

SECTION A

CAREGIVING FOR AN AGING LOVED ONE

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1. INTRODUCTION: CAREGIVING FOR AN AGING LOVED ONE

We are glad that *Pathways for Caregivers* has found its way to you and hope you find it a helpful tool.

Pathways is brought to you by **United Way Caregivers Coalition**. It was created by caregivers for caregivers. The *Coalition* is an initiative of **United Way of Northern New Jersey**, which serves Morris, North Essex, Somerset, Sussex, and Warren counties.

Whether you are planning ahead for the care of an aging loved one or find yourself in the middle of a crisis with decisions that need to be made quickly, information and resources can often be confusing and difficult to access.

Pathways is intended to be a source for information, advice, and ideas about caregiving. While you will find some organizations referenced, *Pathways* is not meant to be a complete list of all agencies and services available in northern New Jersey. Rather, *Pathways* is designed as a sort of “roadmap” to help put you on the right track for your particular caregiving situation and to support you along the way.

For a complete list of resources in the area, your best bets are **NJ 2-1-1** and each county’s **Division of Senior or Aging Services**, also known as the **Aging and Disability Resource Connection (ADRC)**. You will find these organizations referenced throughout this guide.

As you read through *Pathways*, please keep in mind that it is intended to help caregivers who may be facing a wide range of situations. While planning ahead is important, we recommend that you try to focus on the caregiving stage that you are currently in and not look too far into the future. Sometimes looking too far down the road can be a bit overwhelming.

The most important thing to know is that as you take on caregiving responsibilities, you need not do so in isolation. Reach out. Ask for help. Contact the *Coalition* at **888.33.UWCARES (888.338.9227)**. There are resources, organizations, and fellow caregivers who can provide you with the support you need.

Important Reminder!

Information in *Pathways* was current as of printing. Careful effort has been made to provide the most current and accurate information; however information does change. Be sure to double check directly with organizations to confirm the accuracy of information.

2. BECOMING A CAREGIVER FOR A LOVED ONE WITH ISSUES OF AGING

If you support your aging loved one in any way on a regular basis – driving to appointments, helping with daily activities, personal care, housework, shopping, managing finances, speaking with doctors, or providing emotional support – you are a caregiver.

The following activities, when done on behalf of another, are traditionally considered “caregiving:”

- Occasional or daily help managing the household (chores, meals, transportation, etc.)
- Financial and/or business assistance (balancing checkbooks, paying bills, etc.)
- Daily supervision and/or personal care
- Organizing medical care (making appointments, transportation, speaking with doctors, translating, etc.)
- Medication management
- Emotional support

Whether your aging loved one lives with you, in their own home, in a facility, or even a long distance away, if you do any of these things on a regular basis, you are a caregiver...and we hope this guide will be of help to you.

While you may do just a few things for your aging loved one at the moment, it is a good idea to be aware of, and even track, changes that may occur. With an aging loved one, there are warning signs to watch for that signal an increasing need for support.

Warning signs to watch for:

- Difficulty walking or unsteady when standing
- Poor grooming or personal hygiene
- Loss of appetite or changes in eating
- Spoiled food and/or little nutritious food in home
- Difficulty managing medications
- Difficulty managing routine paperwork: bills and finances, mail, etc.
- Loss of interest in activities once enjoyed
- Difficulty concentrating
- Memory loss, confusion, abnormal conversation
- Personality changes
- Unsafe conditions in home

The emergence of or increase in any of the above may signal that it is time to begin providing additional support for your loved one.

Stages of Caregiving

Most caregivers will, over time, experience different stages of caregiving. Coping with these changing stages may require you to develop new skills, manage new stresses, and maintain a level of flexibility as you adapt to your loved one's changing needs.

Realistically, most caregivers experience a steep learning curve, becoming a medical connoisseur, system navigator extraordinaire, assertive advocate, financial guru, and legal expert all in one. For many, this must be done while balancing a full- or part-time job, children, grandchildren, spouse, and other relationships and responsibilities, while trying to maintain their own physical health, mental health, social life, and overall well-being.

Caregiving for an aging loved one presents a variety of challenges. These challenges can arrive suddenly, with a crisis, or can develop over time through a series of small but sometimes disconcerting mishaps and warning signs. You may be the only person providing care, or you may be part of a larger network of family and friends willing to share caregiving duties.

Whatever the particular caregiving situation in which you find yourself, you may be unsure of which steps to take. And throughout any caregiving journey, those steps will most likely change.

Life is a journey – each of us can only take one step at a time and try to do our best along the way.

You Are Not Alone

We don't need to tell you that caregiving can be all-consuming, exhausting, frustrating, and even lonely at times. For any caregiver, the stress of providing care can generate a range of emotions on any given day – frustration, sadness, worry, even anger.

So, do not try to do the entire job alone or take on all your caregiving responsibilities in isolation. A strong network of friends, family, service providers, and community resources can support you in your caregiving role, while helping you maintain your own well-being. In this guide, you can find the resources and people you need to help you take care of your loved one and yourself.

Ask for help whenever you need it. Seeking out information and support will help you provide the best care possible for your family member or friend – and for you. Remember, taking care of yourself means you will be better able to care for your loved one.

Your Changing Role

Throughout your caregiving journey, your loved one may require different levels of care. Having to take on additional responsibilities that your parent, spouse, partner, or friend was accustomed to doing independently can generate a range of emotions for you both. Being informed about and understanding your loved one's particular needs will help you cope with transitions and the changing nature of your relationship with one another.

As your caregiving role changes, flexibility will be key.

If and when you are called upon to take on a new level of care, give yourself time to adjust. Do not expect your life to return to normal right away. The social structure you knew, the friends you had, and activities you did may have to change as you take on your caregiving role. Give yourself time to develop and establish new daily routines.

If you do need to take on more and more daily tasks related to caregiving, it will become even more important to take advantage of community resources and any services for which you may be eligible.

Remember that each caregiving situation is unique – no two caregivers experience the same circumstances or transitions. There is no single way of caring. With the right information, resources, and support you will care for your loved one and yourself in the best way possible.

Call Yourself a Caregiver

It is natural for those of us who provide care for a loved one to think of ourselves as just responsible children, spouses, partners, and friends. People don't often refer to themselves as "caregiver" – but they should.

When we embrace the title of caregiver we define our caregiving journey and give scope to the work we do. When we identify as caregiver – to our families, our neighbors, our employers – we help educate the community about the vital role unpaid family caregivers play in our nation's long-term health care system.

Embracing the new title of caregiver underscores that we are each experiencing a new "job." It helps us understand the vital importance of training, education, and support – all things that come with any new job. We see more clearly the benefits of connecting with caregiving colleagues. Importantly, we can accept that as caregivers we deserve to take regular breaks – without guilt – from our caregiving work. All of which help us provide quality care for our loved ones while protecting our own health and well-being.

3. WHERE TO BEGIN: FINDING THE SUPPORT YOU NEED

Your First Call is an Important One

Whether you are just beginning to provide care for a loved one who is aging, or have been a caregiver for some time but without any real support, the following are some helpful first calls to consider:

Aging & Disability Resource Connection of New Jersey (ADRC)

The ADRC is New Jersey's doorway to information and assistance for older persons, adults with disabilities, caregivers, and professionals looking for services and programs, and is an excellent portal to a wide variety of resources. Services can differ from county to county. Use the phone number below to contact your county's ADRC. Phone is staffed weekdays during normal working hours.

- **877.222.3737**
www.adrcnj.org

NJ 2-1-1

NJ 2-1-1 offers both confidential support to people in crisis and personalized information and referrals to those needing assistance. NJ 2-1-1 now operates statewide, connecting people with the resources they need to solve common life problems. It is staffed 24/7.

