misconduct is entitled to a pension. Additionally, the veteran must have
   a. Not been dishonorably discharged;
   b. Served 90 days or more of active duty with at least 1 day during a period of war time; and
   c. Countable family income that is below a yearly limit set by law.

For more information call VA at 800-827-1000. You can apply by filling out VA Form 21-526 or by applying online at the VA’s website, www.va.gov.

2. Who Is Eligible for Housebound Veteran’s Benefits?
An increased VA pension is paid to a veteran or surviving spouse who is in need of aid and attendance or is substantially confined to his or her home or immediate premises by reason of one or more permanent disabilities. This benefit is also available to a veteran who has an ill spouse. The increase in the veteran’s pension because of his or her housebound status (or that if an ill spouse) is not considered income for Supplemental Security Income or Medicaid purposes.

3. What Are Veteran’s Aid and Attendance Benefits?
An increased VA pension is paid to veterans and surviving spouses who are blind, residents in a nursing home or assisted living facility who need assistance with activities such as bathing, feeding, and dressing. Persons who receive home care as an alternative to institutionalization should also apply for this benefit. In some instances, the veteran can use these funds to pay a family member to provide him/her in home services.

4. What Benefits Are Available to a Surviving Spouse?
A Death Pension is a benefit paid to surviving spouse or unmarried child of a deceased wartime veteran who served 90 days or more of active duty with at least 1 day during a period of war time. The survivor’s countable annual income must be very limited.

5. Who Is Entitled to Veteran’s Disability Compensation Benefits?
Disability Compensation is a benefit paid to a veteran because of injuries or diseases that happened while on active duty, or were made worse by active military service. Veteran’s disability compensation, unlike a veteran’s pension, is not a needs-based program and does not consider the resources or other income available to the veteran or his household. The amount of basic benefit paid ranges from $144 to $3,458 per month, depending on the severity of the disability and the number of dependents in the veteran’s household.
Section 8.5 Health & Long Term Care Services for Veterans in Central Ohio
Ohio is part of Region 10 in the Veterans Integrated Services Network (VISN). It has four full Medical Centers, one Ambulatory Care Center, two Outpatient Clinics and one Community Based Outpatient Clinic, as well as many smaller clinics which are attached to these larger health centers. Each provider has a different set of services.

The VA does not coordinate services with any other payer such as Private Insurance, Medicare, Medicaid or Workers Compensation but a veteran can be receiving these benefits and still be eligible for health care in a veterans’ hospital or clinic. Many of the Veterans Health Centers also offer Geriatrics and Extended Care services for those veterans who qualify.

In Central Ohio, there are 2 large VA Medical Centers (both have smaller clinics associated with them):

**The Chalmers P. Wylie VA Ambulatory Care Center**
420 N. James Rd, Columbus, OH 43219
614-257-5200 or 888-615-9448

**Chillicothe VA Medical Center**
17273 State Route 104, Chillicothe, OH 45601
740-773-1141 or 800-358-8262

Geriatrics and Extended Care at The Chalmers P. Wylie VA Ambulatory Care Center — 614-257-5200 or 888-615-9448

**Home Based Primary Care Program (HBPC)**
The main care provider in this program is a Nurse Practitioner who sees a veteran at home. Other members of the team that come to the home are a nurse, social worker, mental health provider, and dietitian. HBPC is for veterans who have trouble coming to the clinic because of their health care problems.

**Palliative Care Clinic**
Veterans are seen in the Palliative Care Clinic for advanced illness. The team includes a physician, nurse, social worker, and chaplain. The team helps manage symptoms such as pain. They also help veterans plan their goals for care. Veterans in this program will continue to see their primary care provider.

**Community Hospice Care**
Hospice is comfort care in the home for veterans who are near the end of life. VA staff will set up care with Hospice programs in the community.

**Community Nursing Home Care**
VA pays for nursing home care for some Veterans. Staff visit veterans in nursing homes to make sure their needs are being met.
Adult Day Health Care (ADHC)
Veterans who need help in caring for themselves can go to an ADHC Center which provide: care during daytime hours, nursing services, meals and snacks, as well as the chance to be with other people and be active.

Homemaker/Home Health Aid Program (H/HHA)
H/HHA program sends an aide to the home to help with bathing and/or dressing. After these tasks are done, the aide can also help with light housework. The VA works with home care agencies in the community to offer this service.

The Care Coordination/Home Tele-Health Program (CCHT)
CCHT provides monitoring equipment in the Veterans home to collect daily vital signs and health information. A nurse or social worker gets this information and works with your provider for any needed changes in care. This program can help to prevent hospital or ER visits. Examples of medical problems that are followed in this program include:

- Congestive Heart Failure (CHF)
- Depression
- Chronic Obstructive Pulmonary Disease (COPD)
- Bipolar Disorder
- Diabetes Mellitus (DM)
- Substance Abuse
- Hypertension (HTN)
- Schizophrenia
- Coronary Artery Disease (CAD)
- PTSD

The Spinal Cord Injury and Disorders Clinic (SCI&D)
SCI&D serves Veterans with Spinal Cord Injuries, Multiple Sclerosis (MS), and Amyotrophic Lateral Sclerosis (ALS) or Lou Gehrig’s Disease. All Veterans get a yearly exam with regular follow-up by the team. The SCI team includes a neurologist, physiatrist, physical therapist, nurse and social worker. The team works to improve the quality of life of individuals with SCI & D.

Geriatric Evaluation Clinic
This service provides a one-time appointment for older Veterans with many health care needs. The Veteran is seen by a physician, physical therapist, nurse, and social worker. The team provides the Veteran and the VA primary provider with advice for a plan of treatment. Community services may also be arranged.

Community Health Nurse
VA Nurses arrange for Veterans who are home bound to receive nursing and therapy services from community home health agencies The primary provider refers Veterans for this type of care.

Respite
This service provides caregivers with a short-term break from the daily demands of caring for a chronically ill Veteran. Veterans may stay at a VA community living center or attend an Adult Day Health Care setting for up to 30 days per year.
Section 8.6 Two Additional Benefits: Home Improvement & Structural Alternations & Automobile Adaptive Equipment

Adapted Housing Grants for Disabled Veterans

- Veterans with service-connected disabilities or Veterans with non-service-connected disabilities may receive assistance for any home improvement necessary for the continuation of treatment or for disability access to the home.

- A housing grant is available to Veterans who have received a medical determination indicating that improvements and structural alterations to the home are necessary or appropriate for the effective treatment of his/her disability. A Veteran may receive either a Special Home Adaptation (SHA) grant or a Specially Adapted Housing (SAH) grant.

For more information, go to www.va.homeloans/adaptedhousing

- Examples of what the housing grants will pay for include:
  - Allowing entrance or exit from Veteran’s home
  - Improving access for use of essential lavatory and sanitary facilities
  - Improving access to kitchen and bathroom counters
  - Handrails
  - Lowered electrical outlets and switches
  - Improving paths or driveways
  - Improving plumbing/electrical work for dialysis patients

Automobile Adaptive Equipment (AAE)

- The Automobile Adaptive Equipment (AAE) program permits physically challenged persons to enter, exit, and/or operate a motor vehicle. Veterans are trained, through the VA Driver’s Rehabilitation Program, how to safely operate their vehicle with a disability.

- The VA also provides necessary equipment such as platform wheelchair lifts, UVLs (under vehicle lifts), power door openers, lowered floors/raised roofs, raised doors, hand controls, left foot gas pedals, reduced effort and zero effort steering and braking, and digital driving systems.

- Additionally, VA’s program provides reimbursements for standard equipment including, but not limited to, power steering, power brakes, power windows, power seats, and other special equipment necessary for the safe operation of an approved vehicle.

For more information on these and other disability related benefits, go to www.prosthetics.va.gov.

Section 8.7 Death Benefits for Veterans

Funeral and Burial Expenses

- **Service-Related Death:** VA will pay up to $2,000 toward burial expenses for deaths on or after September 11, 2001. If the Veteran died before September 11, 2001, the maximum
service-connected burial allowance is $1,500. If the Veteran is buried in a VA national cemetery, VA may reimburse some or all of the costs of transporting the deceased Veteran’s remains.

- **Non-Service-Related Death:** The VA will pay a limited amount towards both burial and funeral expenses for veterans who die of not service connected circumstances. The amount is higher if the person dies in a VA connected facility. VA burial allowances are flat-rate monetary benefits that are generally paid at the maximum amount authorized by law for an eligible Veteran’s burial and funeral costs. A VA regulation change in 2014 simplified the program to pay eligible survivors quickly and efficiently. Eligible surviving spouses of record are paid automatically upon notification of a Veteran’s death, without the need to submit a claim. VA may grant additional benefits, including the plot or interment allowance and transportation allowance, if it receives a claim for these benefits.

**To Apply:**

- You can apply by filling out VA Form 21-530, Application for Burial Benefits. You should attach a copy of the veteran’s military discharge document (DD 214 or equivalent), death certificate, funeral and burial bills. They should show that you have paid them in full.

**Veterans Cemeteries**

- **All veterans are entitled to a free burial in a national cemetery and a grave marker.** This eligibility also extends to some civilians who have provided military-related service and some Public Health Service personnel, spouses and dependent children. There are no charges for opening or closing the grave, for a vault or liner, or for setting the marker in a national cemetery. The family generally is responsible for other expenses, including transportation to the cemetery.

- For more information, visit the Department of Veterans Affairs’ website at www.cem.va.gov. To reach the regional Veterans office in your area, call 800-827-1000.

There are 5 national cemeteries in Ohio but only 2 are open for new burials. They are:

- **Dayton National Cemetery**
  
  VAMC, 4100 W. Third Street  
  Dayton, OH 45428-  
  Phone: (937) 262-2115

- **Ohio Western Reserve National Cemetery**
  
  P.O. Box 8, 10175 Rawiga Road  
  1088 Rittman, OH 44270  
  Phone: (330) 335-3069

Ohio also has one state Veterans Cemetery that receives federal funding:

- **Ohio Veterans Home Cemetery**
  
  416 Columbus Avenue  
  Sandusky, Ohio 44870  
  419-625-2454 x200
Memorial Markers

- Memorials are available to all veterans, spouses, and dependent children buried in a national cemetery and will be set without charge. For veterans who died before September 11, 2001, markers are available to them, not to the spouse or dependents, for use in other cemeteries unless the grave has already been marked by a private memorial.

- For veterans who died on or after Sept. 11, 2001, the government will provide a headstone even if the grave already has a private marker. The installation cost must be borne by the family when in a non-government cemetery. Several styles of markers are available and must be consistent with existing monuments. Markers for cremains are also available.

- Inscription must include name, branch of service, year of birth, year of death—in this order—and may include emblem of belief, rank, and decorations earned. At private expense, additional items—such as nick-names and terms of endearment—may be added but must be approved by the VA.

- A flag is provided on request for the burial of any veteran. Apply through the VA and pick up at a U.S. Post Office. Family members may wish to purchase a flag case for later display, available through private sources.

point of fact
Beware of commercial cemeteries that advertise so-called “veterans’ specials.” These cemeteries sometimes offer a free plot for the veteran, but charge exorbitant rates for an adjoining plot for the spouse, as well as high fees for opening and closing each grave. Evaluate the bottom-line cost to be sure the “special” is as economical as you may be led to believe.
Navigating the Health Care Maze

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**Section 1: The Hospital Setting**

**Section 1.1 How to Watch for Someone’s Best Interest in the Hospital**

- **As a caregiver, you are often in the role of advocate** for the person being served by the hospital. You are in the best position to inform the hospital staff of the person’s likes and dislikes. Often you are the one who communicates how he/she really feels and what he/she would want done.

- **Ask questions about the hospital’s schedule** including when the doctors usually visit patients on your floor, the hospital’s visiting policies, meal policies/choices as well as when the staff change shifts on that floor.

- **Families sometimes are not aware** that hospital nurses are not allowed to change a prescription once a physician has written it. If a medication has been ordered to have a strict 4-hour schedule for example, a nurse would not be allowed to give it sooner if a person were in serious pain without calling the physician and getting it changed. Therefore, you can ask the attending physician to write prescriptions for some medications to be taken on a PRN basis instead of on a strict schedule. These medications may include: pain, anti-nausea, anti-anxiety, and insomnia relief medications.

- **You may wish to consider the number and frequency of visitors your loved one receives.** Often visitors do not understand how tiring their visits can be for someone who is ill. On the other hand, if your relative is lonesome and wants visitors, you may have to arrange for people to come and see the person in a manner that provides both pleasure and comfort to your relative.

- **Although it may sound odd,** you do not need to permit a patient’s body to be used as a teaching tool. You can express your preferences to limit the number of medical/health care students involved in the care of your loved one.

- **Label all belongings and inform the hospital staff that the person has brought the items.** You may even want to make a list of what the person has brought to the hospital. If something has great value (like a wedding ring for example) you may want to leave it at home rather than risk having it misplaced in the busy hospital setting.

- **Ask for a consultation with the discharge planner on the day of admission to the hospital or as early in the stay as possible.** This is especially important if the person will need home care arrangements after hospitalization or will need a stay in a rehabilitation facility.
• **If a person is confused or has an illness causing dementia**, hospital stays can be very disruptive and stress producing. The Alzheimer’s Association of Central Ohio has produced a fact sheet for those facing this experience. It is called **Hospitalization: Tips to Make it Easier for a Patient with Memory Loss**. For more information you can call the Association at 614-457-6003 or 800-441-3322 or visit their website at [www.alz.org/centralohio/](http://www.alz.org/centralohio/).

### Section 1.2 Your Hospital Rights Under Medicare

- **Medicare pays hospitals a specified amount depending** on the person’s diagnosis not on the number of days a person stays. Under this system, Medicare has set up a means of maintaining patient rights.

- **Date of Discharge**: When your doctor determines that you can be discharged from the hospital, you will be advised of this date. Ask for this **information in writing** from the hospital. You may appeal if you think you are being asked to leave the hospital too soon.

- **Immediate Appeal**: KePRO is the organization authorized by Medicare to provide a second opinion about your readiness to leave.
  - You may call them toll-free, 24 hours a day at **855-408-8557**.
  - If you call them to file an appeal **by noon on the next day after you receive the Notice of Discharge** from the Hospital, you are **not responsible** for paying for the days you stay in the hospital during KePRO’s review.

- **Other Appeal Rights**: If you miss the deadline for filing an immediate appeal, you may still request a review by KePRO before you leave the hospital. However, you will have to pay for the costs of your additional days in the hospital if KePRO denies your appeal.

In addition, if you are dissatisfied with care you are currently receiving or have received in the past, you can also file a complaint with KePRO ([www.keproqio.com](http://www.keproqio.com)).

### Section 2: Visits with Healthcare Providers

#### Section 2.1 Tips to Maximize a Visit

- **Get ready for your appointment:**
  - **Write down all your concerns**, health issues, medications, allergies and any questions you have for the provider. Putting issues in writing helps to remind you to bring them up during the visit. Sometimes it helps to take along someone else to the visit.
  - **Call the office and see if they are running behind**. Get an idea if your appointment will be delayed and if so, see if you can come at a time closer to when you will be seen.
- **Share all relevant information** with your health care provider. Be frank about problems you are experiencing, describe your symptoms, describe your habits, and share your concerns. Health care providers need to have as much information as possible to help you make the right choices.

- **Get the right information.** Ask for clear explanations of diagnosis or conditions, treatment options and medications. Write down what you hear and repeat it back to the provider. Make sure your questions are answered.

**Section 2.2 Your Right to Privacy**

- **In 1996, the Health Insurance Portability & Accountability Act (HIPAA) was passed.** Its purpose was to standardize the billing and privacy practices across the health care industry. All health care providers who transmit any health information in electronic form are covered entities and must follow the privacy practices outlined by HIPAA.

- **Protected Health Information (PHI)** includes diagnosis, medications, drug allergies, drug/alcohol history, the names of other health professionals involved in care, cognitive status, caregiver information, and past history of hospitalizations.

- **Every health care provider has to notify patients of their right to privacy** with a Notice of Privacy Practice Document (NPP). This document states that the protected health information will be used only for the purposes of treatment, payment or business operations. Permission to disclose information for any other purpose must be obtained in writing from the patient.

- **The health care provider MAY discuss** protected health information with the individual’s personal representative (legal guardian or power of attorney for health care) without any additional authorizations being obtained.

**Section 2.3 Understanding Medical Instructions and Jargon**

- Sometimes a family is confused about the name of a procedure or medical instructions. Medical terminology is not always easy to understand or interpret. People who work in the medical field sometimes forget that they do not use everyday language. **Not knowing a term or word is perfectly normal.**

- You have the right to have procedures and medical instructions explained to you in plain language. Do not hesitate to ask for clarification!
Section 3.1 Hospice vs. Palliative Care

- **Hospice care and palliative care are very similar when it comes to the most important issue for very sick people: they both emphasis comfort FIRST.** Most people have heard of hospice care and have a general idea of what services it can provide. What they don’t know or what may become confusing is that palliative care can be both a method of administering “comfort” care and a system of services offered **usually by hospitals or other medical systems.** Both hospice and palliative care call for persons to receive care through a single program that concentrates on the person’s comfort. Where palliative care programs and hospice care programs **differ is in the place of treatment, timing, and type of treatment.**

- **Place of Treatment**
  - **Hospice**
    Generally, once enrolled through a referral from the primary care physician, hospice care is administered in the person’s home or place of residence (even in a long-term care facility). Hospice treatment often relies upon family caregivers, as well as a visiting hospice nurse and other professionals to keep a person as comfortable as possible. While a hospice program can provide care in a hospice facility, or a hospital, this is **not** the norm.

  - **Palliative Care**
    Palliative care teams are made up of doctors, nurses, and other professional medical caregivers, often **AT** the health care facility where a person is receiving treatment for an illness or condition. These individuals will administer or oversee most of the ongoing comfort-care that the person will receive.

- **Timing of Treatment**
  - **Hospice**
    A person must generally be considered to be terminal or within six months of death to be eligible for most hospice programs or to receive hospice benefits from Medicare, Medicaid, and other insurance carriers.

  - **Palliative Care**
    There are no time restrictions. Palliative care can be received by persons at any time, at any stage of illness whether it be terminal or not.
• **Type of Treatment**

  - **Hospice**
    The concentration is on comfort rather than aggressive disease treatment. Persons on hospice elect to forego or stop extensive life-prolonging treatments and concentrate on staying comfortable in the time they have left.

  - **Palliative Care**
    Since there are no time limits on when a person can receive palliative care, it acts to fill the gap for persons who want and need comfort at any stage of any disease, whether terminal or not. In a palliative care program, there is no expectation that life-prolonging therapies will be avoided or stopped.

*Adapted with permission from [www.caregiverslibrary.org](http://www.caregiverslibrary.org).*

**Section 3.2 Hospice Care**

**Section 3.2a Eligibility**

- Under Medicare, and most other insurance carriers, people are eligible for the Hospice benefit if two physicians certify that they have a life expectancy of six months or less if the disease runs its normal course. Some indications that people may meet this criteria include:
  - Progressive decline in functional status despite curative treatments
  - Frequent hospitalizations or Emergency Room visits
  - Repeat or multiple infections
  - Increased or uncontrolled pain
  - Progressive/profound weakness and fatigue
  - Shortness of breath with or without oxygen
  - Dependency (decrease in Activities of Daily Living)
  - Alterations in mental status
  - Weight loss

**Section 3.2b Typical Kinds of Services**

- Generally, someone must enroll in a Hospice program which is listed as a provider for either Medicare or the insurance company.

- **Important**: Medicare and other insurance companies will still pay for covered benefits for any health problems that aren’t related to the terminal illness, such as care for an injury.
• Medicare and most insurance covers the following hospice services when they’re needed to care for the terminal illness and related condition(s):
  - Doctor services
  - Nursing care
  - Medical equipment (such as wheelchairs or walkers)
  - Medical supplies (such as bandages and catheters)
  - Drugs for symptom control or pain relief
  - Hospice aide and homemaker services
  - Physical and occupational therapy
  - Speech-language pathology services
  - Social worker services
  - Dietary counseling
  - Grief and loss counseling for person and the family
  - Short-term inpatient care (for pain and symptom management)
  - Short-term respite care
  - Any other Medicare (or insurance)-covered services needed to manage pain and other symptoms related to the terminal illness, as recommended by the hospice team

Section 3.2c. What Is Not Generally Covered

• When someone chooses hospice care, they have decided that they no longer want care to cure their terminal illness and/or their doctor has determined that efforts to cure the illness aren’t working. Medicare and most insurance will not cover any of the following once someone chooses hospice care:
  - Treatment intended to **cure** the terminal illness.
  - Prescription drugs to cure the illness (rather than for symptom control or pain relief).
  - Care from any hospice provider that wasn’t set up by the hospice medical team. A person must get hospice care from the hospice provider they chose. A person can’t get the same type of hospice care from a different provider, unless they change the hospice providers. However, they can still see their regular doctor if they have chosen him/her to be the attending medical professional who helps supervise the hospice care.
  - Room and board—Medicare and other insurance doesn’t cover room and board if someone gets hospice care in their home or if they live in a nursing home, assisted living facility, or a group home.
- Care in an emergency room, inpatient facility care, or ambulance transportation, unless it’s either arranged by the hospice team or is unrelated to the terminal illness.

**Note:** A person must contact the hospice team before getting any of these services or he/she might have to pay the entire cost.

**Section 3.2d How Long A Person Can Get Hospice Care**

Hospice care is intended for people with 6 months or less to live if the disease runs its normal course. If someone lives longer than 6 months, they can still get hospice care, as long as the hospice medical director or other hospice doctor recertifies that they are still terminally ill. **Important:** Hospice care is given in benefit periods. A person can get hospice care for two 90-day periods followed by an unlimited number of 60-day periods.

**Section 3.2e Stopping Hospice Care**

If someone’s health improves or their illness goes into remission, they no longer need hospice care. Also, they always have the right to stop hospice care at any time for any reason. If someone stops their hospice care, they will get the type of Medicare or insurance coverage they had before they chose a hospice program (such as treatment to cure the terminal illness). If someone is eligible, they can go back to hospice care at any time.

For more information on Hospice care go to [www.leadingage.org](http://www.leadingage.org).

For a list of Hospice providers in Central Ohio, go to [www.coaaa.org](http://www.coaaa.org) and under the “Resource” section, download the booklet “Long Term Care and Hospice Guide.” An assessment by any Hospice provider is free and Medicare and other insurances cover most Hospice providers.

## SECTION 4: MEDICATION MANAGEMENT

**Section 4.1 Safe Medication Use**

Many older adults are on multiple medications to treat health conditions. Below are some tips to help use medications safely:

- **Get all prescribed medications at the same pharmacy** so the pharmacist can maintain an up-to-date list and check for potential problems.
- **Read the medication label and inserts** carefully for special instructions like avoiding certain foods, other medications and possible side effects.
- **Never increase or decrease** a medication’s dosage without checking first with a person’s doctor.
• **Give medications with a full glass of water** unless the written instructions say to do otherwise.

• **Don’t crush or chew pills** or capsules unless you check with the pharmacist first. Many medications have a coating to protect the throat or stomach lining. A crushed pill could release all the medicine at one time instead of the way it is intended.

• **Don’t cut pills in half unless they have a line** across the middle to show they can be broken and you have checked with the pharmacist. Ask the pharmacist if the pills come in smaller dosages.

• **Throw away** all medications that are past the expiration date.

• **Store all medications in a cool, dry area.** Some bathrooms may be too warm and damp for medications.

• **Pay attention to Over the Counter (OTC) medications, vitamins, and herbal products.** These include some pain relievers, anti-inflammatory medications, cough syrups, cold medications, antacids, and allergy medications. Though these medications are generally considered safe, they can cause reactions with other medications. **It is also possible that an excess amount can be toxic.** When in doubt, ask your doctor or pharmacist.

• **Use a pill box or container to keep track of which medications need to be taken at different times of the day.** Most of these can be pre-loaded a week at a time. Sometimes these have color coded slots for several times during a day. There are also multi alarm boxes, talking medication bottles and other assistive devices that can help.

### Section 4.2 Questions About a New Medication

Ask Your Doctor or Pharmacist:

• How and when do I take this?

• What is this medicine for?

• Are there any risks or side effects to taking this medicine?

• What should I do if I experience a side effect?

• Will this medicine work safely with the medications I am already taking?

• What food, drink, other medicines or activities should I avoid while using this medicine?

• Will this medicine affect my sleep or activity levels?

• Are there other special instructions?

• What should I do if I miss a dose?

• Is there a generic (not a brand name) of this medicine available?
Section 4.3 Keeping a Record

It is a good idea to keep a record of all medications a person is taking. Always bring it with you to doctor appointments. You can keep it in a chart form or a list form.

For Example:

Medication Dosage When to Take It?

<table>
<thead>
<tr>
<th>Medication</th>
<th>Dosage</th>
<th>When to Take it?</th>
<th>Physician</th>
<th>Date</th>
<th>Color &amp; Shape</th>
<th>Special Instructions</th>
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Other Information to Put in a Written Medication Record:

- The person’s date of birth.
- Pharmacy name(s) and phone number(s).
- Medications previously used and stopped.
- All current doctor names and phone numbers.
- Over the counter medications, vitamins, and any herbal medications taken recently or currently.
- Known allergies.
- Last immunization dates.
- Date the form was last updated.

Section 5: Avoiding Abuse, Neglect and Exploitation

Abuse can take many forms—physical, sexual, psychological, and financial exploitation, and can include neglect. The issue of abuse and neglect cuts across all racial, ethnic, socioeconomic, geographic, and relationship boundaries. A national study estimates that one in every 25 older Americans is a victim of abuse.

Abuse, neglect and exploitation can come in many forms; from both family and friends who are providing care and from those who are paid to provide care.

While most caregivers intend no harm, abuse and neglect happen more often than we think. Caregiving requires health care and emotional support, which can be demanding work. Caregivers perform these tasks under working conditions that can be stressful, and
caregivers may receive little support from others. They may also find themselves the target of abuse from the individual or other family members. As stress increases, so does the potential for abuse. For whatever reason it occurs, abuse and neglect are harmful.

Section 5.1 Different Types
- **Physical abuse**: Inflicting or threatening pain or injury, or depriving a person of basic needs
- **Emotional abuse**: Inflicting mental pain or distress through verbal or nonverbal acts
- **Sexual abuse**: Touching, fondling, intercourse, or any other sexual activity with an adult, when the adult is unable to understand, physically forced, threatened or unwilling to consent
- **Financial Exploitation**: Illegal taking, misuse, or concealment of funds, property, or assets
- **Neglect by others/self**: Failure by those responsible to provide food, shelter, health care, or protection. Also includes the failure to perform essential self-care tasks, which can lead to illness or injury.

Section 5.2 Recognize the Warning Signs
- Changes in the older adult’s physical **appearances**
- Changes in the older adult’s **personality**
- Observing a dominating or threatening **care giver**
- Observing changes in the older adult’s **home environment**

Section 5.3 Prevention

5.3a Prevention of Victimization by family and friends
- Many times abuse of older adults by family and friends can arise from stress, caregiver burnout and a lack of knowledge about how to provide care. This booklet has chapters which cover all of these topics.
- Family caregivers also often need assistance and support from others. Those in extended families, churches, community groups and neighborhoods can reach out and offer support and assistance. This is particularly true in situations with memory impairment.
- **Those** who become concerned about an older adult’s well being can and should report their concerns to one of the resources listed below. For situations of immediate danger or suspected theft, those in law enforcement should be contacted.

5.3b Prevention of Victimization by Paid Caregivers
- **Older** adults can be **victimized** by home care workers in a number of ways. Some **examples** include: wasting time instead of doing tasks, making personal phone calls, watching television rather than doing a task, stealing money or articles from the home, borrowing money or articles from the person.
• The older adult may **respond** in a number of ways. Common **responses include**: not realizing or acknowledging what is happening, feeling sorry for the worker and continuing to allow the behavior, fearing reprisal if he/she reports the worker.

• **Families** need to be **very vigilant** to prevent victimization. Often the methods used are **not obvious** to the casual observer.

• **Two very effective techniques** to prevent victimization include the **use** of a **task check sheet** and **frequent unannounced visits** to the older relative’s home. Older adults are much less likely to be taken advantage of if the worker knows there are people watching the situation closely.

**Section 5.4 Resources:**


• **ProSeniors** provides a free Legal Hotline for information, advice and referrals for Ohioans age 60 and older. Call 800-488-6070 or visit [www.proseniors.org](http://www.proseniors.org).

• **Ohio Department of Aging, Long-Term Care Ombudsman** provides advocacy for Ohioans receiving home care, assisted living and nursing home care. Call 800-282-1206 or visit [www.aging.ohio.gov/services/ombudsman](http://www.aging.ohio.gov/services/ombudsman)

• **Ohio Department of Job and Family Services, Adult Protective Services** helps vulnerable adults age 60 and older who are in danger of harm, are unable to protect themselves, and may have no one to assist them. Call 855-OHIO-APS or visit [www.jfs.ohio.gov](http://www.jfs.ohio.gov) and search using the term “Adult Protective Services”.
Caring for Someone at Home

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6. Emergency Contact Information
7. Disaster and Emergency Resources
Section 1.1 Getting Professional Input

Look for professional input on ideas to modify your home. Some professionals who can provide you information include:

- Occupational Therapists
- Physical Therapists
- Recreational Therapists
- Rehabilitative Design Consultants.

Medicare and insurance will sometimes pay for professional advice. However, first you will need to ask your physician for a written referral.

Section 1.2 Making The Home Safer/Modifying the Home

A family should **pay particular attention** to **safety** of the living area (especially if it is a house or apartment, built many years ago).

- **Modifications can vary from simple** and very inexpensive to very extensive and expensive. Sometimes all that will be required is a change in traffic patterns.
- **Reducing clutter** is perhaps one of the most helpful modifications in most homes. Families can be very creative in adapting the living space to meet their relative’s needs.
- **Sometimes families are reluctant** to make changes to the living environment because they feel it will change the **resale value** of the home. However, most changes today can be made in a way that they can either be easily removed or can actually increase the value of the home.
- **Many changes** might be tax deductible.
- **Universal Design** is a term which refers to the process of designing homes and products that will be usable by everyone and not have to be modified to accommodate a disability. The principles of universal design are becoming more popular in the building and design fields. If you are building or renovating a space, you may want to consult some information about universal design features.
- Helpful websites include [www.disabilityresources.org](http://www.disabilityresources.org), [www.homemods.org](http://www.homemods.org) and [www.aarp.org](http://www.aarp.org).
Section 1.3 Safety in the Home: Questions to Consider

Lighting
- Is the lighting adequate but not glare-producing?
- Are the light switches easy to reach and to turn on?
- Can lights be turned on before entering rooms?
- Are night-lights used in appropriate places?

Hazards
- Are there throw rugs, highly polished floors or other hazardous floor coverings? If so, where?
- Can they be removed or made less hazardous?
- Do area rugs have non-slip backing and are the edges tacked to the floor?
- Are cords, clutter or other obstacles in the pathways? If yes, can they be cleared?
- Are doorways wide enough to accommodate assistive devices?
- Do door thresholds create hazardous conditions?
- How does the person obtain objects from hard to reach places? (Chairs can be hazards.)

Furniture
- Are chairs the right height and depth for the individual?
- Do chairs have arm rests?
- Are tables sturdy and won’t tip if leaned on?
- Is small furniture placed away from pathways?

Stairways
- Are there light switches at the top and bottom of the stairs?
- Are there securely fastened handrails on both sides of stairs?
- Are all the steps even?
- Should colored tape be used to mark the edges of the steps, particularly the top and bottom?

Bathroom
- Are grab bars placed appropriately for the tub and toilet?
- Does the tub have skid proof straps or a rubber mat in the bottom?
- Is there a tub or shower seat available?
- Can the shower head be replaced by a hand held shower head?
- Is the height of the toilet appropriate?
Bedroom

- Is the mattress firm enough at the edges to provide enough support for sitting?
- If the bed has wheels, are they locked securely?
- Would side rails be a help or a hazard?
- When side rails are down, are they completely out of the way?
- Is the pathway between bedroom and bathroom clear of objects and well lighted at night?
- Would a bedside commode be useful, especially at night?

Kitchen

- Are storage areas used to the best advantage, e.g., frequently used objects in the most accessible places?
- Are appliance cords in good condition and out of the way?
- Are non-slip mats used in front of the sink & refrigerator?
- Are the markings on stoves and other appliances clearly visible?

Emergency

- Is an emergency response system available (911)?
- Does the person know how and when to use it?
- Would a private emergency call service be helpful?
- Is the person’s vital information listed in a place where it would be accessible in an emergency?

Temperature

- Is the temperature comfortable for the person?
- Can the person read the marking on the thermostat and adjust it?
- Is water temperature less than 110 Fahrenheit?
- During hot weather, is there adequate ventilation?
- During cold weather, is the furnace working properly?
Section 1.4 Caregiver US Income Tax Considerations

Under certain circumstances, the caregiver can qualify for income tax benefits that offset their expenses as a caregiver. These tax “breaks” include claiming the person in care as a dependent and receiving a “dependent care credit.” For the older person, certain tax credits also apply and some expenses are deductible.

When a Person Qualifies as a Dependent for Income Tax Purposes

Five tests must be met:

- The person does not earn more than a specified amount of gross income, adjusted each year to match the personal exemption.
- The taxpayer provides more than one-half of the person’s support.
- The person has one of the following relationships with the taxpayer: child, sibling, parent, grandparent, aunt, uncle, niece or nephew, in law, grandchild, great-grandchild, stepparent or child OR the person lived in the taxpayer’s home during the entire tax year and is a member of the taxpayer’s household.
- The person did not file a joint return with a spouse.
- The person is a citizen, national or resident of the United States, Canada or Mexico.

Tax Credit for an Elderly or Disabled Person

- A tax credit may be available to persons who are 65 or over or who are permanently or totally disabled. Special rules and procedures apply for calculating the amount of the credit. See IRS guide #554 Tax Guide for Seniors (2017). The website is www.irs.gov.

What Can Be Deducted for Income Tax Purposes?

- If a person can be claimed as a dependent and the caregiver itemized expenses on his/her tax returns, the caregiver may deduct medical expenses that exceed 7.5% of his/her adjusted gross income (2017).