- **Dial 2-1-1 or 800.435.7555**
www.NJ211.org

Starting Points for Long-Distance Caregivers

Caring for a loved one from a distance can be logistically demanding. Consider connecting with the local Office on Aging where your loved one resides to learn about resources in the area. The national Administration on Aging site can give you local Office on Aging contact information.

- **www.aoa.gov**

If your loved one is a senior, consider locating a qualified geriatric care manager in the area who knows about local resources and who could do an assessment and develop a care plan for you.

- **www.caremanager.org**

The Importance of Being Organized

As you begin your caregiving journey, try to start organizing information right from the beginning. Throughout *Pathways* you'll find helpful hints about how to manage your loved one's medical information, financial information, insurance information, etc. It may seem daunting at first to gather papers and organize folders, but it will save you time and frustration in the long run. For templates, lists, and other resources to help you organize information, visit **United Way of Northern New Jersey's Caregivers Toolbox: UnitedWayNNJ.org/CaregiverTools**.

Additional websites of national organizations with information on caregiving can be found in **Appendix A**.

4. CAREGIVER EDUCATION PROGRAMS

There are a variety of caregiver education programs available throughout New Jersey ranging from in-home instruction to public seminars. These programs are designed to educate caregivers in assessing care needs and in developing the skills necessary to provide care. Programs address issues such as personal care (e.g. bathing, lifting, transferring), disease education, medication management, legal issues, self-care, and more. For information, begin with these organizations:

Aging & Disability Resource Connection of New Jersey (ADRC)

The ADRC is New Jersey's doorway to information and assistance for older persons, adults with disabilities, caregivers, and professionals looking for services and programs. The ADRC is an excellent portal for caregiver education programs in your county. Use the phone number below to contact your county's ADRC. Phone is staffed weekdays during normal working hours.

- **877.222.3737**
www.adrcnj.org

United Way *Caregivers Coalition* (Morris, North Essex, Somerset, Sussex, and Warren)

The *Coalition's Munch & Learn Education Series* offers programs on various aspects of caregiving by professionals in the field. Any local group, including area corporations, faith-based organizations, civic groups, etc., may schedule programs. Contact the *Coalition* Coordinator for a list of topics or to schedule a workshop.

- **888.33UWCARES (888.338.9227)**
UnitedWayNNJ.org/CaregiversCoalition

Additionally, the *Coalition* offers **The Informed Caregiver Video Series** designed to help unpaid family caregivers navigate the challenges of caring for an aging loved one. Videos can be accessed online.

- **UnitedWayNNJ.org/CaregivingVideos**

Alzheimer's Association, Greater New Jersey Chapter

The Alzheimer's Association offers care consultation, support groups, educational opportunities, connection to respite care, and linkage with local community resources.

- **973.586.4300 or 24-hour helpline 800.272.3900**
www.alznj.org

Caregiver Outreach in the Workplace, Cornerstone Family Programs (Morris)

Cornerstone Family Programs provides working caregivers in the Morris County community with a variety of free elder caregiving workshops on-site at business locations throughout the county. Programs are presented by a professional geriatric care manager and change seasonally. Call for a complete list of topics.

- **973.538.5260**
www.cornerstonefamilyprograms.org

DOROT's Caregivers' Connections, Programs by Telephone

Caregivers' Connections is a telephone conference program with informational workshops for those who care for older adults. During sessions, caregivers are able to share concerns, exchange ideas, and get much-needed information without leaving their homes or workplaces. Minimal registration fee; scholarships available.

- **877.819.9147**
www.dorotusa.org

Visiting Nurse Association of Northern NJ (VNANNJ) (Morris)

The VNANNJ In-Home Caregiver Education and Support Program provides FREE in-home education and support to unpaid caregivers residing in Morris County so they may improve their ability and effectiveness as caregivers. The care recipient must be over age 18 and functionally impaired with a chronic disease or disability. There are no income or asset eligibility requirements for this program.

The program provides a registered nurse to meet with the caregiver at their home to conduct an initial assessment and to set up a teaching plan that will help to relieve caregiver stress and increase caregiver effectiveness. Other services include in-home instruction to enable caregivers to identify the skills needed to provide proper care, including lifting and transferring, bathing, personal care, nutrition, disease education, stress management, and accessing community resources. The program allows for up to five professional home visits by a registered nurse, physical, speech or occupational therapist, social worker, or nutritionist to provide educational and support services, including stress management.

- **800.WE.VISIT (800.938.4748)**
www.vnannj.org

Medicare will pay for certain types of family caregiver education when it is provided as part of a patient's medically necessary, face-to-face visit. A physician may be able to bill for family caregiver education as part of the counseling and coordination of care services provided during a patient visit as long as the patient is on Medicare, the caregiver education directly involves the patient, and is medically necessary. This education can take place in a doctor's office or other outpatient facility, a patient's home or private residence, or an assisted living facility or other domicile.

See "Tip Sheet for Providers: Caregiving Education" at www.cms.hhs.gov/Partnerships/downloads/ProviderBillingforCaregiverEducation.pdf.

Educating yourself about the disease or disability affecting your loved one is important. There are many disease/disability-specific websites available. Make sure the information you access is from a recognized and trustworthy organization. Some recommended websites can be found in **Appendix B**.

5. CAREGIVER SUPPORT



It is important for caregivers to recognize that they are not alone, to learn that caregiving is more than a one person job, and to see that taking care of themselves is vital to their loved one's well-being.

– Caregiver Action Network

Caregivers are characteristically unselfish, patient, and steadfast; however, they are often so busy giving care that they forget or neglect to take care of themselves. In fact, studies show that caregivers are at a greater risk for health problems. As a caregiver, your health – both physical and emotional – is as important as the health of the loved one for whom you provide care.

Self-Care – It's Absolutely Necessary

Caregivers often succumb to feelings of stress and anxiety. Stress is a natural by-product of caregiving. All caregivers experience stress. It can manifest itself in both a physical and emotional way. It is vital to find an outlet to relieve it! You may even need to **give yourself permission to take care of yourself**. That is fine, good, and necessary!

Self-care and stress management can be achieved in many ways. Paying general attention to daily activities like healthy eating, exercising, sleeping, and talking with friends is vital. Be sure to schedule (and keep!) your own doctor appointments. Reach out for support. Simplify and structure your routine. Ask for help. These are vital steps you can take as a caregiver to keep yourself healthy.

Even for the busiest of caregivers, **mini-breaks** can be lifesavers. Go to a quiet room or step outdoors and just breathe for 10 minutes; clear your mind and focus only on your breath. Write in a journal. Say a positive affirmation. Light a candle. Listen to music. Call a good friend.

You might consider attending a **support group**, where people share a common experience and provide each other with various types of help, i.e., information, resources, and emotional support. Support groups can be led by a professional facilitator or be self-help groups.

At times caregivers may disagree with decisions made by their loved ones, and even blame themselves if the care they want to provide is not accepted. However, it is often helpful to be flexible in approach and to encourage decisions by loved ones, as long as these decisions do not include truly dangerous choices. **Keep in mind – things will never be perfect, and they don't need to be.**

Other ideas may be helpful. These require a range of time and/or cost. Sometimes referred to as complementary or alternative therapies, there are options for everyone:

- **Aromatherapy** uses liquid plant oils and aromatic compounds to improve mood and health.
- **Art therapy** is based on the belief that the creative process is both healing and life enhancing. It uses art materials and projects as therapeutic tools.