Other Possible Deductible Medical Expenses

- Improvements or additions to the home for medical purposes (to the extent that they do not increase the value of the property)
- Expenses of a guide dog
- Lodging while away from home for a medical reason (meals not deductible)
- Medical insurance (long term care and supplemental policies-with limitations)
- Nursing home expenses (with type of care limitations)
- Transportation costs to take a person to medical care
Section 2.1 Hiring In-Home Assistance

Section 2.1a Agency vs. Individual Considerations

Families often wonder whether they should look towards an agency to provide services or hire individuals to provide them. There is no right or wrong answer and every family should find a solution which best meets its individual situation.

Possible Advantages of Hiring an Agency:

- Some types of care may be covered by Medicare, Medicaid or Other Medical Insurance.
- The agency will conduct an assessment by a professional and develop a plan of care to monitor your relative’s progress.
- The agency will probably be able to provide more than one type of assistance or refer you to other providers if your relative requires more kinds of care.
- The agency can communicate with your doctor and alert him/her to any problems which may develop.
- The agency will pay employee salaries, taxes, insurance and other benefits.
- The agency will provide supervision and training to employees.
- The agency will send a replacement if the regular employee is sick.

Possible Advantages of Hiring an Individual:

- The kinds of assistance provided may be more flexible.
- The hours may be more flexible.
- It may be less expensive if paying privately (i.e., not Medicare, Medicaid, or Insurance).
- The family member receiving assistance may be more accepting of an individual rather than an agency.
- The family may prefer direct supervision of the individual(s) in the home.

There is no right or wrong answer when deciding between an individual or service, and every family should find a solution which best meets the individual situation.

Section 2.1b What to Ask an Agency

- How long has the agency been operating?
- What services does the agency provide?
- Is the agency licensed to operate in the state? (Not all states require agencies to be licensed. Licensure is usually through the state Department of Health.)
- Is the agency accredited? (This is voluntary, but does indicate the agency has met national industry standards.)
• Is the agency certified by Medicare? (Medicare-certified home health agencies have met federal minimum standards and can receive Medicare and Medicaid payment for some services.) Keep in mind agencies may choose not to become Medicare-certified and still provide high quality care.
• Is caregiving staff available 24 hours, 7 days a week?
• What are the fees? What do they cover?
• What payment sources does the agency accept? (Private self-pay, Medicare, Medicaid, Insurance)
• What services are covered by my insurance, Medicare, Medicaid?
• How are agency employees screened prior to employment?
• Are all agency employees bonded and insured?
• What kind of training/certification do employees receive?
• Who supervises the employees? How often?
• Does the agency require a nurse or therapist’s assessment of the patient’s home care needs?
• Does the agency consult the patient’s doctor regarding the patient’s care plan?
• Does the agency include the patient and family in care planning?
• Are there a minimum number of hours required per visit?
• Is there a maximum number of hours that can be scheduled per week?
• Does the agency provide written statements that explain costs and payment options?
• How does the agency handle emergencies?
• How does the agency handle changes in staffing/schedules?

Request and call agency references
In addition to former clients, these might include referring entities such as hospital or nursing facility discharge planners, doctors, and community home care programs.

Section 2.1c Tax Insurance and Personal Considerations

US Tax Rules
• If you pay more than $2,000 in a calendar year (2017) to someone who comes into your home, you are required to pay Medicare and Social Security tax for that individual.
• You may use form 1040 to file and pay the tax. More information is found in the IRS booklet titled (#926): Household Employer’s Tax Guide or at the Internal Revenue Service Web Site (www.irs.gov).

Insurance Considerations
• Check your own (or your older relative’s) home owner’s insurance and confirm that there will be coverage if there is an accident or injury in the home.
• Check that the person has some insurance for malpractice or liability.
• If the person will be driving an older family member, check that the person has liability insurance.

**Personal Issues**

• Decide whether the individual has the personality type to meet the emotional needs of your older relative(s).
• Consider the individual’s personal habits for compatibility with your older relative(s).
• Find out if the individual is a smoker or not.

**Section 2.1d Checking Backgrounds & References**

• Families should always consider having a criminal background check and driving record check on individuals they will be bringing into the home. If you are hiring an agency, ask if they do criminal background checks. Be very cautious about hiring the agency if they do not check out their personnel thoroughly.
• Families should also ask for references and call to check them.

**Possible Questions to Ask References Include:**

• How long have you known the individual?
• Did the individual work for you?
• Is the individual punctual, reliable, trustworthy, patient and courteous?
• How does the individual handle stress, conflicts and emergencies?
• How well does the person follow instructions requests and suggestions?

**Background Checks on Home Care Workers – Resources to Help:**

• Ohio Bureau of Criminal Investigation and Information (BCI&I) has a WebCheck – electronic fingerprinting system; can do both State of Ohio and National (FBI) background checks.
• Available through county sheriff’s offices, some police departments, some Ohio DMV agencies. For other agencies offering the service go to: [www.ohioattorneygeneral.gov/webcheck](http://www.ohioattorneygeneral.gov/webcheck).
• Fees vary slightly; approximate cost $60 for both Ohio and National WebChecks.

**In Franklin County: Community Care Registry (CCR) (phone 614-525-4161 or www.officeonaging.org)**

• A registry and referral service provided by the Franklin County Office on Aging.
• A free service that assists individuals and families with finding and hiring self-employed home care workers. Provides information on pre-screened, experienced home care workers whose qualifications, availability, and service fees match the needs of those seeking help with care.
• Program participants interview and select the home care worker of their choice.
Section 2.2 Managing In-Home Assistance

Section 2.2a Resistance by Older Family Members

Sometimes older family members do not want outside assistance in the home. This resistance can have a variety of sources. It is important to identify the source of resistance before finding ways of overcoming it.

Some common reasons for resistance by an older family member are:

- They lack supervisory skills.
- They have fear and apprehension about strangers.
- They fear loss of control.
- They fear reduced contact with family members.
- They are apprehensive about spending the money for this care.

If you are meeting resistance for any of these reasons, it is best to have a frank discussion with your family member. The purpose and costs of the home care may need to be clarified and compared with other options.

Changes may need to be introduced more slowly and people may need more information to make decisions. Your family may all need to sit down and discuss the concerns and opinions of each member before moving forward.

Section 2.2b Prevention of Victimization

Older adults can be taken advantage of by home care workers in a number of ways.

Some examples include:

- Wasting time instead of doing tasks
- Making personal phone calls
- Watching television rather than doing a task.
- Stealing money or articles from the home, borrowing money or articles from the person.

The older adult may respond in a number of ways. Common responses include:

- Not realizing or acknowledging what is happening.
- Feeling sorry for the worker and continuing to allow the behavior
- Fearing reprisal if he/she reports the worker.

Families need to be very vigilant to prevent victimization. Often the methods used are not obvious to the casual observer.

Two very effective techniques to prevent victimization include:

- The use of a written task check sheet which is signed or initialed by the older individual or a family member.
• Frequent **unannounced visits** to the older relative’s home. Older adults are much less likely to be taken advantage of if the worker knows there are people watching the situation closely.

### Section 3 - Adult Day Health: A Consideration

Many communities have a service available called Adult Day Health Care. The individual lives at home but goes to a center during the day to socialize, do activities and spend supervised time while a caregiver works or engages in other activities away from his/her loved one. Most of these programs are less expensive than 24 hour care and have nursing care and other trained personnel to assist in caring for an individual.

**What does your loved one want or need the service to provide?**

- Supervision
- Social activities
- Assistance with eating, walking, toileting, medication
- Physical, Occupational or Speech Therapy
- Health monitoring (blood pressure, food or liquid intake, weight, blood sugar)
- Nutritious meals/snacks
- Special diet
- Exercise
- Mental stimulation
- Personal care – bathing, grooming

**As the caregiver, in what ways can the adult day service help you?**

- Allow you some free time
- Care for your loved one while you work
- Provide transportation to the center
- Provide practical and emotional support
- Assist in planning for care

**Before visiting a center, call and request brochures with the following information:**

- Eligibility criteria
- Application procedures
- Monthly activity calendar
- Monthly menu

**Questions to Ask an Adult Day Health Program:**

- Who is the owner or sponsoring agency of the adult day center?
- How long has the center been in operation?
- Is the center licensed or certified? (Not required in Ohio.)
• What are the days/hours of operation?
• Is transportation to/from the center available in your area?
• What are the earliest/latest pickup and drop-off times?
• What are the costs for all services including transportation?
• What options exist to assist with the cost of services?
• Can the center serve consumers with memory loss, limited mobility, or incontinence?
• What are the credentials/training of center staff?
• What is the ratio of staff to participants?
• What activities are provided? Are there individual and group activities? Are activities individualized to fit participants’ abilities?
• Meals – can special diets be accommodated? Are meals appealing, balanced?

Make an appointment to visit at least two centers that might meet your needs.
• Did you feel welcomed by center staff?
• Did staff spend time exploring your needs and answering questions?
• Were services, procedures, and costs clearly explained?
• Was the center clean and odor-free?
• Was the entire facility wheelchair accessible?
• Are participants involved in planning activities – their care planning?
• Was the environment comfortable – spacious, well-lighted, comfortably furnished?
• Is there a place to isolate individuals who are ill?

Request references from the centers you are considering and check them out.
• Give your loved one an opportunity to “try out” the center for part of a day.
• Keep in mind it may take several visits for your loved one to become comfortable with the new setting and routine.

Section 4: Products to Assist in Home Care

Listed below are 10 products which can help caregivers provide assistance more safely and effectively at home. This is by no means a complete list and hundreds of products are available either from durable equipment suppliers or through home health catalogs. For information on what may be useful for your situation consult a physical therapist or occupational therapist.

1. Gait or Transfer Belt *(also called lifting strap)*

Description: A gait or transfer belt is worn around the older person’s waist. It provides a secure point for the caregiver to hold while assisting the person in standing, walking or transferring. It is available in a variety of styles. We strongly recommend that you use one.

Cost: $10-$25 Medicare usually does not cover this product.
2. Lifting Belt for Helpers
Description: A lifting belt can be worn by a person when he/she assists someone to transfer. These belts were originally marketed as back protection and support. We know now through research that the belts do not offer protection in and of themselves, but that people who wear them have less back injuries. Researchers suspect this occurs because the belt causes the helper to be more aware of his/her back when he/she wears it.
Cost: $30-$45 Medicare does not cover this product.

3. Sliding Board
Description: A sliding board is approximately 2 feet long and 8-10 inches wide, usually with a handle on one side and one edge slightly sloped. It can be used between surfaces of similar heights as a “bridge” to assist someone to slide from one surface to the other. The person should have some strength in their arms and be able to move him/herself over. Examples are a wheelchair to a raised toilet, a wheelchair to a chair, a bed to a wheelchair, or a wheelchair to a car seat.
Cost: $10-$25 Medicare does not cover this product.

4. Gliding Board
Description: A gliding board is a curved version of a sliding board with a round disk in the middle, which moves the person across its surface. It can make transferring much safer for the person and for the person assisting in the transfer.
Cost: $50-$200 depending on the size. Medicare does not cover in most cases.

5. Draw Sheet
Description: A draw sheet is simply a folded sheet placed under a person who has difficulty turning over in bed. It is folded so that there is approximately 20 inches on each side of the person in bed. One or two caregivers can grasp this extra cloth to carefully reposition the person in the bed. A draw sheet can help avoid putting excessive pressure on the bed-bound person’s skin or bones. It can also ease the strain on the caregiver’s back.
6. Lift Seat or Lift Chair

**Description:** Many manufacturers make assistance devices for chairs. The **portable models** are commonly called lift seats. A person places this device on whatever chair he/she chooses. It commonly has a spring mechanism that assists the person to stand when he/she is ready. Chairs with the lift mechanism **permanently** built into them have the appearance of a regular chair but can mechanically lift to assist the person to stand and sit.

**Cost:** The lift seats (portable models) are $40-$200 and the lift chairs (permanent models) are $600-$1,500. Medicare will cover the motors of the lift chairs but not the lift seats.

7. Mechanical/Hoyer Lift or Hoist

**Description:** A mechanical lift should be used when the person cannot assist at all in a transfer, when he/she outweighs the caregiver, or when the caregiver cannot assist in a transfer for a health reason. Mechanical lifts are used quite often in health care settings. They are large and rather costly. However, having one to assist in transfers may be the only way a person can remain at home. A caregiver should receive professional instruction when renting or purchasing a lift.

**Cost:** $800-$2,000 Medicare can cover this product with a doctor’s order.

8. Standing Lift

**Description:** A standing lift is **smaller and easier to use** than a full size mechanical lift. It assists the person to stand and transfer from a wheelchair to a bed or to a raised toilet seat. It should not be used with someone who cannot assist at all. Standing lifts are relatively new and not available in all places. Caregivers should receive **professional instruction** if they purchase or rent one.

**Cost:** $1,000-$4,000 Medicare can cover this product with a doctor’s order.

9. Walker

**Description:** A device to assist with stability in walking and maneuvering. Can be used in the home or outside it. Walkers come in variety of sizes and colors. Most are square framed though some are shaped like a triangle. Some have wheels and handbrakes, and seats. Others have baskets for carrying items from one location to another. Families should look at a wide variety of walkers before deciding upon one that best fits the person’s needs.

**Cost:** $100-600. Medicare can cover some models with a doctor’s order.
10. Shower Chair/Transfer Bench

Description: These products are designed to either assist a person to transfer into a bathtub or remain seated while taking a shower. They are available in a variety of models, heights and lengths. They fit in most standard tubs or showers and are constructed of sturdy material which is easy to clean and sanitize.

Cost: $50-200. Medicare does not cover this product.

SECTION 5: Pressure Ulcers and Their Care

People who stay in bed or in wheelchairs for long periods of time are at great risk of developing pressure ulcers also called pressure sores or bed sores. These are painful and difficult to heal once they are formed. It is better to prevent them from forming.

Pressure ulcers can be caused when skin is:

- Rubbed or dragged against a surface
- Irritated by urine or feces
- Left in a position for an extended period of time (two hours or more) with limited movement.

Section 5.1 Preventing Pressure Ulcers

- A bed bound person needs to change position at least every two hours and a wheelchair-bound person needs to shift about every 15 minutes.
- When washing an area of the person’s body, PAT—never rub—with a warm soapy wash cloth and PAT an area dry as well.
- Massage areas GENTLY which have been under pressure with lotion to increase circulation and replace moisture.
- Gently clean urine or feces immediately with warm water and soap.
- If incontinence is an issue, avoid using disposable pads that hold the moisture on the skin. A waterproof cloth pad that can be laundered and reused is a good alternative.

Section 5.2 What to Look for:

The first signs of a pressure ulcer include:

- Redness on unbroken skin lasting 15-30 minutes or more. On people with darker skin, the ulcer may appear to look blue or purple. Compare the spot to the same area on the other side of the person’s body.
- A small open area like a cut.
- An abrasion, scrape, blister, or shallow indentation.
- Texture changes—the skin feels mushy instead of firm to the touch.
- A gray or black scab. Beneath the scab may be a pressure ulcer. Do not remove the scab—this could cause infection.
Section 5.3 If You Think a Pressure Ulcer is Developing:

- Remove pressure from the area immediately.
- Recheck the skin in 15 minutes and if the discoloration is gone, no other action is needed.
- If the redness is not gone or an open area develops, call your doctor immediately.
- Do not massage the area or the skin around it if you suspect a pressure sore is developing.
- Do not use a heat lamp, hair dryer, or other “potions” that could dry the skin around the area.

Section 6: Working with Wheelchairs

Section 6.1 Parts of a Wheelchair

Standard wheelchairs usually:

- Are propelled manually
- Have two large rear wheels
- Have two small front wheels
- Have footrests which might fold and detach
- Have armrests which might detach
- Can be folded

Basic parts of standard wheelchairs:

1. Handgrips
2. Soft seat and back (usually vinyl)
3. Armrests
4. Footrests
5. Front wheels
6. Rear wheels
7. Tilt bar
8. Brakes or locks
9. Brake lever

Note:
Standard wheelchairs may have modifications that make them more comfortable or safer for the person. However, these modifications may make working with the wheelchairs more difficult or complicated. When in doubt, get professional advice.

Power wheelchairs are basically the same design as manual chairs, except they are much heavier and generally do not fold.
Section 6.2 Wheelchair DOs and DON’Ts

DO:
- **Think** of the wheelchair as an extension of the person. Wheelchairs replace body movements.
- **Ask** permission before you assist. If your help is declined, stand by ready to assist.
- **Treat** the wheelchair *carefully*.
- **Prepare** the person for movement with a verbal cue.
- **Always assume** wheelchair brakes can **fail**. Place the wheelchair on level ground if possible.
- **Check handgrips** before attempting to move; they should not slip.
- **Wear** supportive, non-skid shoes.

DON’T:
- **Lift** a wheelchair by the *wheels*. The chair can spin around, spilling the person.
- **Lift** a wheelchair by the *armrests* or *footrests*. Both of these can detach.
- **Take** a wheelchair up or down *multiple* steps without assistance. This is a dangerous procedure even with assistance.
- **Cross** a wet, spongy or uneven surface with a wheelchair. These surfaces can cause a person to tip forward from the chair. Even a sidewalk crack can be unsafe. Turn the wheelchair backward and allow back wheels to go first if you have no other option.

Section 6.3 Folding and Unfolding a Wheelchair

To fold:
- **Face** the side of the chair.
- **Push** the center of the back outward.
- **Grasp** the front and back of the seat.
- **Pull** the seat up and **squeeze** the handgrips together.

To unfold:
- **Push** down with both hands at the same time on the *front* of each *seat rail* until the chair unfolds. *(Do not* pull on armrests, footrests, or wheels.)*

Section 6.4 Taking a Wheelchair Up and Down

**Taking a wheelchair UP a curb or step**
- **Face** the wheelchair **toward** the step or curb.
- **Grasp** the push handles firmly.
- **Tip** the wheelchair **back**, using one foot on the tilt bar for leverage.
- **When** the front wheels **clear** the step or curb, move the chair forward until the back wheels are **against** the curb or step.
- **Push** your body **forward** against the back of the wheelchair, as you lift **straight up** on the push handles, to **roll** the **back wheels up** and over the step or curb.
Taking a wheelchair DOWN a curb or step

- **Face** the wheelchair away from the step or curb.
- **Stand** on the ground below the curb or step.
- **Grasp** the push handles firmly.
- **Pull** the chair slowly toward you.
- **Be prepared** for an increase in the weight and for the force of the chair against you as it rolls down the curb or step.
- **Lower** the chair slowly and gently until the back wheels are on the ground.
- **Tilt** the wheelchair back, using one foot on the tilt bar for leverage.
- **Pull backward** until the front wheels and footrests clear the step or curb.
- **Lower** the front of the chair slowly.

**SECTION 7: ASSISTING SOMEONE TO STAND/SIT**

Section 7.1 When You Assist, Always...

- Remember you want to avoid injuring the person and yourself.
- If you will be assisting someone often, you should receive professional instructions. Ask a physical therapist or other professional to provide guidance for you in assisting your relative.
- The guidelines are very simple and may already be familiar to you. These are:
  - Ask permission first and listen for a response.
  - Prepare the area ahead of time.
  - Use the person’s existing skills.
  - Use your voice to help guide him/her (Count 1,2,3 with the person).
  - Wear low, non-skid shoes.

Remember the Principles of Body Mechanics:

- **Turn** your entire body; do not twist at the waist.
- **Bend** down at your knees/lift with your legs, not your back.
- **Bring** objects as close to your body during the lift as possible.
- **Keep** one foot in front of the other, shoulder length apart.
- **Lift** with your mind, then with your body (In other words, plan your moves.)
- **When** in doubt, get assistance.
Section 7.2 Two-Handed Assistance to Stand

- **Stand sideways** in front of the person with your feet together. You can be faced either to the left or the right.
- **Place** your feet in front of the person’s feet to prevent them from sliding. The person’s feet should be firmly on the floor about 8 inches apart. You may need to assist the person to move their feet into position. Both you and the person should be wearing flat, close toed shoes to prevent injury.
- **Bend** your arm closest to the person up 90 degrees at the elbow and parallel to the ground.
- **Grasp** the wrist of that arm with your free hand forming a kind of human grab bar.
- **Allow** the person to **grasp** your forearm with both of his/her hands.
- Slightly **bend** your knees.
- Count to 3 with the person and on the count of 3, move your outside leg sidewise about a foot and **shift** the weight of your body toward that leg. This movement will allow your person some momentum to rise up into a standing position.
- **Wait** until the person is securely standing before moving your feet.

Section 7.3 One-Handed Assistance to Stand

- **Stand sideways** in front of the person with your feet together facing the direction of the person’s **good arm**.
- **Place** your feet in front of the person’s feet to prevent them from sliding. You may need to assist the passenger to move their feet into position. The person’s feet should be firmly on the floor about 8 inches apart.
- **Form** a cup with your hand closest to the person and “catch” the person’s elbow gently into it and allow him/her to grasp your arm above the elbow. Then place your other hand on the person’s wrist to secure your hold.
- Slightly **bend** your knees.
- Count to 3 with the person and on the count of 3, move your outside leg sidewise about a foot and shift the weight of your body toward that leg. This movement will allow your person some momentum to rise up into a standing position.
- **Wait** until the person is securely standing before moving your feet.
Section 8: Assisting Someone to Transfer from Seat to Seat

Section 8.1 When to Use this Technique

- When the person can bear weight on his/her legs and pivot.
- When the person can hold on to handles, or other surfaces.

Do NOT Use this technique:

- When the person cannot bear weight on his/her legs.
- When the person is much heavier or taller than you are.
- If you have a disability which makes lifting or turning a health hazard.

Alternatives to Standing Pivot Transfer

- Two person transfer (one person on each side of the person needing assistance)-using a gait belt.
- Use a mechanical or standing lift to transfer the person.

Section 8.2 Standing Pivot Transfer

- Place the wheelchair as close to the seat or bed as possible, at a 90-degree angle.
- Lock wheelchair brakes and remove the footrests & face the person.
- Place one foot between the legs of the person & one foot in front of the chair.
- Secure the gait belt around the person’s waist. It should fit snugly without being too tight.
- Clasp your wrists firmly to the gait belt behind the person’s back. The person’s arms should not be around your shoulders. They should be holding on to one of the seat arms or pushing up from the seat.
- Count to three with the person.
- On the count of 3, using your legs, assist the person to come to a full standing position.
- Slowly pivot the person and turn toward the wheelchair, until the person’s legs are against the front of the other seat.
- Bending your knees, lower person gently to the seat and remove the gait belt.
Note:
In some cases, the person will not have to stand all the way up in order to transfer. He/she can rise slightly and pivot to the bed, vehicle, toilet or chair.

Section 9: Positive Physical Approach and Hand Under Hand Assistance

When a person has any form of disability or sensory loss, it is helpful to approach and assist a person using the following techniques.

Section 9.1 Positive Physical Approach™
- **Approach** from the Front—NOT from the side or from behind a person!
- Go slow.
- Get **low**—match person’s eye level.
- **Pause** at the edge of personal space (about 1½ arms’ length)
- **Offer** your hand shake with a greeting and a smile.
- **Use** the person’s name (which name do they prefer?)/Introduce yourself.
- **Wait** for a response.
- Wait for the person to allow you to move in closer.
- Get to the side—the person’s dominant side.
- **Use** Hand UNDER Hand assistance.

Section 9.2 Hand UNDER Hand Assistance™
- **Offer your hand** to the person’s dominant hand.
- **Slide your hand around** so that the thumbs are encircling and the person’s hand is on **TOP of your hand**. Your hand is underneath theirs (supporting theirs).
- **Move** to the person’s dominant side.
Uses of this Stance

• Use this stance to **exert** light palm pressure—which can be calming.
• Use this stance to **gauge** a person’s response to touch.
• Use this stance to **allow a person** to have some privacy in personal care.
• Use this stance to **establish** safe physical boundaries.
• Use this stance to **guide** the person’s hand and arm movement.

Your Other Hand

• Can place on the person’s shoulder if they will tolerate a little light pressure.
• Can hold on to the person’s opposite hand to steady while walking (see illustration).
• Can use to assist in personal care (i.e., holding the shower wand).

*Positive Approach and Hand Under Hand Assistance are approaches developed by Teepa Snow OTR/L and used with permission by Positive Approach to Change (PAC) 2017. For more information and other training materials go to [www.teepasnow.com](http://www.teepasnow.com).*

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**SECTION 10: CONCERNS FOR OLDER DRIVERS/FAMILIES**

Section 10.1 Questions for an Older Driver

1. Do other drivers often honk at you?
2. Have you had some accidents?
3. Are you getting lost, even on well-known roads?
4. Are you taking medicine that may cause drowsiness or confusion?
5. Do you have difficulty climbing stairs or walking?
6. Have you fallen, tripped or stumbled once or more in the last year?
7. Do cars or pedestrians seem to appear out of nowhere?
8. Have family, friends, or doctors said they were worried about your driving?

If the answer is **yes** to one or more of the questions above, you may want to have your driving evaluated and consider not driving as much or not at all.

Section 10.2 Questions for Caregivers

**Does Your Loved One:**

1. Drive at inappropriate speeds?
2. Respond slowly or not notice pedestrians, bicyclists, and other drivers?
3. Ignore, disobey or misinterpret street signs and traffic lights?
4. Fail to yield to other cars or pedestrians who have the right-of-way?
5. Fail to judge distances between cars correctly?
6. Appear drowsy, confused or frightened?
7. Have had one or more accidents or near accidents in the last 2 years?
8. Drift across lane markings or bump into curbs?
9. Forget to turn on headlights after dusk?
10. Experience difficulty with glare?
11. Find it hard to turn his/her head, neck, shoulders or body while driving or parking?
12. Lack the strength to turn the wheel quickly in an emergency?
13. Get lost repeatedly in familiar areas?

If the answer is yes to one or more of these questions, you may want to explore whether medical issues are affecting your loved one’s skills or have his/her driving evaluated.

Section 10.3 Guidelines from the Ohio Bureau of Motor Vehicles (2017)

Question: What is the procedure for reporting someone who should not drive because of age or because of a medical, physical or vision problem?

(Answer supplied by Ohio DMV 2017)

The Ohio Motor Vehicle laws allow the Registrar of Motor Vehicles to require an Ohio licensed driver to submit a medical statement and/or take a driver license examination upon receiving information giving “good cause to believe” that the driver is incompetent or otherwise incapable of safely operating a motor vehicle.

The Ohio Administrative Code states that “good cause” is considered to be a request for recertification received from a law enforcement agency, court, physician, hospital, or rehabilitation facility. To take action on a request received from a law enforcement agency or court, we require that the agency or court has had personal observation of the subject’s driving or personal contact with the driver. We cannot take action on the recertification request if it is based solely on the person’s age or hearsay.
The Bureau will also take action on a written and signed request submitted by a relative, friend, neighbor, etc. However, we are required to first conduct an investigation to determine if there is sufficient cause to require a medical statement and/or driver license examination.

Again, age cannot be the only basis for the request. The letter writer must provide us with enough information so that we can locate record of a valid Ohio driver license or temporary permit issued to the person. If we cannot find a record of an Ohio license or temporary permit, no action can be taken.

Legally, we must inform the driver who is the subject of our investigation or recertification procedures of our source of information. Therefore, before an investigation or any other action is taken on request received from a family member, neighbor, friend, nurse or social service agency, we must receive permission to use the letter writer’s name as our source of information. However, information received from a physician is considered confidential.

There is currently no Ohio law that requires a medical professional to report to the Bureau a patient who should not drive, nor is there any liability protection for the person that chooses to make a report. Any changes in our policies and procedures for reporting and recertifying unsafe drivers would necessitate the enactment of new laws by the Ohio Legislature.

If someone would like to submit a written request to the Bureau to have a driver recertified for driving privileges, you may send or fax the letter to the Ohio Bureau of Motor Vehicles.

Attention:
Driver License Special Case Section/Medical Unit
P.O. Box 16784
Columbus, Ohio 43216-6784
Fax: (614) 752-7271, Attention Medical Unit

The letter should include a release allowing us to use the letter writer’s name as our source of information. Ohio’s motor vehicle laws currently do **not** provide for mandatory retesting of elderly drivers, as it is considered discriminatory. All drivers, regardless of age, are only required to pass a vision screening prior to being issued a renewal driver license.

**Section 10.4 Some Other Suggestions**

**Consult with the doctor.** There may be a health problem, or medication that is affecting a person’s ability to drive.

Request a referral from a person’s doctor to:

- **The Ohio State University Rehabilitation Driving Program**, for a driving evaluation. The program includes a comprehensive evaluation, driver simulation, and driving recommendations. Some insurance plans will cover all or a portion of the fee. You may also call the OSU program at 614-293-3833 to request information or visit the website: [www.medicalcenter.osu.edu](http://www.medicalcenter.osu.edu).

- **The Grady Memorial Hospital Driver Rehabilitation Program** for Instruction and Vehicle Education Program at 740-615-2660 or [www.ohiohealth.com/grady](http://www.ohiohealth.com/grady).
If you would like to “brush up” your driving skills, contact the AARP 55 Alive, Driver Safety Program 888-227-7669 or www.aarp.org.

- These driver education classes alert older drivers to changes in traffic, their own changing physiology, and current regulations. Some insurance companies offer discounts for completing the courses. AARP also has many written materials about the driving decision.

Other online self tests and checklists are at:

- AAA’s Roadwise Review at www.seniordrivers.org
- AAA Foundation for Traffic Safety www.aaafoundation.org

Remember, the most difficult driving situations are:

- Night, Dusk, or Dawn
- Highway
- Rush Hour
- Bad Weather
- Unfamiliar Areas

Avoid these situations if you are feeling unsure of your ability to drive in them. Check with the Association for Driver Rehabilitation, www.driver-ed.org and the Easter Seals–Project Action www.projectaction.org for information on referrals and other transportation alternatives.

Download a copy of the Central Ohio Transportation Guide from www.coaaa.org under “Resources” or call 800-589-7277 to request a hard copy.

SECTION 11: SAFETY AND DISASTER CONSIDERATIONS

Section 11.1 Steps to Emergency Preparedness

Create a Personal Support Network

- Have a written list of at least 3 people who can help you if needed.
- List ICE (In Case of Emergency) in your cell phone contacts.
- Have a communication plan with those you know both in and out of town.
- Keep emergency numbers posted. Include utility contact numbers.

Create a ‘Grab & Go’ box to include:

- Your priority list of items to take (home items, adaptive equipment)
- Small amount of cash
- Emergency contact names and numbers including doctor, clergy, etc.
- Copies of License, State ID, Passport or a recent photo of you (name on back)
- Copies of birth certificate, SS card, benefits eligibility letter (SSI/SSDI)
• Financial power of attorney, health care power of attorney and living will documents
• Written instructions for your personal care/transport/medical equipment
• Copies of prescriptions for medicines and glasses
• Copies of all insurances; medical, home, car
• Copies of other important family documents along with a family photo
• List of bank and credit card account numbers
• Household goods inventory and computer disc backup
• All items should be in a plastic zip-lock bag to protect from moisture

Have specific plans for various emergencies and locations (home and away)
• Know the hazards that can occur where you live: tornadoes, power outage, etc.
• If you live in an apartment, assisted living, or long term care facility be aware of the disaster plans and nearby exits.
• Have a battery operated/crank radio tuned to weather/disaster news.
• Keep a cell phone with an extra battery to contact help if phone lines are out.
• Know the location of the nearest disaster shelter and community resources.

Keep a basic disaster kit prepared
• Keep a kit at home, in your car, for work, for travel.

Section 11.2 Basic Disaster Kit Supplies

This needs to be pre-packed in a container and checked yearly to update expired items
• 3-day nonperishable food supply and manual can opener
• 3-day water supply (one gallon/person/day)
• Portable battery operated radio and extra batteries
• First aid kit: bandages, antibiotic cream, alcohol wipes, etc.
• Flashlight and extra batteries
• Hand sanitizer, moist towelettes, toilet paper, dust mask
• Special needs: glasses, hearing aid and batteries, contact lens solution
• Diabetic, respiratory or other medical supplies if needed
• Infant needs: formula, food, diapers
• Whistle or noise maker
Additional supplies to consider:
• Matches in a waterproof container
• Kitchen accessories and cooking utensils
• Extra clothing and blankets
• Empty large coffee can/chip tin for emergency bathroom needs
• Small basic tool kit: hammer, screwdriver, spade
• Duct tape, plastic garbage and zip-lock bags
• Pet supplies: leash, food, water, carrier
• Backup batteries for adaptive equipment: scooters, breathing machine, etc.
• Alternative power, heating and cooking sources
• A local map

Section 11.3 Sheltering at Home
• Keep the contact numbers for your utility companies nearby.
• Know how to turn off your utilities and water if needed.
• Get your disaster kit and check status of supplies.
• Keep your ‘Grab & Go’ box nearby.
• Turn on NOAA Weather Radio and follow recommended instructions.
• Turn off or unplug unnecessary appliances.
• Check in with your personal support network; otherwise only phone for emergencies.
• If your electricity goes off, avoid opening your refrigerator/freezer as much as possible.

Section 11.4 If You Must Evacuate
Section 11.4a Basic Steps
Assume that you’ll have 3-5 minutes to evacuate
1. Collect your basic disaster kit and ‘Grab & Go’ box (includes cash, coins etc.).
2. Contact your personal support network and tell them where you are going.
3. Take food and water supplies with you.
4. Take your medications, medical supplies, and adaptive equipment.
5. Take a cell phone and batteries.
6. Make sure your gas tank is full if driving yourself to shelter.
7. If permitted take your pet and necessary supplies.
8. If you have a laptop computer take it with you along with your disc backup.
9. Turn off all lights and unplug all appliances including computer.
10. If you have a disability, take your written instructions for your care needs and any adaptive equipment usage.
Section 11.4b If You Are Traveling by Car

- Always keep your tank between half and full.
- Items to keep in your trunk:
  - Flares, flashlight and batteries, tire repair kit, white flag and jumper cables
  - Basic first aid kit, some food supplies and some water
  - Blankets/jacket/hat/gloves/scarf
  - Small shovel, basic tool kit, and kitty litter for if you get stuck in mud/snow/ice
  - Mini version of the basic emergency kit specifically for car
  - Seasonal supplies: sunscreen, hat, umbrella for shade, etc.