- **Chiropractic** is a health care discipline that believes that realignment of the spine will alleviate any nerve interference that directly affects how stress manifests itself in the body. This can be especially helpful if you are physically moving your loved one from place to place, which takes a toll on your body; a chiropractor can teach proper lifting techniques that best protect your back.
- **Massage therapy** is several disciplines that utilize body techniques to promote healing.
- **Music therapy** is the systematic use of music to improve one's emotional stability.
- **Reiki** is a system of subtle energy healing using the laying on of hands and distinct healing techniques, designed to relax, de-stress, and heal.
- **T'ai Chi** is a slow, gentle body movement that helps the flow of body energy by breathing deeply and meditating. The gentle flowing motion reduces stress and improves health.
- **Yoga** is a physical and mental discipline, and also a lifestyle practice, the goal of which is the union of the mind, body, and spirit.

These are just some types of therapies that can help you manage your stress, as well as reduce pain, anger, anxiety, and even depression. Choose one or more that is right for you. Whether relaxing muscles and reducing inflammation, or improving strength, balance, and mobility, or getting a more restful sleep...these are all critical ingredients of self-care that will help you protect your own emotional and physical health as you continue your caregiving journey.

Respite for Caregivers

Respite literally means a period of rest or relief. Respite care gives a caregiver temporary relief from the responsibilities of caring for a loved one with chronic illness, physical, cognitive, or psychiatric disabilities. Respite is important for all caregivers, and is a key component to maintaining caregiver health. And caregiver health is, ultimately, vital for the loved one requiring care. Caregivers should take respite breaks regularly, **without guilt**.

Length of respite care can be anywhere from a few hours to several weeks. Services that provide respite may be used for a variety of reasons ranging from emergencies to vacation, and with a range of frequency from a few hours per week or month, to weekends, even to everyday respite. Respite can be in-home or at respite centers. All members of the family will benefit when respite becomes a regular event.

In-Home Respite

In-home respite services consist of a worker who comes to the family home so that the caregiver can leave the house for a period of time. These services are usually provided by agencies that recruit, screen, and train workers. This type of respite is usually less disruptive to the individual needing care, provided there is a good match between the worker and the individual. Caregivers looking for this type of respite support would contact **home health care** agencies.

Out-of-Home Respite

Out-of-home respite can take place in adult day centers, assisted living communities, or skilled nursing facilities. This type of respite often offers peace of mind to the caregiver, while providing a stimulating environment for the aging individual. However, centers usually restrict the length of stay and may exclude individuals based on severity of disability. Caregivers looking for this type of respite would contact **adult day centers, assisted living communities, and skilled nursing facilities**.

One good local starting point for lists of in-home respite agencies and respite centers is the ADRC.

Statewide Respite Care Program

This program provides respite care services for older adults and for functionally impaired persons age 18 and older to relieve their unpaid caregivers of stress arising from the responsibility of providing daily care. You must meet specific income requirements to be eligible. To reach the Statewide Respite Care Program provider in your county, contact the Aging and Disability Resource Connection (ADRC).

- **877.222.3737**
www.adrcnj.org

General Caregiver Support

Jewish Family Service of MetroWest New Jersey (Essex, Morris, and Sussex)

Care consultation service provides caregiver support and connection to community resources to help with caregiving responsibilities.

- **973.765.9050**
www.jfsmetrowest.org

County Caregiver Coordinators & Support Programs

Some county ADRCs have a person designated to work with caregivers and caregiver programs.

- **Essex County**
973.395.8389
- **Morris County**
800.564.4656
www.morrishumanservices.org/adv/caresupport.asp
- **Sussex County**
973.579.0555, x1225
- **Warren County**
908.475.6591

United Way *Caregivers Coalition* (Morris, North Essex, Somerset, Sussex, and Warren)

Open to the public and free to join, the *Coalition* is a unique hub of information, education, and connection for caregivers. Made up of caregivers and professionals who support them, the *Coalition* helps caregivers find the specific services they need, and connect with peers and professionals who share experienced advice. Those who tap into the *Coalition* report reduced stress, enhanced skills, improved access to resources, a renewed commitment to self-care, and meaningful connection to one another. All are welcome. *Coalitions* meet monthly in each county.

- **888.33UWCARES (888.338.9227)**
UnitedWayNNJ.org/CaregiversCoalition

Caregiver Counseling/Psychotherapy

There are many counseling and support services available in our region through local hospitals, human service agencies, and private practitioners. In some instances, counselors may make home visits or will arrange to meet with, and support, those who are providing care to aging family members and/or friends. People with insurance should check with their insurance company to ensure that the provider is in their network.

Mental Health Association in New Jersey, Inc.

Affiliate offices throughout New Jersey work for mental health for children and adults through advocacy, education, training, and services.

- **800.367.8850**
www.mhanj.org

New Jersey Directory of Mental Health Services By County

www.state.nj.us/humanservices/dmhs/news/publications/mhs/directory_by_county.html

Aging & Disability Resource Connection of New Jersey (ADRC)

The ADRC is New Jersey's doorway to information and assistance for older persons, adults with disabilities, caregivers, and professionals looking for services and programs, and is a good portal for referrals to counseling services. Services can differ from county to county. Use the phone number below to contact your county's ADRC. Phone is staffed weekdays during normal working hours.

- **877.222.3737**
www.adrcnj.org

Other Supports for Caregivers

Self-Help Groups

Self-help groups can be of great help to those trying to cope with the demands of caregiving. There are many local, state, and national groups that can be found by contacting the New Jersey Self-Help Group Clearinghouse. If the Clearinghouse cannot direct you to an appropriate group that is already set up, they will be able to help you to join with others to start one.

- **NJ Self-Help Group Clearinghouse**
800.367.6274
www.njgroups.org

Internet Support

If you are unable to attend support groups in your community, these websites may offer help:

- www.caringroad.org
- www.strengthforcaring.com
- www.caregiveraction.org
- www.caregiver.org
- www.caregiving.org
- www.wellspouse.org

Telephone Support

DOROT's Caregivers' Connections

DOROT's Caregivers' Connections, a telephone conference program, offers support to those who care for older adults. Through weekly telephone support groups facilitated by geriatric social workers and care managers, caregivers receive emotional support and have an opportunity to ask questions, get answers, and end the isolation that plagues many caregivers. Minimal fee; scholarships are available.

- **877.819.9147**
www.dorotusa.org

Travel

When you are planning a trip with an individual with aging issues or a disability, it may be necessary to consider issues such as accessibility of rooms and transportation, bringing service animals, etc. Most travel destinations can make accommodations. There are agencies and organizations that cater specifically to the needs of individuals with disabilities in travel, both with and without caregivers. Some helpful resources include:

- **AAA**
www.aaa.com
- **Disability Travel and Recreation Resources**
www.makoa.org/travel.htm

Worship

For information on faith-based supports:

- **New Jersey Coalition for Inclusive Ministries**
<http://rwjms.rutgers.edu/boggscenter/projects/NJCoalitionforInclusiveMinistries.html>

Service Animals

The Americans with Disabilities Act (ADA) defines a service animal as any guide dog, signal dog, or other animal individually trained to provide assistance to someone with a disability. If the animal meets this definition it is considered a service animal under the ADA, regardless of whether it has been licensed or certified by a state or local government. Service animals perform some of the functions and tasks that the individual with a disability cannot perform. Individuals who are blind use guide dogs. A service animal might alert someone with hearing impairments to sounds, or pick up and carry items for someone with mobility impairments.

Under ADA, privately owned businesses that serve the public, such as restaurants, hotels, retail stores, taxicabs, theaters, concert halls, and sports facilities are required to allow people with disabilities to bring service animals into any area where customers are generally allowed. For information:

- **Canine Companions for Independence**
www.cci.org

- **Canine Partners for Life**
www.k94life.org

- **Pet Partners**
www.petpartners.org

- **Seeing Eye, Inc.**
www.seeingeye.org

6. CARE/CASE MANAGEMENT FOR AGING LOVED ONES

Care/case managers work individually with older adults and their caregivers to create a plan of care that meets the needs of the older adult. The terms “care” and “case” manager are used interchangeably to describe professionals who link people to available resources and advocate on their behalf. Case managers do a comprehensive assessment and then, in collaboration with the older adult and caregiver, develop a care plan. The case manager is an expert on available resources and helps the older adult and/or caregiver arrange for and coordinate necessary services. The case manager acts as an advocate for the older adult, ensures that services continue to meet the older adult’s needs over a period of time, and reassesses changes that may require additional services or readjustments in the care plan.

Remember, working with a case/care manager is a partnership – the care manager knows the community resources – and you know your loved one – don’t be afraid to voice your concerns or preferences in services to be provided.

Public Case/Care Managers

Public case/care managers are funded through various federal, state, and county tax dollars and are provided free of charge to the older adult. Case management is usually available through your county’s Office on Aging and other local agencies. For information, start with:

- **Aging & Disability Resource Connection of New Jersey (ADRC)**
877.222.3737
www.adrcnj.org

- **Cornerstone Family Programs**
973.538.5260
www.cornerstonefamilyprograms.org

- **NewBridge Services**
973.839.2520
www.newbridge.org

- **SAGE Eldercare – Guidance, Planning, Support Services (GPS)**
908.598.5529
www.sageeldercare.org

- **Visiting Nurse Association of Somerset Hills**
908.766.0180
www.visitingnurse.org

Private Case/Care Managers

Private case/care managers may be either private consultants or someone who works for a for-profit or not-for-profit organization. Private case/care managers usually work for a fee and may provide a wider range of personal services without geographic limitation. To locate a local Professional Geriatric Care Manager:

- **National Association of Professional Geriatric Care Managers**
520.881.8008
www.caremanager.org

- **New Jersey Geriatric Care Managers**
www.njgcm.org, search on “*private geriatric care managers in New Jersey*”

Safety, Abuse & Other Important Care Issues

Please see **Section D, Chapter 2, Keeping Your Loved One Safe**, for important safety information, including what to do in instances of abuse or domestic violence, how to keep a wandering loved one from getting lost, information about guardianship, obtaining official identification for your loved one, and more.

7. SOCIAL SECURITY, MEDICARE & MEDICAID INFORMATION FOR AGING LOVED ONES

Key Benefit Programs

There is a wide range of programs directed toward older adults. There are public programs on the national, state, and local levels. There are programs for which everyone over a specific age is eligible. There are also programs for which a person must meet specific criteria or live in a particular county. It is important for aging adults to be connected to the programs for which they are eligible so that they have the assistance to meet their needs.

BenefitsCheckUp

Sponsored by the National Council on Aging, this comprehensive online resource helps screen for more than 2,000 federal, state, and local programs in all 50 US states and provides detailed information and how to apply. Types of programs included can help with medications, food, utilities, health care, housing, in-home services, and transportation.

➤ www.benefitscheckup.org

NJ Helps

The NJ Helps Services website is designed to give consumers a one-stop shopping resource for the wide range of programs, information, and services provided by the US Department of Human Services and its partners to assist individuals, families, and communities throughout New Jersey.

➤ www.njhelps.org

As a caregiver for a loved one, you should review and organize all key financial information (including tax and insurance information) and keep it in an easily accessible place. Let a trusted family member or friend know where this information can be found. For documents that can help you organize information, visit **United Way of Northern New Jersey's Caregivers Toolbox: UnitedWayNNJ.org/CaregiverTools**.

Social Security Programs

Social Security

Social Security is the short name for the **Title II Old Age, Survivors and Disability Insurance** programs. It insures individuals and family members when the working family member retires, dies, or becomes disabled. Workers qualify for benefits by paying Social Security taxes. As you work and pay taxes, you earn "credits" that count toward eligibility for future Social Security benefits.

The major categories of benefits paid for through your Social Security taxes are:

1. Social Security Retirement Benefits

Social Security is a federal program providing retirement income for those who have paid into the Social Security system. Note that the “normal” retirement age is being gradually increased from age 65 to age 67. You can get Social Security retirement benefits as early as age 62, but if you retire before your full retirement age, your benefits will be permanently reduced based on your age. For example, if you retire at age 62 your benefit would be about 25 percent lower than what it would be if you waited until you reach full retirement age.

NOTE: Sometimes health problems force people to retire early. If you cannot work because of health problems, you should consider applying for Social Security disability benefits. The amount of the disability benefit is the same as a full, unreduced retirement benefit. If you are receiving Social Security disability benefits when you reach full retirement age, those benefits will be converted to retirement benefits.

For caregivers, the important aspects of Social Security involve the application process, taxation, and appeals. Upon application, Social Security will check their records to determine the exact benefit rate. This rate is a function of age and amount of reportable earnings. Once receiving a benefit, the checks increase automatically with the cost of living.

If your loved one is not able to manage his or her own financial affairs, you or another trusted individual can be appointed as a “representative payee” to handle Social Security matters. The benefits are then made payable to you, the representative payee, who must use the funds for the personal care and well-being of the beneficiary. Records and receipts must be kept to show how the money was spent or saved. This must be reported to the Social Security Administration.

NOTE: Some people have to pay federal income taxes on their Social Security benefits. This only happens if the beneficiary has other substantial income such as wages, interest, dividends, and other taxable income that must be reported on the tax return in addition to Social Security benefits.

2. Social Security – Disability Insurance (SSDI)

The loved one you care for may have developed issues along the way that qualify as a disability. The definition of disability under Social Security is different than other programs. Social Security pays only for total disability. No benefits are payable for partial disability or for short-term disability. Disability under Social Security is based on a person’s inability to work. An individual is considered disabled under Social Security rules if he/she cannot do work that he/she did before, and the individual cannot adjust to other work because of his/her medical condition(s). Benefits can be paid to people at any age who have enough Social Security credits and who have a severe physical or mental impairment that is expected to prevent them from doing “substantial” work for a year or more.

3. Social Security Family Benefits

It is important for families to know that if their family member is eligible for retirement or disability benefits, other members of the family might receive benefits, too. If the spouse is at least 62 years of age, or under 62 but caring for a child under age 16 or a child with a disability, he or she may also be eligible for benefits. Unmarried children age 18, age 19 but still a full-time student who has not yet graduated from

high school, or 18 or older with a disability may also be eligible. Former spouses if they are age 62 or older and unmarried may qualify for benefits if the marriage lasted for at least 10 years.

4. Social Security Survivor Benefits

Certain members of your family may be eligible for benefits if the family wage earner dies. The family members who may be eligible include: a widow(er) age 60 or older, 50 or older if disabled, any age if caring for a child under age 16, unmarried children under age 18, under 19 but still in school, or 18 or older with a disability. Parents may also be eligible to receive benefits if they are at least 62 and if the deceased provided at least one half of their support. A special one-time payment of \$255 may be made to the spouse or minor children if they meet certain requirements. If divorced, an ex-spouse could be eligible for a widow(er)'s benefit.

Supplemental Security Income Benefits (SSI)

Supplemental Security Income (SSI), often also referred to as Social Security, is a federal income supplement program funded by general tax revenues and not Social Security taxes. It provides a minimum income to low-income people who are 65 or older, blind, or disabled. Where Social Security is an insurance program requiring "paying into system," SSI is a needs-based program. The basic SSI benefit is a monthly cash payment. Living arrangements or monetary assistance from friends or family may reduce benefits. The monthly benefit rate varies depending on the state you live in. Most people who get SSI also qualify for Medicaid, food stamps, and other assistance.

It is important that the caregiver or recipient monitor SSI payments; they should report any change in a situation, any overpayment, underpayment, etc. If an underpayment is discovered, you are entitled to retroactive benefits. While there is no time limit to reporting an underpayment, appeals of agency decisions must be filed within 60 days of the date of the decision.