Section 11.4c Specific Considerations for People with Disabilities

- Have written instructions for care needs to include if you need help with: Walking, transferring, standing, communicating, personal care needs or adaptive equipment.
- Use your personal support network.
- Have your emergency contacts list located in a conspicuous place in your home.
- Have identification or ID bracelet ON persons who may tend to become confused.
- Keep a seven-day supply of medications on hand.
- Have backup batteries for medical equipment or scooters.
- Identify your evacuation route. Remove objects that block your path.
- Consult the Red Cross website for Disaster Preparedness and look up ‘Persons with Disabilities section [www.redcross.org/services/disaster/beprepared.html](http://www.redcross.org/services/disaster/beprepared.html).

Section 11.4d Specific Considerations for Pets

- Have ID on your pet and a current rabies tag.
- Have medical records of immunizations and any medicine your pet needs.
- Take food, water and sanitation needs.
- Take a eash and carrier: your pet may be hard to manage in the stress of an emergency.
- Take photos of your pet in case it gets lost.
- Keep a bag packed for your pet. Include a comfort toy or item.
- Make prearrangements for where to leave your pet if you have to evacuate since shelters may not take pets unless they are service animals.
- Make note of hotels outside of your area that take animals or a facility that can shelter pets in an emergency.
Section 11.4e If You Are Traveling by Air or Staying in a Hotel

- Travel with a mini basic disaster supply kit.
- Take copies of all prescriptions (medications, eyeglasses).
- Energy bars and nuts are a great food source for travel.
- Give your itinerary to a trusted friend and check in with your personal support network.
- Count how many seats away you are from the exit in an airplane.
- Count how many doors away from the stairwell you are from your hotel room.
- Read the fire evacuation instructions on the back of the hotel room door.

Section 11.5 Specific Emergency Plans

Section 11.5a Tornado

- Know the safest place in your home. Usually on first floor or basement or an interior wall away from windows.
- Take a radio, flashlight, cell phone and your disaster kit with you to the location.

Section 11.5b Fire

- Keep a smoke alarm on each floor. Check/change batteries with the time changes.
- Have a fire exit plan and practice home fire drills.
- Know what to do if you have special needs or a disability.
- Keep a fire extinguisher (ABC type) in/near the kitchen and know how to use it.
- If there’s a fire in a part of the house:
  - Before leaving your room: feel the door with the back of your hand at the top of the door, feel the doorknob. If HOT, Do NOT open!
  - If you open a door and smoke pours in, close the door and block cracks with wet towels if possible.
  - When leaving home drop to the floor and crawl if there is smoke.
  - Once you leave the house do NOT go back in. Tell the firemen if you suspect someone is still inside.
  - Have a designated place outside to meet so you know everyone is out.

Section 11.5c Snow

- Keep at least a 3-day supply of food and water (one gallon per person per day) on hand at all times.
• Use food in your refrigerator first and then food from your freezer. Open these doors as little as possible.
• Keep battery-operated lights or flashlights available with backup batteries. Also have a supply of candles and matches.
• Keep your first aid kit nearby.
• Dress in layers to stay warm.
• Always keep a supply of needed medications.
• Consider alternative cooking sources if your electricity/gas is off: camp stoves with propane (be sure to follow safety guidelines) or fireplace.
  - Use caution and follow all safety guidelines when using alternative heat sources.
  - Kerosene heaters are not recommended.
• Have a plan for an alternative place to stay within close driving distance.

Section 11.6 Emergency Contact Information

Section 11.6a Emergency Information About Me Forms (P. 79-80 of this manual—can be torn out.)

This is a means to communicate vital information between individuals, their caregivers, and emergency personnel in case of medical emergency. The form should be carefully completed. Please place on the front of your REFRIGERATOR and attach any pertinent legal documents (i.e., Living Will, Durable Power of Attorney for Healthcare, DNR Orders). Download more forms at www.coaaa.org.

Section 11.6b Ohio Next of Kin Registry

Any person can ADD emergency contacts to his/her Driver’s License or Ohio State ID at no cost. Emergency services personnel, safety and highway patrol officers can access this information in the event of an accident or incident. To access paper or web forms go to www.bmv.ohio.gov.

Section 11.6c Project Lifesaver

Project Lifesaver provides timely response to save lives and reduce potential injury for adults and children who wander due to Alzheimer’s, autism, and other related conditions. There are 6 Project Lifesaver programs in Franklin County and 6 in the surrounding counties. Most are located in Sheriff’s or Police Departments. Citizens enrolled in Project Lifesaver wear a small personal transmitter around the wrist or ankle that emits an individualized tracking signal. If an enrolled client goes missing, the caregiver notifies their local Project Lifesaver agency, and a trained emergency team responds to the wanderer’s area. Check the website for a program in your area www.projectlifesaver.org.
Section 11.6d Medic Alert + Alzheimer’s Association Safe Return

MedicAlert® + Alzheimer’s Association Safe Return® is a 24-hour nationwide emergency response service for individuals with Alzheimer’s or a related dementia who wander or have a medical emergency. It provides 24-hour assistance. If an individual with Alzheimer’s or a related dementia wanders and becomes lost, caregivers can call the 24-hour emergency response line (800-625-3780) to report it. A community support network will be activated, to help reunite the person with the caregiver. With this service, critical medical information will be provided to emergency responders. If a citizen or emergency personnel finds the person with dementia, they can call the toll-free number listed on person’s MedicAlert + Safe Return ID jewelry. MedicAlert + Safe Return will notify the listed contacts, making sure the person is returned home. The cost is approximately $62.00. The website is www.alz.org.

Section 11.7 Disaster and Emergency Resources

• Know the phone numbers for your local:

  City Hall:
  Fire:
  Police:
  Electric Company:
  Gas Company:
  Red Cross:
  Nearest Emergency Shelter:

• HandsOn Central Ohio — 614-221-2255  
  Call 211 to get information on how to link to services www.handsoncentralohio.org

• Federal Emergency Management Agency www.fema.gov
• Department of Homeland Security www.ready.gov
• American Red Cross www.redcross.org
• Download “Disaster Preparedness for Seniors by Seniors” www.healthinaging.org
• Download “Emergency Preparedness for Older Adults” www.cdc.gov
EMERGENCY INFORMATION ABOUT ME

This is a means to communicate vital information between individuals, their caregivers, and Emergency personnel in case of emergency.

The form below should be carefully completed. Please place on the front of your REFRIGERATOR and attach any pertinent legal documents (i.e. Living Will, Durable Power of Attorney for Healthcare, DNR Orders).

INFORMATION FOR: ____________________________________________

Date Form Completed: ________________ Date of Birth: ________________

Address: ____________________________________________________

Home Phone #: ________________ Cell Phone: ________________

Medicare #: __________________ Medicaid #: __________________

Family Doctor: ________________ Doctor’s Phone: ________________

Preferred Hospital: __________________________________________

Insurance Company: ________________ Policy #: ________________

Home Health Care Agency: ________________ Phone #: ________________

Medical Eqpt. Co. ________________ Phone #: ________________

Pharmacy: ________________ Phone #: ________________

Other Information on Services: __________________________________

___________________________________________________________

IN CASE OF EMERGENCY CALL:

Name: ___________________________ Name: ___________________________

Address: __________________________ Address: __________________________

___________________________________________________________

Phone: ___________________________ Phone: ___________________________
**EMERGENCY INFORMATION – Page 2**

Do you currently have any of the following?

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Normal Pulse Rate: ________________ Normal Blood Pressure: ________________

Allergies to Medications: ____________________________________________

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Other Medical Related Information: ____________________________________________

For more information, or to request more forms, please contact the COAAA at 800-589-7277
Caring for Someone in a Care Facility

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**Section 1: Red Flags for Care Facility Placement**

Research has shown that experiencing one or more of the factors listed below often lead families to place a loved one outside the home in a care facility.

- The person receiving care has dementia that produces unpredictable behavior, violent behavior or frequent wandering. The caregiver is often very upset by this behavior.
- The person receiving care has incontinence of bowel or bladder and the caregiver is having difficulty preventing skin breakdown.
- The caregiver is unable to safely lift and transfer the person receiving care.
- The caregiver is experiencing chronic (long term) sleep deprivation.
- The caregiver has health problems which are often untreated. The most common are knee, hip, back or shoulder problems.
- The caregiver is experiencing resentment toward other family members, service providers, “the system,” or the person receiving care. This resentment is felt quite often not just once or twice.
- The caregiver is experiencing other significant life stressors like: divorce, death in the family, dependent children, financial problems, employment problems.

Adapted with permission from: *Taking Care of Aging Family Members* by Wendy Lustbader & Nancy Hooyman, 1994.

**Section 2: Making the Choice of a Facility**

- **Chances are that there is more than one facility** in your area that offers the care your loved one needs. If you have the time, it is best to **personally visit** as many as possible. Do not be afraid to ask lots of questions and visit at different times of the day.
- **Look on the website**, [www.medicare.gov](http://www.medicare.gov) under the “Nursing Home Compare” section to obtain a list of facilities in your area and some information about each one. You may even check the various facilities’ websites before you call and make an appointment for a visit. You can also visit [www.ltc.ohio.gov](http://www.ltc.ohio.gov) for information on facilities.
- **During the visit, use a checklist** like the one provided in Medicare’s free booklet, “Guide to Choosing a Nursing Home” which is available from its website or by calling 800-800-4227. A variety of other books are available from the library that have checklists as well.
- **Pay particular attention to the location of the facility** and try to choose one that is **close** enough that family and friends can visit often. One of the best ways to ensure quality care is to have family and friends visit often who will advocate on behalf of the person in the facility.
- **Talk to family, friends and others who have had recent experience with particular facilities.** Though each person’s experience is different and facilities can have staff changes, they can offer valuable insight into a facility’s particular strengths and weaknesses.
Questions to Ask When Visiting a Facility

- Is the facility Medicare or Medicaid certified?
- What services and supplies are included in the daily rate?
- What kind of activities are available on a daily basis?
- How much choice do residents have in meal selection, wake/sleep times, and bathing options?
- How are roommates selected? (if applicable)
- How are complaints handled?
- What is the staff to resident ratio on all shifts?
- Are therapies available if needed? At what additional cost?
- How is pain managed?
- What are visiting hours? Are there restrictions?
- Who is available to answer concerns “after hours?”

Section 3: Admission to a Facility

3.1 Short-Term Care in a Nursing Facility

- A nursing facility may be needed for a short-term stay for rehabilitation, or for short-term respite care.
- A short-term stay for rehabilitation will typically happen after a hospital admission. For individuals with Medicare the person must have been admitted to the hospital for three consecutive midnights for Medicare to pay for the rehabilitation in a nursing home. It is important to verify that the person was actually admitted to the hospital and not there under observation status. **Medicare ONLY pays for rehabilitation in a nursing facility when the person was actually admitted to the hospital.** Medicare typically pays the full cost of the rehabilitation stay up to 20 days. The person must require a skilled nursing service or speech, physical, or occupational therapy. The rehabilitation stay may be less than 20 days if it is determined that the person is no longer benefiting from the therapies or, is no longer in need of a skilled nursing service. If the need for a skilled service continues past the 20 days, Medicare pays the “skilled nursing charge only” up to 100 days. At that point, the person either pays for the daily room and board charges, or applies for Medicaid to pay for these charges. If an individual has a Medicare Supplemental or “Medigap” policy there may be additional coverage for a rehabilitation stay.
- If an individual will be going to a nursing facility for rehabilitation, a hospital discharge planner will help explore which nursing homes have a “skilled bed” available and will make the arrangements for your loved one to be transferred. If the individual or their family has a preference of a facility this needs to be shared with the discharge planner. However, there is no guarantee that a particular facility will have a bed available at any given time. If possible, it is a good idea to do some advance research to help you select a facility that will meet you or your loved one’s needs.
Note!
It is important to monitor a loved one’s progress during a rehabilitation stay. Individuals and/or their families can request a discharge planning meeting with facility staff to determine what care will be needed once rehabilitation ends. There are times when an individual has not recovered enough to return to living in the community. If this appears to be the situation, discuss transitioning the person to a long-term stay in the facility with the admissions staff or social worker as soon as possible. The facility may not have a long-term bed available and will need to assist you with finding one in another facility. If the individual transitions to long-term care, they will either pay privately or need to begin the application process for Medicaid.

3.2 Transitioning to a Long-Term Nursing Facility from the Community
• Most people who reside in a nursing facility long-term are considered to be at an “intermediate level of care”. This is the term you would use when inquiring about bed availability in a facility.
• Nursing facilities may offer specialized services such as onsite dialysis or secured “memory care units” for residents who would be at risk for wandering away from the facility. If highly specialized care is needed, the choice of facilities may be limited to one or two in a given area. This is also typically the case for individuals who are dependent on a ventilator to help them breathe.
• Try to determine at least three facilities you would consider at any time. There is no guarantee that a particular nursing facility will have a bed available when you need one. Some nursing facilities have waiting lists for their long-term or “intermediate level of care” beds. If a preferred facility has a waiting list, you can add your loved one’s name to the facility’s list and transfer them from another facility when a bed becomes available.

3.3 Paying for Long-term Care in a Nursing Facility
• The average monthly rate for nursing home care in Ohio as of July 2017 is $6570. For long-term care in a nursing facility most people use their own financial resources until their assets are reduced and they become eligible for Ohio Medicaid.
• If an individual has long-term care insurance, this can help with the cost of nursing home care both for short-term respite stays and long-term residence for a period of time. Check with the insurance company to determine the extent of coverage under the policy. Long-term care insurance may require verification from a doctor that the individual requires long-term care. It may also have an “elimination period” before benefits can start. Consult the nursing home admissions staff if you need assistance in determining long-term care insurance benefits.
• If an individual does not have the financial resources to pay for nursing home care, they will need to apply for “Institutional Medicaid in Ohio” and be approved before they can be admitted to a nursing home. In Ohio, applications are made through the County Department of Job and Family Services in the county where the person will be residing.
• When Medicaid pays for nursing facility care, the individual’s income is paid monthly to the facility. This is termed their monthly “liability”. Ohio Medicaid then covers the remainder of the person’s monthly cost of care in the facility. The individual is allowed to keep $50 per month as a personal needs allowance.

When Medicaid Pays for Nursing Facility Care: Keep in Mind:
• A spouse who continues to live in the community, can retain assets up to $120,900 (July 2017). This amount changes yearly. The spouse in the nursing facility can have no more than $2,000.00 in assets.
• In many cases the “community spouse” can retain some of the income of the spouse who will be living in the nursing facility to meet their living expenses. Actual amounts will vary and are determined by the County Department of Job and Family Services.
• If there are significant assets, it is wise to seek legal consultation regarding Ohio Medicaid rules prior to spending down financial resources. This can also help with determining the amount of income that the “community spouse” can expect to receive from of the spouse living in the nursing facility.
• Seniors 60 and older in Ohio can obtain a limited amount of free legal consultation through a legal hotline, maintained by ProSeniors, 800-488-6070. The organization does not provide ongoing legal services in Central Ohio, but it can provide guidance.
• You can also search for an elder law attorney with expertise in Ohio Medicaid Law at www.naela.org.

3.4 Short-term Respite Stays in a Nursing Facility
• Many facilities accept individuals for a short-term “respite” stay. You can search at www.ltc.ohio.gov to find these. Respite stays provide family or friends who are providing care in the home temporary relief from their caregiving responsibilities. Both Assisted Living Facilities and Nursing Facilities provide short-term respite stays.
• The person’s care needs will determine which type of facility you select.
• Medicare does not pay for short-term respite stays. Respite stays in a nursing facility may be paid for with an individual’s own resources, or if they have Medicaid coverage. If Medicaid is paying for a short-term respite stay the State of Ohio requires a face to face assessment of the individual’s level of care. This is to determine that the individual’s needs require nursing home care. The nursing facility will make the arrangements for this assessment.
Section 4: Getting the Best Care in a Facility

Section 4.1 Suggestions for Care

- **The role of a care facility is to help each resident maintain** everything he/she is able to do at admission and reach a better level if possible. Sometimes residents in facilities do show decline but this could be due to one of three reasons: progression of a disease, onset of a new disease or condition, or the resident’s decision to refuse treatment. The care a person receives in the facility should **never** be the cause of a physical or emotional decline.

- **The United States has set up a process for facilities** to use in planning for each resident’s treatment. The process is very goal oriented.

- **A comprehensive health assessment** must be completed within 14 days of admission. This is called a **Minimum Data Set (MDS)**. It includes the persons’ functions on the Activities of Daily Living (ADL’s) like walking, bathing, eating, toileting and dressing as well as other activities and whether the person needs assistance with these. In addition, it includes the person’s patterns, preferences, routines and habits.

- **A Care Planning Conference** is then set up with representative staff from all departments who will be interacting with this individual to determine the goals for this person’s care.

- **Family representatives must be informed of the time of the conference and allowed to attend.** In addition, the resident must be allowed to attend if he/she requests.

- **Care planning meetings are required at admission and then once a year thereafter.** However, if the person’s physical condition changes, there should be a meeting and a family can request a meeting at any time. The care plan itself with its goals and related activities should be updated every 90 days.