For more information about any of the above Social Security benefits:

- **Social Security Administration**
800.772.1213
www.ssa.gov

Reminder! Information in *Pathways* was current as of printing. Careful effort has been made to provide the most current and accurate information; however information does change. Be sure to double check directly with organizations to confirm the accuracy of information.

Medicare & Medicaid Programs

Medicare

Medicare is a federal program of health insurance. It pays for acute illness situations. It is not designed to provide benefits for long-term or custodial care. To be eligible, one must be 65 years of age and have paid into the Social Security system. If the person you care for is 65 or older and is already receiving Social Security benefits, he or she will be enrolled automatically in Medicare. Individuals receiving Social

Security Disability benefits will get Medicare coverage automatically after they have received disability benefits for two years. If he or she is not already receiving Social Security, you will need to call the Social Security Administration.

Note: if an individual does not sign up for Medicare when first eligible, he or she may have to pay a penalty or a higher premium to sign up later. Open Enrollment occurs each year, from mid-October until mid-December. During that time, each Medicare enrollee is encouraged to review all their options for coverage for the coming year.

Medicare Part A

Part A is primarily hospital insurance. Following payment of a deductible, Medicare Part A will pay patient expenses for 60 days of hospitalization. After 60 days, the patient is required to pay a greater amount of the hospitalization cost. Part A will help pay, in certain circumstances, for limited stays in skilled nursing facilities, home health care, and hospice care. Most people do not have to pay a monthly premium for Part A.

Medicare Part B

Part B pays for doctors' services, outpatient care, outpatient physical and speech therapy, some home health care, ambulance services, and some medical equipment and supplies. Medicare Part B also covers preventative services. Part B is optional and requires a monthly premium. There is also an annual deductible that must be met before Medicare starts to pay its share.

Medicare Advantage Plans (also known as MA Plans or Medicare Part C)

Medicare Part C offers Medicare Advantage Plans that combine your Medicare Part A (Hospital) and Part B (Medical). Private insurance companies approved by Medicare provide this coverage. In some cases the premiums and/or copays can be lower than in the original Medicare plans. Medicare Advantage Plans offer a number of types of plans including Preferred Provider Organization (PPO) Plans or Health Maintenance Organization (HMO) Plans. There is also the Private-Fee-for-Service (PFFS) and the Special Needs Plan (SNP). These plans coordinate your loved one's medical care with some plans having stricter network and referral requirements than others. Many of the plans include Medicare Part D (Prescription Drug coverage). It is important that you read the plan information carefully to ensure you are selecting the right plan for you or your loved one.

Medicare Prescription Drug Plan Part D

Medicare offers prescription drug coverage for everyone with Medicare. This is called Part D. This coverage may help lower prescription drug costs and help protect against higher costs in the future. It can give you greater access to drugs that you can use to prevent complications of diseases and stay well. These plans are run by insurance companies and other private companies approved by Medicare. Part D is optional.

If your loved one joins a Medicare drug plan, they usually pay a monthly premium. If they decide not to enroll in a Medicare drug plan when first eligible, there will be a penalty if they choose to join later. If your loved one has limited income and resources, they might qualify for extra help paying for Part D costs.

This is only a general overview of the system. Individual circumstances and situations will vary. For more information, or a comprehensive look at the details of this program:

- **Centers for Medicare & Medicaid Services (CMS)**
800.MEDICARE
www.medicare.gov

Medigap

Medigap is also called “supplemental insurance.” Generally, a person must have Medicare Part A and Part B to buy a Medigap policy. There is a monthly premium for Medicare Part B. In addition, a premium must be paid to the Medigap insurance company. A Medigap policy is health insurance sold by private insurance companies to fill the “gaps” in original Medicare Plan coverage. Medigap policies help pay some of the health care costs that the original Medicare Plan doesn’t cover. If your loved one is in the original Medicare Plan and has a Medigap policy, then Medicare and your Medigap policy will both pay their share of covered health care costs.

- <http://www.medicare.gov/find-a-plan/questions/medigap-home.aspx>

The State Health Insurance Assistance Program (SHIP)

SHIP is a statewide program that provides free, objective information and assistance about Medicare, Medigap, and other Medicare insurance plans. Trained volunteer counselors are available to help you make informed choices. To contact counselors:

- **State Health Insurance Program (SHIP)**
800.792.8820
www.state.nj.us/humanservices/doas/services/ship

Medicaid

In October 2012, the US Department of Health & Human Services, Centers for Medicare & Medicaid Services approved New Jersey’s request for a **Comprehensive Medical Waiver (1115)**. This waiver will completely overhaul New Jersey’s Medicaid program in order to give the state more flexibility in delivering Medicaid, as well as the opportunity to maintain or improve patient care at lower costs. It will expand existing managed care programs to include managed long-term services and supports, and expand home and community-based services to some populations.

The changes to the program have implications not just for poor families eligible for Medicaid, but also for seniors facing the prospect of a nursing home, those that obtain behavioral health or addiction services from the state, and New Jersey residents with developmental disabilities.

New Jersey’s Department of Human Services (DHS), Division of Medical Assistance and Health Services (DMAHS) is in the process of developing a **Medicaid Managed Care Program (MMCP)** that will rebalance long-term care services, improve healthy outcomes and quality care, and protect consumer choice and independence.

Also, when the new **Comprehensive Medicaid Waiver (1115)** fully goes into effect, anticipated to be by late 2014, the four current Medicaid Waiver Programs will be absorbed into **MMCP's** four contracted **Managed Care Organizations (MCOs)**.

The Waivers being absorbed are: **Global Options (GO) Waiver, AIDS Community Care Alternative Programs (ACCAP) Waiver, the Traumatic Brain Injury (TBI) Waiver, and the Community Resources for People with Disabilities (CRPD) Waiver.**

The current **Community Care Waiver (CCW)** will switch from the Division of Developmental Disability to the Division of Disability Services.

As this process moves towards completion and implementation, you may obtain further consumer and client information and updates on this and all aspects of New Jersey Medicaid by contacting New Jersey Medicaid directly.

Your county Medicaid offices can also help you with information on applying for Medicaid. These offices are usually found within the county's welfare agency or Board of Social Services. Contact information for your county can be found at:

- **NJ Medicaid**
800.356.1561
www.state.nj.us/humanservices/dmahs/clients/medicaid/

Community Care Medicaid Waiver (CCW) (Switching to Division of Disability Services in 2014)

This waiver is for individuals registered with the NJ Division of Developmental Disabilities (the disability had to have manifested before the age of 22) who are Medicaid eligible. The program pays for the services and supports they need to live in the community. Services offered by the program include: case management, rehabilitation, individual supports, environmental and vehicle accessibility adaptation, personal emergency response system, and respite care.

Use the Division of Developmental Disabilities contact information until the switch to Division of Disability Services goes into effect, after which, contact the Division of Disability Services.

- **NJ Division of Developmental Disabilities, regional office**
973.927.2600
www.state.nj.us/humanservices/ddd/index.html
- **NJ Division of Disability Services**
888.285.3036
<http://www.nj.gov/humanservices/dds/home/index.html>

Medicaid Only/Nursing Home

This program provides nursing home care for those who qualify medically and financially. Participants must be in need of support in areas such as washing, dressing, self-feeding, self-toileting, walking, and cognitive awareness. There is an income cap and the resource evaluation includes a five-year look-back to rule out the transfer of resources for less than their fair market value.

Medically Needy Nursing Home

This program shares the medical guidelines for Medicaid Only/Nursing Home (see above). The income limit is expanded to accommodate those individuals with incomes that exceed the Medicaid Only/Nursing Home income cap. The resource limit is also expanded, but contains the five-year look-back.