- **Most facilities also have resident and/or family councils** that meet regularly. These can also be a forum to voice concerns.

- **If concerns continue, residents and their families can contact the Long Term Care Ombudsman Program** whose purpose is to assist in settling problems, questions, and complaints about care not only in nursing facilities but also in other living situations and community based care settings. In Central Ohio, contact the Long Term Care Ombudsman at Easter Seals at 800-536-5891 or [www.centralohio.easterseals.com](http://www.centralohio.easterseals.com).

- **To make a formal complaint**, contact the Ohio Dept. of Health at 800-342-0553. **Hint:** Also put all complaints in writing to the Director of the Facility/Company/Agency.
Section 4.2 Your Rights in a Facility

In 1987, the Nursing Home Residents Bill of Rights was passed into Federal Law. Residents should receive these rights in writing upon admission to the facility. The facility must maintain identical policies and practices for all individuals regardless of payment source.

The Bill of Rights includes:

1. **The Right to be Fully Informed.**
   - The right to be informed of all services available and all charges.
   - The right to a copy of the facility’s rules and regulations.
   - The right to be informed of the address and telephone number of the State Ombudsmen, the State licensure office and other advocacy groups and the facility shall post these numbers.
   - The right to daily communication in their language and the right to assistance if there is sensory impairment.

2. **The Right to Participate in One’s Own Care.**
   - The right to receive adequate or appropriate health care.
   - The right to be informed of their medical condition and to participate in treatment planning. The resident and their representative shall be invited to participate in care planning.
   - The right to refuse medication and treatment.
   - The right to participate in discharge planning.
   - The right to review their medical records.

3. **The Right to Make Independent Choices.**
   - The right to know that choices are available.
   - The right to make independent personal decisions.
   - The right to choose their own physician.
   - The right to participate in activities of the community inside & outside the facility.
   - The right to vote.
   - The right to participate in a resident council.

4. **The Right to Privacy and Confidentiality.**
   - The right to private and unrestricted communication with any person of their choice, including privacy for telephone calls, unopened mail, privacy for meetings with family and friends and other residents.
   - The right to privacy in treatment and caring for their personal needs.

5. **The Right to Dignity, Respect and Freedom.**
   - The right to be treated with consideration, respect and with the fullest measure of dignity.
   - The right to be free from mental and physical abuse.
• The right to be free from physical and chemical restraints.
• The right to self-determination.

6. **The Right to Security for One’s Possessions.**
• The right to manage their own financial affairs.
• The right to file a complaint with the State survey and certifications agency for abuse, neglect or misappropriation of their property.

7. **The Right to Remain in a Facility.**
• The right to be transferred or discharged only for medical reasons, for their welfare if their needs cannot be met in the facility, if the health and safety of other residents is endangered or for non-payment of stay.
• The right to receive Notice of Transfer. A thirty-day Notice for Transfer out of the facility must be given. The notice must include the reason for transfer, the effective date, the location to which the resident is being discharged, a statement of right to appeal, the name, address and telephone number of the state long-term care ombudsman.
• The facility must provide sufficient preparation of residents to ensure a safe transfer or discharge.

8. **The Right to Raise Concerns or Complaints.**
• The right to present grievances for themselves or others to the staff of the nursing home, or to any other person, without fear of reprisal.

Section 4.3 Eight Preventable Problems in Care Facilities

Residents who are most at risk of developing these problems are:

• **Immobile or unable to move** without help due to injury, disease, drugs, or restraints.
• **Non-communicative** or unable to be understood due to injury or disease.
• **Confused** or unable to remember due to injury, disease or drugs.

1. **The person experiences bowel or bladder incontinence** not caused by a disease or medical problem. The most common preventable incontinence is caused by the person’s immobility or poor memory.
   • **Preventative Measures:** Nursing home staff must take the resident to the toilet regularly according to his/her care plan and upon his/her request. They should use adult incontinence briefs only to protect skin against accidents between toileting. Residents should not be told to relieve themselves in their clothing because the incontinence brief is on. Catheters should only be used to: obtain a sterile specimen, remove urine from the bladder in the event of nerve damage and help heal a skin wound.

2. **The person is dehydrated or malnourished.**
   • **Preventative Measures:** The nursing facility should provide nourishing food and beverages that the resident enjoys. **The person should have assistance with eating and**
reminders to drink fluids frequently if he/she requires it. The person should be reminded and assisted to consume fluids in between meals. Family and friends can help especially if the person takes a long time to eat. Tube feeding because the staff is too busy to help residents feed themselves is never appropriate. It is an uncomfortable, invasive procedure that seriously diminishes quality of life.

3. **The person is poorly dressed and groomed. Mouth and foot care are not adequate.**
   - **Preventative Measures:** The nursing staff should help the resident to groom and dress as needed. Clothes should be clean, though spills can occur during meals and activities. The person’s mouth should be kept clean and free from food. Dentures should be clean and well fitting. His/her feet should be kept clean and dry. Lotion should be used to soften his/her skin and toenails should be filed.

4. **The person develops pressure ulcers (sores).**
   - **Preventative Measures:** The nursing staff should be changing the person’s position at least every two hours if the person cannot move on his/her own. Two people should move heavy, immobile residents to avoid friction again sheets and clothing. The facility should use preventative equipment: sheepskin booties on heels and elbows, special mattresses, special cushions in wheelchairs. Residents should be assisted out of bed each day and pillows should be placed between knees, ankles, arms and body.

5. **The person’s arms and legs develop contractures.**
   - **Preventative Measures:** The nursing staff should perform range-of-motion exercises for each joint from head to toes at least daily in residents who are not mobile. Each resident should be assisted out of bed at least once daily. Pillows/foam rolls should be used to cushion knees, ankles, arms and body. Residents should not be tilted to one side in a chair.

6. **The person experiences a decrease of independence in dressing, grooming, eating toileting, and walking.**
   - **Preventative Measures:** The nursing staff should provide assistance to promote independence in all areas. For example, if a resident can eat alone but takes a long time, staff should not try to feed the resident to save time.

7. **The person experiences problems with medications: drug interactions, wrong types of drugs and/or incorrect dosages.**
   - **Preventative Measures:** The nursing staff should reassess drugs to see why they are administered and how they affect residents. They should be looking for: a drop in blood pressure that causes falling, dry mouth or skin, poor appetite, upset stomach, vision change, excess urination, restlessness, or personality change.
8. The person experiences a problem seeing and hearing due to lack of hearing aids or eyeglasses.
   • Preventative Measures: The nursing staff should ensure that hearing aids and eyeglasses are operating and kept in a safe place. Hearing aids need replacement batteries and eyeglasses should be cleaned often.

SECTION 5: RESTRAINTS—PHYSICAL AND CHEMICAL

In the past, it was common for residents of care facilities to be routinely restrained using physical or chemical restraints.

Physical restraints prevent a person from moving freely. These include: restraining vests, belts, wrist restraints, chairs with tray tables, and full side rails on beds. Chemical restraints are medications used to control a person’s behavior.

Today, facilities are moving away from using restraints on a routine basis. The facility must show that a restraint does more good than harm in order to use it. There must also be a physician’s order to use a particular restraint. The resident or his or her legally designated representative must agree to the restraint.

Facilities sometimes must get very creative to avoid the overuse of restraints but almost always the quality of care provided to residents goes up when less restraints are used.

SECTION 6: TIPS FOR VISITS AND OUTINGS

What to Bring:
   • Food – that special something that will not usually be on the facility menu – coney islands, deviled eggs, pizza, KFC, limburger cheese, onions! You may need to check and see if the person has diet restrictions.
   • Music – whatever the person enjoys.
   • Photo albums, home videos
   • Movies, sports videos
   • Books, magazines
   • Animals (check the facility policy on animal visitation)
   • Be Creative!

What to Expect:
   • On any given day when you walk in the door your loved one may be eating, sleeping, participating in an activity, or getting a bath. He/she may be cheerful, sad, angry, or in pain. He/she may be welcoming, preoccupied, reflective, confused, or even hostile.
   • If finances and the person’s functioning permit, have a phone installed, to help he/she stay connected, and to help you plan your visit.
You may want to consider leaving a guest book in someone’s room for visitors to sign and make comments. This can be a nice reminder for people with memory challenges as to who visited that day or week. This book can also help families keep track of who is visiting from the family so that they can coordinate times and logistics.

Best Advice – Go with the Flow!!

- It may be today that the person just needs your presence and not your conversation.
- It may be a day when the person needs some reassurance because he/she is a little more confused.
- He/she may need to walk to work off some anxiety, or get outside in the sunlight to raise spirits.
- It may be a day when he/she needs to vent some frustration not AT you, but TO you.
- It may be a day when you drop off the goodies you brought, give a hug and kiss and stay only a short while.

When You Can’t Visit:

- If you are unable to make a regularly scheduled visit, call the unit and ask the staff to get word to your loved one so they don’t worry.
- Have balloons, flowers, or other goodies delivered.
- If you are traveling, send postcards throughout your trip.
- Send cards and letters anytime so he/she gets a pleasant surprise in the mail.
- Enlist family and friends to visit when you can’t.

Tips for Outings from the Facility

- If you plan to take your loved one on outings consider the following:
- It is important to gauge your loved one’s endurance, especially if they have not had any recent outings.
- Get input from facility staff.
- Help your loved one mentally prepare for a trip. Begin discussing it well in advance. He/she may need to build up stamina with short trips.
- Be sure clothing is practical and appropriate for the weather.
- Plan for handling incontinence.
- Obtain any medications needed while the person is out of the facility. Take extra doses if possible.
- Be sure you are capable of safely transferring your loved one.
- Be sure you understand how to use any required medical equipment.
Section 7: Leaving a Facility

If a person chooses to leave a facility, he/she may at any time no matter what the payment source. However, the facility can charge a fee if the person doesn’t give it proper notice.

A person cannot be forced to leave a facility unless:

- It is necessary for the welfare, health, or safety of that person or others.
- The person’s health has declined to the point that the facility cannot meet his/her care needs.
- The person’s health has improved to the point that the facility is no longer necessary.
- The facility has not been paid for the services the person received.
- The facility closes.

Except in emergencies, the facility must give a 30-day written notice of their plan to discharge or transfer someone. The person has a right to appeal the transfer or discharge. Facilities cannot make someone leave if they are waiting to get Medicaid unless the facility is not Medicaid certified.
Family Dynamics and Caregiving

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SECTION 4:
OVERCOMING OBSTACLES IN FAMILIES (p. 97)
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2. Techniques to Overcome Obstacles
   a. Identification of Family Strengths
   b. Active Listening
   c. Use of “I” Statements
   d. Family Meetings
Section 1: Characteristics of Families

- Every family is unique. This is clear as we all think about our families and all of those we know.
- Cultural diversity exists in families and in our country it is often important to examine our cultural heritage when examining our families.
- Membership in families is not voluntary. Like it or not we are born into them and for most, those bonds are very strong. Though some people symbolically “belong” to a family they were not born to, most of us have a family of origin.
- The past is important in family caregiving. Like people, families have pasts. Past events, conflicts, relationships and bonds can have an influence on current caregiving concerns.
- Families are complex to start with but some issues which make them more complex are longevity of the population (we now have four and five generations), divorce and remarriage.
- Most people have difficulty stepping back and viewing their own families impartially. This is especially true with the parent-child bond. It is very difficult to view parents’ current and past choices without judging them against our own lives and experience.

Section 2: Myths and Realities

- **Myth** – In the good old days, families took care of their own members—not like today.
  - **Reality** – In the good old days, the average life expectancy was in the 50s. Families had very few older family members. The older family members were more likely to be helping the younger family members than vice versa. There were no formal services so families had no choices about assistance for the most part.
- **Myth** – Today families are not involved in providing assistance to older members. They just ignore them and then put them in a nursing home.
  - **Reality** – Survey after survey shows family contact is very frequent for most older and disabled adults. Families are involved in the care for over 90% of both those living at home and those in a care facility. Families provide more hands-on care than all service providers combined. Some families have problems with distance, some are overwhelmed with the care needs, and some have work conflicts but most are involved as much as they are able.

Section 3: Common Caregiving Challenges

Section 3.1 Spouses Providing Care

Staying Healthy

- Spousal caregivers often face the huge challenge of staying healthy themselves.
- Often they neglect their own health because they feel that no one else is able to care for their spouse like they do. In fact, they often do provide the best quality of care.
Sometimes adult children do not see how much care is actually being provided by the well spouse.

- Spouses often need to allow others to help care for the individual in order to take care of their own physical or mental needs.

**Guilt Feelings**

Types of guilt which are typical in spouses:

- Guilt for not doing enough
- Guilt for forbidden feelings (anger, resentment, dislike)
- Survivor guilt (guilt for being healthy while the other person is not)

**Suggestions for Coping with Guilt Feelings**

- Identify the source of the guilt
- Identify what is currently being done
- Look at what can realistically be done
- Identify when anger and blame are actually guilt
- Give permission to oneself to not be perfect

**Intense Range of Emotions**

Four emotions which are very common in caregiving spouses:

1. Ambivalence
2. Anger
3. Fear
4. Worry/anxiety

Sometimes spouses report they feel like they are on a roller coaster of emotions.

- This can cause stress and eventual burnout.
- Talking with other spouses in similar situations can be very helpful.
- Taking a break from caregiving can also relieve this stress.

**Section 3.2 Adult Children Providing Care**

**Relationship Role changes**

Ill people often cannot perform tasks that they have for many years. Sometimes gradually and sometimes suddenly, their role in the family or in the community changes. Adult children often face difficult choices as they assume duties formerly completed by their older parents. Parents sometimes respond with anger towards the son or daughter who is taking over tasks and responsibilities. This can be a source of conflict in families.

**To minimize the negative effects of role changes it is best to:**

- Change roles as gradually as possible especially when the ill person has been doing a certain task for many years.
• Allow ill persons to have as much control as possible. Sometimes adult children must see beyond their own worries about health and safety to allow the ill person to continue in a role which has been meaningful.

• Acknowledge with words how difficult the transition has been and will continue to be for all parties.

Differences in Motivations - Safety vs. Independence

• In many families, there is a very real difference between the adult children’s desire for safety and the parents’ desire for as much independence as possible.

• These dueling motivations can create anger and resentment on both sides. It can also cause communication to be impaired as parents choose not to let children know about falls, problems and other issues to avoid losing more independence.

• Families often must acknowledge that this different motivation exists and then move towards finding a middle ground in which children allow risk and parents retain as much independence as possible.

Inclusion of Other Generations in Caregiving Responsibilities

• Adult children are often very reluctant to involve their own children in caregiving.

• Some of the reasons could be: “they are so busy, they have their own lives, they have small children”.

• They often bring energy and different kinds of assistance and support (i.e., knowledge of technology, their own small children who can cause joy).

• They change and often enhance the family dynamics.

• Involving them and allowing them to contribute often builds stronger bonds within the family.

Section 3.3 Issues Between Adult Siblings

Unresolved Sibling Rivalry

• Sibling rivalry which existed in the childhood and teenage years either gets resolved or goes below the surface in adulthood.

• It often resurfaces when one or both parents need assistance. It complicates caregiving because it brings anger and resentment rooted in the past into the process.

• Sometimes rivalry can be resolved to some extent by being acknowledged and sometimes it can be ignored successfully.

• Every family will find its own unique solution.

Inheritance Concerns

• Inheritance concerns take different forms in different families. Sometimes it is the money, sometimes it is the house, sometimes it is the things in the house.
• Sometimes it is not the adult children who are concerned but the parents. Sometimes other relatives are involved. These concerns can greatly complicate the caregiving scenario and the choices made.
• Families need to discuss these issues clearly and without anger. Parents should put wishes in writing. Often legal advice can be useful in helping families to draw up appropriate documents and make decisions around inheritance.

Differences in Perception of Needs and Care
• Different relatives perceive needs and care choices differently. All can be perfectly valid choices in the face of disabling illness.
• However, these differences often cause conflict in families especially between siblings. Siblings need to honestly discuss all options and try to understand each other’s positions even if they do not agree with them. Sometimes consensus only emerges after these discussions. Sometimes people have to agree to disagree.
• What is most important is to come to the decision which best meets the needs of the ill person(s).

Section 4: Overcoming Obstacles in Families

Section 4.1 Common Communication Obstacles
So many things left unsaid...
Families often do not discuss the issues around illness and caregiving. Some reasons are:
• We expect people to know without us saying
• We don’t want to argue
• The truth is difficult to face
• We don’t want to complain
• We don’t want to hurt others

“Dance” between guilt and resentment
• On the one hand, people are resentful for the time they spend, for what is happening to their lives, for what they are giving up for caregiving.
• On the other hand, they feel guilty for not doing enough because they love their family member. They keep going back and forth between the two and effective communication does not happen. Instead the cycle continues and can intensify.

Relevance of the past
• Past hurts, relationships, events etc. have an impact on present events in families. Often these past events have not been resolved to the satisfaction of all parties and there are hidden feelings involved.
• Past trauma especially results in buried emotions. Sometimes it is said that people “build a wall around their emotion” after trauma. In these cases, especially effective communication may be blocked by past events.