Medicaid Benefits in Assisted Living Facilities

This program provides residential care in an assisted living facility. Participants must need medical support, but they are more independent than those in nursing homes. Assisted living facilities provide all medical necessities plus housekeeping, laundry, congregate meals, planned social activities, and case management. The financial guidelines are the same as Medicaid Only/Nursing Home (see above). Note that many assisted living facilities require 18-24 months of private pay before potentially accepting Medicaid for the resident.

- **NJ Medicaid**
800.356.1561
www.state.nj.us/humanservices/dmahs/clients/medicaid/

Medicaid's Personal Preference Program

This program allows Medicaid eligible individuals who are now receiving or eligible to receive Personal Care Assistant (PCA) services to direct and manage their PCA services. Program participants work with a consultant to develop a Cash Management Plan that is used to identify the services needed and the individual/agencies they want to hire to provide the services. The program requires greater consumer responsibility, but offers participants greater control, flexibility, and choice. If a participant is cognitively impaired or is unable to make decisions on their own, a representative can assist them.

- **NJ Division of Disability Services**
888.285.3036
<http://nj.gov/humanservices/dds/projects/ppp/>

Additional Programs

Jersey Assistance for Community Caregiving (JACC)

This New Jersey cost sharing program provides home-based services and case management for nursing home eligible seniors who are not eligible for Medicaid or Medicaid Waiver services.

- **877.222.3737**
www.adrcnj.org

Alzheimer's Adult Day Services Program

This New Jersey program partially subsidizes the out-of-pocket cost of adult day services for persons with Alzheimer's or a related dementia. Applicants must meet eligibility criteria and receive services at a participating adult day provider.

- **609.588.6532**
www.state.nj.us/humanservices/doas/home/alzheimer.html

8. LEGAL MATTERS RELATING TO AGING LOVED ONES

As a caregiver, it is important to be familiar with your loved one's key financial and insurance information, and to keep copies of important documents, including those submitted to assistance programs. Take time to review insurance coverages, including home, auto, health, disability, and life, and keep records that include location where actual policies are kept and current contact information for each applicable agent. Keep all records in an easily accessible place and be sure to share with another family member where this important information can be found.

A list of key legal terms relating to caregiving as well as templates and lists for organizing documents and important information can be found online at **United Way of Northern New Jersey's Caregivers Toolbox: UnitedWayNNJ.org/CaregiverTools**.

The following is intended as a general informational overview of legal issues that caregivers should consider as they care for their loved one and does not constitute legal advice. For specific legal advice, always seek professional counsel.

It is important that the person for whom you provide care understands his or her legal rights, and that they take the necessary steps to protect themselves and their interests. Depending on circumstances, it may be important for you as the caregiver to be involved as well in legal matters. Of course, the depth of your involvement may change as care needs increase.

Legal Capacity

A starting point for legal documents is having the mental capability to understand the meaning and importance of these documents. Stated differently, legal capacity is the level of judgment and decision-making needed to create legally binding wills, trusts, and powers of attorney.

Legal Services

Some free civil legal services are available to low-income seniors through:

Legal Services of New Jersey (LSNJ)

LSNJ is a nonprofit organization that provides legal information, advice, and referral to low-income residents of New Jersey with civil legal problems. LSNJ has offices in all 21 New Jersey counties and a hotline intake worker will refer you to a local office for assistance.

- **888.LSNJ.LAW (888.576.5529)**
www.lsnj.org

Elder Law

Elder law deals with the varied legal issues faced by the aging population and their caregivers. It combines elements of estate planning, trusts, wills, guardianship, power of attorney, advanced medical directives, eligibility for government programs and benefits, housing, finance, rights of the aging, and other issues which confront all of us as we age. A good first step in locating an elder law attorney in your area would be to contact:

National Academy of Elder Law Attorneys

The National Academy of Elder Law Attorneys (NAELA) is an organization of attorneys in the private and public sectors who deal with legal issues affecting older adults and people with disabilities. Their website includes a section to help locate an elder law attorney in your area.

➤ **703.942.5711**
www.naela.org

Key Legal Documents & Issues

Helping to organize your loved one's legal documents is a big, but critical job. It may take time to gather all the information you need and to maintain and update documents over time, but the peace of mind that comes with having these documents in order is worth all the effort.

Power of Attorney

A power of attorney is a legal document transferring decision-making authority to a person (agent) designated by your loved one in advance. The power can be related to the management of your loved one's property or related to decisions about medical treatment.

A "durable" power of attorney goes into effect when your loved one signs it, and stays in effect for their lifetime unless they cancel it. Your loved one must put specific language in the document stating that they want their agent's power to stay in effect even if they become incapacitated. A "springing" power of attorney is another option, but this document only becomes effective when a specific event happens, such as when your loved one becomes incapacitated. Your attorney must carefully draft a "springing" power of attorney to avoid any difficulty in determining exactly when the "springing" event has happened.

Unlike many other uses of the term "disability," which might refer to a physical handicap, when the term is used within a power of attorney, "disability" means lacking mental capability to manage property or make decisions about medical treatment. A person in a coma would be a clear example of someone having a disability and being unable to make a decision independently.

Caregivers should be aware of what, who, and where powers of attorney have been provided. These documents should be current, accessible, and understood by the caregiver.

Power of Attorney over Financial Decisions

See Section D, Chapter 5.

Power of Attorney over Medical Decisions

The power of attorney over medical decisions appoints a person to represent your loved one in making his or her medical decisions. It defines the limits and extent of such power.

Other terms used to describe a power of attorney over medical decisions are “power of attorney for health decisions,” “health care proxy,” “medical directive,” and “advanced directive for health care.”

Caregivers should also be aware of some key laws governing medical directives. The Patient Self Determination Act ensures that all adult patients know the extent of their right to control health care decisions, particularly through the use of health care directives.

A living will is a type of advanced directive related to medical decisions for the terminally ill. The living will comes into play when a person’s condition is terminal with no expectation of recovery. The living will sets forth the type of medical care, the extent of life support, the possible removal of life support, and instructions as to how and where your loved one would like to be cared for in the final stage of life.

The New Jersey Advance Directives for Health Care Act requires a doctor or hospital to find out if your loved one has any **advanced directives**.

Finally, make sure that all those named in your loved one’s power of attorney are aware, have a copy of the document, and have access to the original should they need to act for your loved one under that power. Also, make sure to have one or two back-ups named on these documents.

Living Will

A living will, as mentioned above, is a type of directive providing comprehensive instruction as to the medical situations where a patient would want to be kept alive and what measures should or should not be used to prolong life or delay death.

A living will is a critical legal document for you, the caregiver, as it clearly articulates the wishes of your loved one. Without such instruction, you as the caregiver could be left speculating as to how, when, and to what extent your loved one wants medical means to continue or not continue his or her life. Your loved one’s guidance is most instructive and important. His or her directions go a long way to help ease your burden in carrying out decisions that your loved one may not be able to make independently.

Will

Elder planning often starts with a will, an important document in any elder plan. Caregivers should be familiar with the uses of a will. A will is the written statement of a person’s wishes as to the disposition of his or her property following death. It takes effect upon death. Up until death (providing mental capacity as discussed above), a will can be amended or revoked.

In legal terms, the person whose will it is is known as the “**testator**.”

Understanding Capacity: To make a valid will, the person must possess the **mental capacity** to know what he or she is doing. It is not an excessively high standard of “awareness” but does require awareness of some essential facts. For example, does the person know if they are married and if their spouse is alive? If they have children, can they name them, know approximately how old they are, and

where they live? Do they know, roughly, what they own, such as houses and bank accounts, and do they understand that the purpose of a will is to leave the things they own to the person whom they name in the will? If the person cannot be conversant about such basic facts, more than likely they do not have the mental capacity to execute, modify, or rescind a will.