Section 4.2 Techniques to Overcome Obstacles

Section 4.2a Identification of Family Strengths

• It can be very helpful to identify family strengths, whatever they may be.
• So often families are stressed and not communicating effectively that all they see is the problems. It can be difficult to recognize the positive that is happening and has happened. Every family has strengths that can be brought to the caregiving process.
• Examples of family strengths are: the number of people, skills that people possess, a long history of family closeness, geographic proximity to each other.

Section 4.2b Active Listening

Active listening can help all parties feel understood even if they do not agree. It can diffuse potentially stressful situations and allow people to communicate honestly.

The steps of active listening include:

• Giving the speaker full attention
• Encouraging people to speak
• Confirming what the person said
• Asking open ended questions
• Acknowledging feelings
• Making certain all concerns have been heard

Section 4.2c Use of “I” Statements

• Use “I” messages (Start statements with “I feel”, “I need”, “I am frustrated...” etc. instead of “You.” This tends to keep both sides from getting defensive.

Section 4.2d Family Meetings

• Family meetings can be held in a variety of settings and under a variety of circumstances.
• They should include as many family members involved in care as possible.
• Sometimes a family may want to bring in an outside moderator to facilitate communication.
• Families should plan the topics of discussion carefully and set ground rules (i.e., stay to the topic, do not bring in past problems) ahead of time.
Caring for a “Difficult” Family Member

**SECTION 1:**
WHAT IS “DIFFICULT” BEHAVIOR? (p. 100)

**SECTION 2:**
WHEN BEHAVIOR BECOMES ABUSIVE (p. 100)

**SECTION 3:**
CIRCUMSTANCES & SUGGESTIONS (p. 101)
1. Desert of Time
2. Need for Balance Between Giving & Receiving
3. Circle of Influence Decreases
4. Impact of Regret
5. The “Fear” Factor

**SECTION 4:**
DEMENTIA: DEFINITION, EFFECTS AND PROVIDING THE BEST CARE (p. 103)
1. Definition and Effects
2. Challenging Behaviors with Dementia
   a. Short Term Memory Loss
   b. Hallucinations and Delusions
   c. Wandering and Getting Lost

**SECTION 5:**
IMPROVING THE RELATIONSHIP (p. 106)
1. Communicate More Effectively
2. Examine Your Own Feelings About Caregiving
3. Enlist Support and Assistance
Section 1: What is “difficult” behavior?

What behaviors do you find difficult?

Five Issues to Consider:
1. Sometimes “difficult behavior” is not doing things the way we want them done.
2. What one person may find difficult—another may not.
3. Most of us develop coping techniques early in our lives and these coping techniques go with us as we age. Some people therefore have what may be termed “difficult” behavior their entire lives and chronic illness makes these behaviors more pronounced.
4. Perceptions change over time—what may be termed “inspiring” at one point of life may be called “difficult” at another point. Behaviors which may have served people well at another point in life may not serve them as well in a period of chronic illness and vice versa.
5. Chronic illness often involves new and unfamiliar challenges for both caregivers and those receiving care. Even the best relationships are sometimes stressed under such circumstances.

Section 2: When behavior becomes abusive

• There is a fine line between these two but abusive behavior tends to destroy the underlying relationship. The relationship can get to a point that it is beyond repair.
• Often happens gradually - step by step.
• Apparent powerlessness of physically frail persons can be deceiving.
• Abusive behavior can go both ways.
• May involve alcohol or drugs.

Examples of potentially abusive behavior on behalf of the person receiving care:
• Finding fault with errors make in good faith.
• Faking symptoms to get extra attention.
• Waking caregivers thoughtlessly during the night.
• Asking for help out of whim rather than need.
• Giving away resources promised to family members.
• Demanding help beyond the caregiver’s capacity.

Caregivers have the right not to be subject to abusive behavior regardless of the situation.
Section 3.1 The Desert of Time

- Time is opportunity for those without illness and time can become a burden for those who are not able to do what they used to do.
- People may give great importance to events that in earlier times would have not raised an eyebrow.
- People may spend a huge amount of time preparing and waiting for a ten-minute visit. They may get angry at family members for being late or not staying long enough.
- Families often do not fully recognize or understand this issue.

What Is Helpful?

- Suggesting/facilitating useful and interesting activities to fill the time more effectively.
- Making an effort to be on time and finding ways to make visits truly enjoyable.
- Suggesting to friends and other relatives ways that they can help the ill person fill the time (i.e. bring pictures, mementos, activities of shared interests etc.)

Section 3.2 Need for Balance Between Giving & Receiving

- There is a powerful need for balance in our culture. It is difficult for most people to receive without giving in return. We spend most of our lives maintaining this balance in our families, among our friends, and in our organizations.
- Asking for assistance without a means of repaying it, is not something most of us are comfortable doing. However chronically ill people find themselves accepting assistance very often.
- There can become this lack of balance in relationships which can be very uncomfortable and lead people to conceal their true needs from family and friends. It can lead them to react with anger or resentment at people who are there to “help.”

What Is Helpful?

- Try as much as possible to build balance into any caregiving arrangement.
- Ill people should be allowed and expected to contribute.
- This can take many forms, not just financial. Families can get very creative.

Section 3.3 Circle of Influence Decreases

- For many ill people, the issues about which they formerly had influence decrease. For example, people often no longer have jobs or major family responsibilities. They may not have been able to keep responsibilities at clubs or at church.
- They may seem unduly concerned with their own health, with food, with the organization of their belongings in the house etc. They may seem to have become very self-centered.
• If they were relatively self-centered before becoming ill, they may become even more so.
• Family members do not always understand these changes though they are quite common.

What Is Helpful?

• To assist ill people who find themselves in this situation: let them retain as much decision-making and control over their own lives as possible.
• Family members can also be sources for new interests, hobbies, and responsibilities.
• Sometimes people also need touch, exercise, and other sensory stimulation to remind themselves that there is a wider world of which they are a part.

Section 3.4 Impact of Regret

• When faced with chronic or life threatening illness, many people review their lives. They look back on decisions they made, the families they came from, the tragedies and the joys.
• Many people want to discuss these issues with someone who will listen. Often it is an enriching experience for both parties. In some cases, however, the ill person is filled with regrets for what could have been, for decisions made long ago, for events that happened long ago. Sometimes all the other people involved have died or are unavailable.
• This overwhelming sense of regret can cause clinical depression, it can cause illness to get worse, and it is certainly painful to watch.

What Is Helpful?

Sometimes family members can be of great assistance by:

• Allowing people to talk about these issues without offering platitudes or advice
• Listening without judgment
• Bringing people together for reconciliation
• Reconnecting the person with his or her religious tradition
• Professional counseling can assist some persons to come to a sense of healing.

Section 3.5 The Fear Factor

Fear is a natural product of chronic and disabling illnesses. Most people are not comfortable admitting they are afraid. Fear often manifests itself as either anger or anxiety.

ANGER

• People who have anger as a result of fear can lash out at those who try to assist them. Often they are angry at medical providers as well. They often have limited safe outlets for anger so caregivers receive the brunt of their anger.
What Is Helpful for Anger?

- Look for the source of the anger/fear
- Count to 20/Leave the room
- Develop statements which understand but defuse the person’s anger
- Use humor appropriately

ANXIETY

- People can also worry excessively as a result of fears. This anxiety can become disabling.

What Is Helpful for Anxiety?

- Often caregivers can alleviate some worries by seeking and offering realistic information. Information is very empowering but ill people may not be in a position to gather information about the illness, living options, care options and other issues.
- Counseling and medication can assist the person to feel less anxiety.

SECTION 4: DEMENTIA — DEFINITION, EFFECTS AND PROVIDING THE BEST CASE

Definition:

- Dementia is a term used to describe a group of symptoms involving impaired mental functions. Dementia progresses at different rates in different individuals. It is not a normal part of aging. If a person is suffering from dementia, it is very important to determine what is causing the symptoms.
- A person should always have a complete medical assessment. Some causes are reversible and treatable.

Dementia includes the loss of:

- Short term memory and one or more of the following:
  - Ability to use words
  - Ability to work with figures
  - Ability to solve problems
  - Ability to be oriented to time and place
  - Ability to reason and make judgments

Dementia which is reversible can be caused by medications, clinical depression, thyroid disease, dehydration, alcohol, poor nutrition, and urinary tract infections among other things.
Dementia which is irreversible can often be treated to lessen or slow the symptoms. It may be caused by diseases like Alzheimer’s, Pick’s, Huntington’s, brain tumors, or vascular disease/arteriosclerosis.

Section 4.1 Challenging Behaviors with Dementia

• Persons with some form of dementia can behave in ways that are very challenging for family and friends to understand. Below are a few of these common behaviors and some suggestions to cope with them.

Section 4.1a. Short term memory loss – Someone with this symptom may:

• Forget the names of family, friends, or recent events.
• Forget more than one short instruction at a time.
• Forget how to do everyday tasks like dressing and eating.

What Is Helpful?

• Get the person’s attention before beginning to speak.
• Enhance your speech with gestures, pointing, nodding, visual aids, notes.
• Repeat, Rephrase, and Demonstrate instructions.
• Use names rather than pronouns.
• Be Patient. Remember that the person is not choosing to forget.

Section 4.1b. Hallucinations and Delusions

• A person experiencing hallucinations sees, hears, smells, tastes or feels things which are not there but are very real to the person.
• A person experiencing delusions thinks things are happening that are not. Both of these may make the person fearful, suspicious of others and argumentative with caregivers. These symptoms are often very unsettling to caregivers.

What Is Helpful?

• Do not argue or try to reason with the person about what they believe is happening or what they are seeing or hearing. It will usually make the situation worse.
• Ignore a hallucination/delusion that is not causing a problem or upsetting the person.
• Offer reassurance in a calm, gentle manner.
• Distract a person by refocusing them on a simple activity
• Remember that the person’s behavior is not deliberate. It is a result of what is causing the dementia.

Section 4.1c Wandering/Getting Lost

• Wandering can be caused by a number of issues including: hunger, need to use the restroom, boredom, sensory overload, inability to recognize surroundings, disorientation to time and place (i.e., waking up at night and thinking it is time to get up).
• This behavior may be complicated by the fact that the person cannot tell caregivers why they are restless or wandering.

• Caregivers sometimes need to try and anticipate situations carefully in order to minimize wandering and the possibility of the person getting lost.

What Is Helpful?

• Make the environment as **safe and secure** as possible in case the person wanders at odd times.

• Place **familiar objects**, furniture and pictures in surroundings. Help direct the person with clearly labeled rooms (using pictures, decorations or plaques).

• Learn to **identify** when the person is hungry, in pain, uncomfortable or has to use the restroom.

• **Distract** the person with conversation, food, drink or activity.

• **Remove** items that may **trigger** the desire to go out: shoes, coat, purse, car keys etc.

Section 4.2 Providing the Best Care for Someone with Dementia Symptoms

• Consider attending a support group or educational program sponsored by the Central Ohio Alzheimer’s Association [www.alz.org/centralohio](http://www.alz.org/centralohio). They have a 24-hour support line 800-272-3900 and their website has lots of fact sheets and information on it.

• Many excellent resources are also on You Tube. Several good channels are:
  - Pines of Sarasota (Teepa Snow, Occupational Therapist)
  - University of California at Los Angeles (UCLA) Dementia Series
  - Morningside Ministries ([www.mmlearn.org](http://www.mmlearn.org))

• Learn and practice Positive Physical Approach and Hand Under Hand Assistance which is described in Chapter 3 of this booklet

• Practice Relaxation Techniques and **Taking Care of You Activities** listed in Chapter 7 of this booklet

• **Find out about Long Term Care Options** by going to [www.coaaa.org](http://www.coaaa.org) in the “Resources” section and download the booklet “Central Ohio Long Term Care and Hospice Providers”
Section 5: Improving the Caregiving Relationship

Section 5.1 Communicate More Effectively
- Effective communication can be difficult in any situation. It can be even more so in a family involved in caregiving. People do not express feelings for fear of hurting another; people do not want to ask for help for fear of being a burden; people respond in anger or frustration to difficult behavior and so on.
- Communication is a two-way street. It involves both listening carefully and expressing yourself clearly.
- Sometimes we have to unlearn old habits.

Steps to effective communication:
- Use “I” messages (Start statements with “I feel...”, “I need...”, “I am frustrated...” etc. instead of “You”). This tends to keep both sides from getting defensive.
- Respect the rights and feelings of other people by what you say or do.
- Be clear and specific.
- Speak directly to the person(s) involved.
- Listen as you want others to listen to you.

Section 5.2 Examine Your Own Feelings about Caregiving
- Caregivers sometimes need to examine their own feelings as they consider the behaviors of the person for whom they are caring. Feelings of guilt, fear, resentment, and anxiety are very common.
- These may be influencing caregivers’ responses to difficult behavior. They may be even making the ill person’s behavior worse.
- If you realize that you are feeling resentful or experiencing more anxiety than usual, you may need to get some assistance to relieve your own stress in order to respond in a more effective way.

Section 5.3 Enlist Support and Assistance
- Caregivers need to educate themselves and seek the information, support and assistance which is right for their families.
- Some sources include: National Family Caregiver Support Program, caregiver support groups and the information in Chapter 8 of this handbook.
Preventing Burnout in Caregiving

Section 1:
*Common Emotions of Caregivers and Signs of Stress* (p. 108)

Section 2:
*Clinical Depression* (p. 108)

Section 3:
*Alleviating Stress & Burnout* (p. 110)

1. Set Healthy Boundaries
2. Examine Your Expectations
3. Consider Respite Care & Adult Day Health Services
4. Consider Attending a Support Group

Section 4:
*Suggestions for Taking Care of You* (p. 112)

1. General Tips
2. Relaxation Techniques
3. Tips for Better Sleep
4. The Pathway to Change
5. My Action Plan
SECTION 1: COMMON EMOTIONS AND SIGNS OF STRESS

The Roller Coaster of Emotions

- Anger
- Isolation
- Frustration
- Increased Closeness
- Depression
- Helplessness
- Laughter
- Grief
- Embarrassment
- Worry
- Guilt
- Joy

Warning Signs of Stress & Burnout in Caregiving

- Become irritated over every little thing
- Lose the ability to laugh often
- Experience sleep disturbances (too much or not enough)
- Have difficulty thinking about how to get through a day
- Blame others for the situation
- Feel overwhelmed
- Are unable to concentrate
- Have stomach distress
- Either gain or lose weight
- Use alcohol and drugs to cope
- Neglect your own health
- Do not participate in activities, which you used to enjoy
- Feel like you have to do it ALL

If you experience one or more of these symptoms, you should take steps to alleviate the stress. Caregivers who do not do so, risk deterioration in family relations, job performance, mental and physical health.

SECTION 2: CLINICAL DEPRESSION

Clinical Depression is a treatable illness. It is not:

- Just the blues
- A person feeling sorry for him/herself
- Emotional weakness
- A bad mood
- Feeling stressed
- Laziness
**Symptoms of Clinical Depression**  
(Usually the person has two or more of them and they last more than two weeks)  
- Sleep disturbance (too much or too little)  
- A significant weight gain or loss  
- Tiredness, lack of energy or sudden, uncharacteristic burst of activity  
- Loss of interest in ordinary pleasurable activities and grooming  
- Sadness, frequent crying  
- Uncharacteristic withdrawal from other people  
- Increased alcohol or drug consumption  
- Thoughts of suicide or a suicide attempt  

**Clinical Depression can be caused by:**  
- Losses, recent deaths of family or close friends  
- Chronic illnesses (Stroke, heart disease etc.)  
- Medications  
- Bio-chemical changes in the body  

**Types of Treatment of Clinical Depression**  
(used in combination usually)  
- Psychotherapy: “Talk Therapy”- Individual or group setting  
- Medications (Primarily Anti-Depressants but also other medications)  

**Where to Go for Help/or More Information**  
- Your family physician  
- Employee Assistance Program (EAP) — Ask your employer  
- National Institute of Mental Health (800-421-4211 or www.nimh.nih.gov)  
- National Mental Health Association (800-433-5959 or www.nmha.org)  
- National Foundation for Depressive Illness (800-239-1265 or www.depression.org)  
- National Suicide Prevention Lifeline (800-273-8255 or www.suicidepreventionlifeline.org)
Section 3.1 Set Healthy Boundaries
In the area of caregiving, establishing healthy boundaries refers to a caregiver setting realistic expectations on his/her own involvement or response to a situation. Caregivers do not have the ability to set limits on an older relative’s behavior. However, they can control their own response in a way that prevents becoming stressed and burned out.

Some additional notes on setting healthy boundaries:

- Research has shown that women (especially daughters) have a harder time setting healthy boundaries in a caregiving situation than men do.
- In establishing healthy boundaries, it seems helpful to identify the stressful situation, decide upon a realistic limit, write it down, try it and be willing to modify it later.
- Once a limit has been set, the situation will usually get more stressful initially. Caregivers should expect this to happen.
- Caregivers should think about setting one practical boundary at a time.
- Boundaries are not punishments or retribution but rather a means of remaining physically and emotionally healthy in the caregiver role.

Section 3.2 Examine Your Expectations
Expectations of Your Self:

Do you find yourself feeling guilty about not doing enough?

Caregivers very often expect that they should handle every situation they encounter with little or no assistance or support from others. Almost everyone needs some kind of assistance to get through this very difficult time of life.