Capacity is measured at the time a person makes and signs his or her will. This is important as many elders, who may be beginning to lose mental capacity, may have good days and bad days. As long as the person makes the will or changes the will on a day in which they had mental capacity to understand what they were generally doing, and this can be later proven, then the legal system will uphold the wishes.

A will accomplishes a number of important issues: a) a will allows for the nomination of an executor; without a will, the state would determine who is to serve as executor of your loved one's estate; b) a will avoids "intestacy." Intestacy is where, in the absence of a will, state law dictates who inherits a person's probate assets; c) a will allows a person to define who gets what property. Often a person wants to provide a specific person with a specific item of property. A will allows for such special bequests. A person may want to distribute property unequally to children, as children often have different needs; a will allows for such unequal distributions. A person may want to disinherit a natural heir; a will allows for disinheritance; d) a will allows for the nomination of a guardian or trustee, if the person dies with minor children.

As stated above, a will dictates who inherits your loved one's "probate assets." Not all assets are "probate assets." That depends upon how the assets are owned. Assets which are "not" probate assets pass directly to the person named as "beneficiary" or co-owner of the asset. Examples of assets which could pass directly and avoid probate would be joint accounts, assets in a revocable living trust, pay-on-death accounts, transfer-on-death accounts, annuities with a named beneficiary, life insurance with a named beneficiary, certificates of deposits with a named beneficiary, individual retirement accounts with a named beneficiary, and assets jointly owned ("tenancy by entireties").

It is important to note that many of these assets have a "named beneficiary," which should be reviewed annually as life changes.

Trusts

A trust is a contractual three party arrangement where one person transfers property to another person to hold in trust for the benefit of a third person. While that may sound confusing, a properly designed trust accomplishes as much as a will, while providing a greater flexibility for life and estate planning. A trust may be "revocable" or "irrevocable." A trust may be created while your loved one is living (living trust) or created via a will (testamentary trust).

Irrevocable Trust

An irrevocable trust cannot be amended or changed. The person transferring the property (the "trustor") cannot later change his or her mind. There are tax and planning reasons why a person would transfer property through an irrevocable trust.

Revocable Trust

A revocable trust can, by its definition, be amended or changed. Like a will, the person transferring the property can change his or her mind or change the terms of the trust. It is completely flexible. As such, a revocable trust serves a wide variety of needs related to lifetime planning, extending control over your loved one's estate following death, and minimizing succession transfer costs, such as probate avoidance and reduction of estate taxes.

A "living" trust is generally "funded" by the "grantor" or trust maker. This simply means that the "grantor" has transferred assets currently owned into the trust. Examples of property to be placed or funded into a living trust would be real estate, annuities, stocks, bonds, and bank accounts. Vehicles can be owned by the trust depending on the situation. Special tax deferred investment accounts such as IRAs and pension rights are usually not owned by a revocable living trust, but can be assigned to a trust.

A revocable living trust does all that a will does, plus more. It allows for the continued management of your loved one's assets should he or she become disabled. A trust avoids the need, delay, and cost of probate. A will becomes a public document; a trust does not and, thus, is a great way to keep your loved one's affairs more private.

Guardianship

When no advance directive exists and a person becomes unable to manage his or her personal or property affairs, life's decisions, including medical decisions, come to a halt. In that situation, the caregiver, or other involved individuals/organizations, must go to the court and petition for a letter of guardianship. Guardianship is basically court supervised decision-making by another person appointed by the court.

Guardianship takes two forms: 1) **A guardian of the property** has authority to manage the financial affairs for the older adult or person with a disability. 2) **A guardian of the person** has authority to make health care decisions for the person. New Jersey sets forth a priority of persons who may serve as guardian, with the spouse or next of kin first in line for consideration.

Appointment of a guardian is a court process governed by statute. It requires a Complaint often filed by a family member ("petitioner"), two doctors stating the person is mentally unable to handle his or her own affairs, a court appointed attorney to represent the elder, and the petitioner's attorney. Then a hearing will be scheduled. Following the hearing, a judge will rule on the Complaint or request for guardianship and, if appropriate, issue a judgment appointing guardianship. If at some later time your loved one gains the capacity to manage his or her affairs, the guardianship can and should be terminated.

Burial Fund

A burial fund is money set aside to pay for burial expenses. This money can be in a bank account, other financial instrument, or a prepaid burial arrangement. This can be helpful to eliminate emotional stress and financial burden on a caregiver or other family member at the time of a person's death.

Probate: Made Simple

The following section is intended to provide a broad overview of the necessary steps you would need to take following the death of a family member. The Executor is the person named in a will who is responsible for ensuring the wishes of the deceased are followed, debts and taxes are paid, and the estate is distributed to the proper beneficiaries.

Perhaps a starting point is “ownership.” Everyone owns something. As an owner of property, real or personal, you have what lawyers call an “estate.” Real property is land and buildings. Personal property is everything else such as bank accounts, stocks, bonds furniture, money, life insurance, automobiles, jewelry, and all other personal effects.

It is your right, as an owner of property, to select whom this should be given to upon your death. There are several ways to make such selection. You can write a will, you can create a trust, you can jointly own property, or you can name a beneficiary for each asset. If you do none of the above, upon your death no one knows what property you would want to go to whom. At that point, state law enters the picture and, using the County Surrogate’s office, an administrator is appointed and property is distributed according to state law.

How to Probate a Will

Probate is the process that permits the transfer of your assets as directed by your will. Under New Jersey law, a will may be admitted to probate 10 days after the date of death. To submit a will to probate, one goes to the County Surrogate with the original will, a raised seal copy of the death certificate, contact information for the executor, and contact information for the next of kin and each named beneficiary. It is best to call ahead to find out the specific procedure as process varies county by county.

A will is a legal document. Upon death, the will directs how and to whom your property should be given. A will must name an executor. An executor is legally empowered to manage another person’s money; therefore, the law requires the executor to accept a “fiduciary” duty to both the estate and the beneficiaries of the estate. This is a high legal standard of care and thus the executor should always take great care and maintain detailed records.

There are three types of wills: standard, self-proving, and holographic. Most wills today are self-proving wills, meaning two witnesses watched the will signing, and then in front of each other and in front of a notary they also signed the will. The advantage of a self-proving will is at time of probate the witnesses do not have to physically appear before the surrogate court. With a standard will, state law requires witnesses to appear before the surrogate in order to have the will admitted to probate. This can cause much delay in the probate process. A holographic will has no witnesses, is written by hand, and is most subject to being contested and time delayed.

Whatever type of will is executed, it should be kept in a safe place accessible upon the testator’s death. Family members, those close to the testator, and, most importantly, the person named as executor should be aware of the will and where it is kept.

It is important to be aware that unless it is properly prepared, a will is not effective. Individuals should not write their own will unless knowledgeable about the legal requirements for an enforceable will.

Upon death, the executor needs to take certain basic steps:

- Locate the original will.
- Present a raised seal death certificate, names and addresses of all persons named in the will, and names and addresses of next of kin to the Surrogate. If the will is self-proving, it can be probated in a very short time. If the will is not self-proving, one of the witnesses to the will must come in to the Surrogate's office or present proof of their signature.
- The Court will issue the Executor's Certificate and Letters Testamentary. These documents legally appoint the executor as administrator for the estate.
- Within 60 days of the will's probation, the executor must notify all heirs and beneficiaries named in the will with proof sent to the Surrogate's Court of the testator's death.