Expectations of the Care Receiver:

What can your loved one do for him/herself in spite of the disabling condition?

What has he/she lost in the course of the illness? Being put in the position of receiving daily assistance is very difficult for most people. It is important to try to understand what this experience must be like for them and to allow them to retain as much control and decision-making over their lives as possible.

Family/Friends:

Do you find yourself feeling angry with family or friends for not assisting more?

How often do you ask clearly for specific assistance? Do you find yourself thinking “they should offer to help; I shouldn’t have to ask.” The primary caregivers in families very often find themselves doing more than other family and friends. They often need to learn to state their expectations clearly to others in order to allow or get more assistance in daily care.
Section 3.3 Consider Respite Care and Adult Day Health Services

Respite care is short term assistance by an outside provider (usually in the home) which allows the primary caregiver time free from his/her responsibilities. In Central Ohio, there are a variety of respite programs available with a variety of fee structures.

Adult Day Health Services provide assistance in a structured environment. Often they provide supervision with medications, social contact, leisure and therapeutic activities, nutritional meals, and transportation to and from the center. There are a variety of adult day centers available in Central Ohio with a variety of fee structures.

The value of respite care and adult day services cannot be overstated. Accessing and using outside support is not a sign of weakness but a sign of strength. Providing opportunities for your loved one to be with others and for you to have a healthy break in routine is an opportunity that benefits everyone. We all need the opportunity and time to step away from the intense caregiving experience so that we can be refreshed and replenish our energies to continue being there for our loved ones. For more information, see the website of the National Adult Day Services Association (www.nadsa.org).

Section 3.4 Consider Attending a Support Group

Both disease specific and more general caregiver support groups exist in Central Ohio. Some support groups offer primarily emotional support and practical suggestions while others are more educational. Support groups can be very helpful to caregivers feeling isolated or needing practical information.

Groups to Contact for Support Group Information:

Central Ohio Area Agency on Aging (www.coaaa.org)

- Monthly Dementia Support Group, 2nd Tuesday from 10:00am - 11:30am at 3776 S. High St., Columbus, Ohio 43207
- Conversations on Caregiving, 3rd Wednesday of each month, from 3:30pm – 5:00pm at 3776 S. High Street, Columbus, Ohio 43207

Call 614-645-7250 to register for either one.

Alzheimer’s Association Chapters (www.alz.org/centralohio) 614-457-6003 or 800-272-3900 (24/7 Helpline)

Central Ohio Parkinson Society Inc. 614-486-1901 (www.centralohioparkinson.org)

Syntero Counseling Services 614-457-7876 (www.syntero.org)

- Caregiver Consultation Program
- Support groups for widows and those with low vision.

A complete listing of Central Ohio Caregiver Support Groups can be found at the website www.coaaa.org under “Resources.”
Section 4.1 General Tips

- Treat yourself: Get a massage, buy a new outfit, buy flowers, get an ice cream cone.
- Think of something that would be a total waste of time. Then do it!
- Take a break every day — even if it’s only 10 or 20 minutes for quiet time.
- A brisk walk helps release muscle tension and clear the mind.
- Consider getting a pet. Stroking a pet lowers blood pressure.
- Take up a hobby or revive an old one.
- Try a bowl of Cheerios and milk before bed to promote sleep.
- Reduce your daily caffeine intake — especially in late afternoon.
- Take care: exercise, eat a well balanced diet and receive regular medical check-ups.
- Maintain old friendships and develop new ones.
- Plan your days to achieve a sense of balance.
- Self-care for caregivers is not a luxury, it is a necessity.

Section 4.2 Relaxation Techniques

There are many different types of relaxation techniques — see what works best for you.

**Awareness Breathing (Deep Breathing)**

1. Erase any stressful thoughts from your mind.
2. Relax your arms and shoulders. (You can be lying down, sitting or standing.)
3. Now take a deep breath. Let your abdomen — and then your chest — fill with air.
4. Exhale slowly. Repeat the process until your breathing is regular and steady. Let your mind concentrate on each breath.
5. Feel relaxed and in control.

**The Relaxing Sigh**

1. Start by standing up or sitting up straight.
2. Sigh deeply, letting out a sound of deep relief as air rushes out of your lungs.
3. Inhale naturally — Just let the air flow in.
4. Repeat 8-10 times, if possible.
5. After each exhale, shake your hands to ‘do away’ with the tensions you are feeling.

**Imagery or Visualization**

1. Close your eyes and take 3 long breaths. Breathe in through your nose, hold for 2 seconds and slowly exhale through your mouth.
2. Imagine yourself in an ideal place — a sunny tropical beach, a clear mountaintop, on a lake or in a candle lit cabin. The place can be anywhere that is pleasant to you.
3. Use all your senses — smell, touch, hearing, taste — to create your favorite scene.
4. Feel and visualize your entire body relaxing in the scenario.

**Stretching**

1. Do slowly and easily without bouncing. Bouncing could cause injury.
2. Stand with feet about shoulder length apart. With your arms straight up above your head, gently bend to the side at your waist and stretch, keeping your feet flat on the floor. Now do the other side — using slow gentle movement.
3. Gently and slowly roll your head in a counter clockwise position about 3 times, now reverse the direction.
4. Gently roll your shoulders forward and then backwards. This will help stretch and relax tight muscles.
5. If you feel discomfort at any time, STOP!

**Section 4.3 Tips for Better Sleep**

Sleep is as important as food and air. Quantity and quality are very important. Most people need between 7½ to 8½ hours of uninterrupted sleep. The amount of sleep you need to rest and restore your mind and body might be different than others.

To determine how much sleep you need, observe how much it takes for you to feel rested and alert during the day.

**Keep regular hours.**

- Try to go to bed about the same time and get up at the same time every day. The arising time is the most important pace setter for your internal clock.
- Even if you stay up late or have trouble sleeping at night, waking up at the same time can help your body get back into a healthy sleep pattern.

**Establish relaxing rituals before bedtime.**

- Do the same thing each night to tell your body it’s time to wind down. For some people, that may be a warm bath, light bedtime snack, reading a book or listening to relaxing music. Find what works for you and then do it on a regular basis.

**Avoid bright light around the house before bedtime.**

- Dim light signals the internal body clock that it is time for sleep.
- Reserve your bed for sleeping. Extensive reading, working and worrying in bed can cause your bed to be a place of stress rather than a place of relaxation.

**Avoid all stimulants in the evening.**

- Avoid things that contain caffeine within six hours of bedtime. This includes coffee, tea, sodas and chocolate. Stimulants can delay restful sleep.
Nicotine is a stimulant. Studies have shown that people who smoke cigarettes have more difficulty falling asleep and staying asleep. Nicotine raises the blood pressure, increases the heart rate and stimulates brain-wave activity. Also, remember the fire hazards of smoking in bed.

**Be aware that the “night cap” has a price.**
- Avoid alcohol within three to four hours of bedtime. Alcohol may act as a sedative but it disrupts sleep patterns and causes awakenings later during the night. Also, be aware that alcohol interacts negatively with medications.

**Organize your day.**
- Regular times for eating meals, taking medications, performing chores and other activities will help keep our inner clocks running smoothly.

**Exercise regularly.**
- Regular exercise can help you go to sleep more easily and increase the quality of sleep. Moderate physical exercise in the afternoon or early evening is more effective for improving sleep.

**If you nap, try to nap about the same time each day.**
- Mid-afternoon is considered the best time for a nap because it usually doesn’t interfere with going to sleep at your regular bedtime.

**Check your medications.**
- Many medications cause insomnia. Ask your doctor or pharmacist about the type, dosage and timing of medications least likely to interfere with your sleep.

**Create a safe and comfortable sleeping environment.**
- Keep your bedroom at a comfortable temperature. Make sure there are locks on all doors and smoke alarms on each floor. A lamp that is easy to turn on and a telephone by your bedside may be helpful. In addition, the room should be dark, well ventilated and have all nonessential sounds blocked out. However, there should be a nightlight in the hallway or bathroom.
- If you can’t get to sleep for over 30 minutes, get out of bed and do something boring or relaxing in dim light until you are sleepy.
- You should consult your doctor if you are not able to get into a routine of restful sleep, or if you are so tired during the day that you are unable to function.

For more Information, visit the National Center on Sleep Disorders, which is within the National Institutes of Health. Website: [www.nhibi.nih.gov/about/ncsdr/](http://www.nhibi.nih.gov/about/ncsdr/)
Section 4.4 The Pathway to Change

If you are a caregiver with many competing demands on your time, suggestions for taking care of yourself may likely prompt the response, “How?”

How do I increase exercise?

How do I improve my nutrition?

How do I make time for leisure activities, relationships, or rest?

It is important to understand that these suggestions all involve significant changes in behavior.

Change is hard. We usually have many years of doing (or not doing) something a certain way. Whether you need to drink more water, manage your time, or stop smoking, it will take time to learn how to incorporate this change into your life.

• Do not expect immediate success without some effort and possibly discomfort.
• Do revise your strategy until it works.
• Remember, willpower and determination alone rarely guarantee success.
• Lasting change is truly a step-by-step process that requires preparation, planning, learning, and a great deal of practice.

Making a Change: Steps to Consider

Step 1. Examine Your Current Behavior and the Benefits of Change.

• Research shows we must be truly convinced of the benefits to be successful in changing our behavior.

• Start with an accurate picture of your current behavior by keeping a diary for at least one week. Record when, where, and with whom the desired behavior increased or decreased. Include your thoughts and feelings at the time.

• Watch for patterns. People, places, times, our feelings and thoughts all influence our behavior. This information will help you identify barriers to change and plan to overcome them.

• Ask yourself the following questions:
  - Is my current behavior providing the degree of health and functioning I want for myself at this time?
  - What is the long-term impact of my behavior on my health and functioning, ten, twenty, or thirty years from now?
  - Write out the benefits of your current behavior and the benefits of the proposed change. Which do you want more?

• For more information to decide on making a change, talk with your doctor, request some screening tests, obtain information from health organizations, or self-help groups.
Step 2. Commit to a Goal and Create A Plan to Reach it

- Write a statement of your goal, for example, “I want to be a person who exercises regularly.” Keep it positive, and present-focused.
- Make sure your goal is realistic. Rarely is anything in life all or nothing, including success. State your goal in terms of “consistently” or “regularly” rather than “always” or “never”.
- Create a self-contract that includes:
  - What you want to accomplish
  - The benefits of achieving your goal
  - The obstacles you have identified
  - A specific plan of action that includes how you will handle obstacles
  - A reward you will give yourself when you are successful (and some smaller ones for progress along the way!).
- Give yourself some praise often with statements such as:
  - “I take time to exercise.”
  - “I enjoy my evening walk.”
  - “I am proud of my efforts to manage stress.”

Step 3. Adapt Your Plan to Make it Work for You

- Get accurate information on how to safely and effectively work toward your goal. If your goal is health-related be sure to discuss it with your doctor before getting started.
- Identify smaller short-term goals, which you can achieve along the way to your main goal. Small successes will reaffirm, “I can do this.”
- Identify and consult a role model. Find someone who has been successful in making the same change and find out what worked for her or him.
- Seek support through the buddy system or a group. Working along with others who have common goals will provide you with encouragement, motivation, understanding, and valuable information.
- Approach change as a learning process. Real progress toward change includes learning how to get around the barriers.
- Plateaus, setbacks, and slip-ups are not disasters! They are to be expected. Examine the “who, what, when, and where”, as well as your thoughts and feelings, to help you avoid them in the future.
Section 4.5 My Action Plan

When writing an action plan, be sure it includes:

1. What you are going to do.
2. How much you are going to do.
3. When you are going to do it (i.e., what time of day).
4. How often you are going to do it.

Example: This week I will read a favorite book (what) for a half hour (how much) in the midafternoon when my spouse sleeps (when), three times- Monday, Wednesday, and Friday (how often).

This Week I Will:

______________________________________ (What)
______________________________________ (How Much)
______________________________________ (When)
______________________________________ (How Often)

How confident are you that you will complete your entire action plan during the week?
(circle one)

1  2  3  4  5  6  7  8  9  10
Not at all                                      A great deal

Check off each day you accomplish your plan — then make comments:

___ Monday
___ Tuesday
___ Wednesday
___ Thursday
___ Friday
___ Saturday
___ Sunday

Reprinted with permission from The Arthritis Helpbook by Kate Lorig and James Fries (1998).
Keep Your Goal in Sight and Keep Going!
SECTION 1: WEBSITES OF INTEREST

Allows you to access federal government websites that have to do with aging issues (Medicare, Social Security, Veterans Administration, etc.) Also links to aging services websites in each state.

State of Ohio – www.aging.ohio.gov
Ohio Department of Aging website. Includes the Long Term Care Directory. www.ltc.ohio.gov also has links to Area Agencies on Aging in the State of Ohio for local services.

Caregiver Information
- www.caregiver.org – Family Caregiver Alliance website with fact sheets and on line discussions.
- www.nextstepincare.org – Checklists and other materials to explain caregiving issues.
- www.caregiverlibrary.org – Information and links for caregivers on a wide variety of topics.
- www.videocaregiving.org – A website which has a variety of videos. It has interviews, demonstrates techniques and can be very helpful for a variety of different needs.
- www.youtube.com – large website which has many, many helpful videos. Groups that have good videos for family caregivers are UCLA, Mayo Clinic, Rural VA, Pines of Sarasota (Teepa Snow is an educator for them).
- www.alz.org – The Alzheimer’s Association works on a global, national and local level to provide care and support for all those affected by Alzheimer’s and other dementias.

Health and Medication information – www.medlineplus.gov. A comprehensive website of the US government which contains easy to read information on diseases, medications and treatments. Updated regularly.

Disability Product Information – www.abledata.com. A comprehensive website listing and describing about 10,000 products which are available to help people with disabilities.

Information for Adults with Disabilities – www.disabilityrightsohio.org. Has many fact sheets on benefits, rights, and other important issues for those in Ohio with mental or physical disabilities.
Legal Issues in the State of Ohio – www.proseniors.org. Includes easy to understand fact sheets on legal and benefit issues for residents of Ohio. It also offers limited legal advice through its phone number 800-488-6070.

Hospice and End of Life Information – www.leadingageohio.org. Ohio Hospice and Palliative Care Organization Has a list of hospice providers in the State of Ohio and links to other related organizations. Two publications which are helpful are entitled “Choices: Living Well at the End of Life” and “Conversations at the End of Life.”

Conversations Project – www.conversationsproject.org. Much information on how to have family conversations about future wishes and end-of-life care. Has checklists and booklets that give ideas and tools.

 SECTION 2: THE NATIONAL FAMILY CAREGIVER SUPPORT PROGRAM

A nationally funded program operated in Central Ohio by the Central Ohio Area Agency on Aging (COAAA). It provides the caregiver workshops, and funds services designed to assist caregivers on a short term basis. The services include: information and assistance, counseling, respite, and other supplemental services.

For more information, call 866-589-7277 or visit the COAAA website (www.coaaa.org). Or in your county, call one of these agencies:

- **SourcePoint (Delaware County)**
  740-363-6677

- **Community Action of Fayette County**
  740-335-7282

- **Licking County Aging Program**
  740-345-0821 or 800-452-0097

- **Pickaway County Senior Center**
  740-474-8831

- **Meals on Wheels of Fairfield County**
  740-681-5050

- **Franklin County Office on Aging**
  614-525-6200

- **Madison County Senior Center**
  740-852-3001

- **Union County Senior Services**
  800-248-2347 or 937-644-1010

Request a copy or download our other guides:

- **Central Ohio Housing Guide**
- **Central Ohio Long Term Care & Hospice Guide**
- **Central Ohio Private Homecare Guide**
- **Central Ohio Utility Guide**
- **Central Ohio Prescription Guide**
- **Central Ohio Support Group Guide**
- **Central Ohio Transportation Guide**
- **Central Ohio Moving & Transitions Guide**
- **Central Ohio Respite Guide**
- **Books, Videos, & Websites for Family Caregivers.**
Navigating the Medicare system can be difficult.

Our experts at the Central Ohio Area Agency on Aging are ready to answer your Medicare questions!

Call us today to receive free unbiased information to help you make informed decisions.

We do not represent or sell insurance products.

Your Aging and Disability Resource Network

800-589-7277  www.coaaa.org
OhioHealth John J. Gerlach Center for Senior Health
Providing a positive perspective to aging

As part of our network of exceptional neuroscience care, the OhioHealth John J. Gerlach Center provides healthcare programs and support services specifically designed for the unique needs of older adults.

WE support older adults and their families in our community as well as those who receive health services from our central Ohio hospitals — OhioHealth Riverside Methodist Hospital, OhioHealth Grant Medical Center, OhioHealth Doctors Hospital, OhioHealth Grady Memorial Hospital and OhioHealth Dublin Methodist Hospital.

Programs and services offered at the Gerlach Center include:

+ Comprehensive geriatric medical consultation
+ Senior and caregiver education, computer tutoring and fitness programs
+ Cognitive neurology
+ OhioHealth Delay the Disease™
+ Volunteer opportunities
+ Support groups

Call (614) 566.5858 or visit OhioHealth.com/SeniorHealthServices

OhioHealth John J. Gerlach Center for Senior Health
3830 Olentangy River Road
Columbus, Ohio 43214