Executor Duties

After the will is probated and the Surrogate has issued both the Executor's Certificate and Letters Testamentary, the executor is ready to begin carrying out his or her responsibility of safeguarding the property, paying expenses and taxes, and distributing the remainder of the estate to named beneficiaries. Some simple suggested steps:

- Set up a system to keep track of all the paperwork.
- Find records such as annuity policies, bank statements, birth certificates, account statements, checkbooks, credit card statements, health insurance policies, investment records, life insurance policies, marriage license, military service records, pension records, real estate deeds, registration for cars and boats, retirement account statements, social security records, tax returns, W-2 forms, and other such documents.
- Order copies of the death certificate – the funeral home will be helpful. A death certificate will be required as official evidence of death when closing down financial accounts, filing claim benefits, life insurance claims, and settling real estate.
- Follow the will's instructions. A typical will doesn't contain many specific directions. Most wills set forth a broad list of powers. However, carefully read the will and if it contains specific instructions, you must follow them.
- Set up an Estate or Trust Bank Account – once you have been appointed executor, you will want to open a bank account in the name of the estate. This account will need its own taxpayer ID number for the IRS. Once opened, you can transfer the decedent's bank accounts into it. You may have to secure certain tax waivers from the State of New Jersey. You can use this account to pay debts, taxes and expenses of administration. Keep good records of all transactions.
- Don't take risks – when it comes to managing property and investments, you must act with prudence, which means reasonable skill and caution. Your goal is to safeguard the property until it can be distributed to the named beneficiary. That is part of your fiduciary responsibility. Put the estate first and be fair to all beneficiaries.
- Keep estate assets separate from your own. It is never acceptable for you to mix estate assets with your own assets. All income generated by the estate must go into the estate checking account. You can never use estate assets personally even if you intend to pay them back.

- Send notifications of death. Check the decedent's calendar and cancel appointments. Draft a form letter and notify banks, charities, credit card companies, health care providers, former employers, insurance companies, landlords, membership organizations, subscriptions, pension payers, post office, social groups, state government, veteran groups, and volunteer organizations.
- Call Social Security as soon as practical **(800.772.1213)** and return the Social Security payment for the month of death.
- Keep property secure. The executor is responsible for ensuring the deceased person's property remains safe until it is transferred to inheritors. Real estate and cars should be of particular attention.

Taxes

State Inheritance Tax: The New Jersey Transfer Inheritance Tax has four classifications of beneficiaries. Spouses, children, stepchildren, grandchildren, parents, and grandparents are Class "A" beneficiaries not subject to state inheritance tax. Charities and not-for-profits are Class "E" beneficiaries, and are not subject to state inheritance tax. Siblings and sibling-in-laws are Class "C" beneficiaries and are exempt for the first \$25,000. Other beneficiaries, including step-grandchildren, nieces, nephews, aunts, and uncles are classified as Class "D" beneficiaries, and if property passes to any one of them in excess of \$499, the entire amount passing to that person is subject to New Jersey Inheritance Tax.

Estate Tax: Estates subject to estate tax should seek professional tax and accounting advice. Estates valued at more than \$675,000 are subject to New Jersey Estate Tax and estates valued at more than \$5,250,000 are subject to Federal Estate Tax.

Income Tax: The executor is required to file a final income tax return for the deceased. The deceased's estate may also be responsible for filing an estate trust tax return. The executor is responsible for ensuring all income is reported, taxes paid, and appropriate returns filed on a timely basis.

Conclusion

This overview is very general and many items of estate administration have not been covered. For example, individual situations may include other issues like administration of a trust, children under 18 years of age, property that does not go through probate, transferring joint tenancy and other survivorship property, claiming monies from retirement plans, special procedures for small estates, and handling bypass trusts. For these and other issues, professional advice is strongly recommended.

9. DAY & HOME CARE PROGRAMS FOR AGING LOVED ONES

The following is an overview of **adult day care, home care, and hospice** programs. There are a variety of resources available, including private pay services and services that are subsidized for those who qualify. Again, good places to start when looking for resources in New Jersey are:

Aging & Disability Resource Connection of New Jersey (ADRC)

The ADRC is New Jersey's doorway to information and assistance for older persons, adults with disabilities, caregivers, and professionals looking for services and programs, and is an excellent portal to a wide variety of resources. Services can differ from county to county. Contact your county's ADRC for local information. Phone is staffed weekdays during normal working hours.

- **877.222.3737**
www.adrcnj.org

NJ 2-1-1

NJ 2-1-1 offers both confidential telephone support to people in crisis and personalized information and referrals to those needing assistance. NJ 2-1-1 now operates statewide, connecting people with the resources they need to solve common life problems. It is staffed 24/7 and can be accessed by dialing 2-1-1.

- **Dial 2-1-1 or 800.435.7555**
www.NJ211.org

Adult Day Programs

Adult day programs are also known as "adult day services." There are three types of day programs: **Medical, Social, and Alzheimer's/Dementia Care.**

Each type of service provides care with a planned program of activities designed to promote well-being through social activities and/or health related services for adults who are isolated or need assistance in activities of daily living. These services operate during the day. Lunch is usually provided. In some cases, transportation to and from the facility is also available. Payment for services includes private payment and, in some instances, Medicaid.

Medical Day Programs

These programs provide medical services ranging from preventative and therapeutic to diagnostic and rehabilitative. Medical day facilities for older adults are licensed and regulated by the New Jersey State Department of Health and Senior Services.

Social Day Programs

These programs are centered on the goal of independence for your loved one. Social activities such as exercise, arts and crafts, and lectures are aimed at improving the participant's social, physical, and emotional well-being.

Alzheimer's/Dementia Care Programs

Some adult day programs are specifically designed for aging individuals diagnosed with Alzheimer's disease or dementia, and have specially trained staff.

Alzheimer's Adult Day Services Program

This New Jersey program partially subsidizes the out-of-pocket cost of adult day services for persons with Alzheimer's disease or a related dementia. Applicants must meet eligibility criteria and receive services at a participating adult day provider.

- **609.588.6532**
www.state.nj.us/humanservices/doas/services/aads/

Home Care Options

Home care allows older people to remain in their own homes while receiving the assistance they need to help them remain independent. Services are delivered at home to people who are recovering, disabled, chronically or terminally ill and in need of medical, nursing, social, or therapeutic treatment and/or assistance with the essential activities of daily living. Generally, home care is appropriate whenever a person prefers to stay at home, but needs ongoing care that cannot easily or effectively be provided solely by the caregiver and circle of family or friends.

Services may be provided as frequently as needed, ranging from weekly visits to 24-hour stays. Accepted payment methods include private pay, commercial insurance, and Medicare or Medicaid.

Home Health Care Coverage

Home health care may be covered under Medicare, Medicaid, veterans benefits, or insurance. A person qualifies for these services if they have a "skilled need" for a nurse or rehab therapist (physical, occupational, speech therapist). These skilled services generally last a short time (6-8 weeks). A home health aide may also come for a short visit to provide personal care during this time. Often these services are ordered when your loved one comes home from the hospital, but they may be ordered by a doctor in order to prevent a hospitalization.

When there is not a skilled nursing need or if home health care is needed beyond the period covered by insurance, home care services can be paid for directly by the patient and family members. Your county's ADRC may also know of programs that assist, such as Jersey Assistance for Community Caregiving (JACC). (See Chapter 7)

- **877.222.3737**
www.adrcnj.org

Home Care Agencies

These agencies provide personal care (bathing, dressing, toileting), meal preparation, household chores, and supervision. These services are available by a certified home health aide on an hourly basis or as a 24-hour live-in and are generally paid privately. Make sure that the home care agency you are dealing with is licensed under New Jersey law. Some companies merely refer caregivers to clients; they are not licensed or monitored by the state and are not required to screen, do background checks, etc. In this case, you actually become the employer and are responsible for worker's taxes, insurance, etc.

Suggested Interview Questions for a Home Care Agency

- Is this agency a licensed Health Care Service Firm under New Jersey law?
- Are its workers "employees" or "independent contractors?" Who is responsible for their payroll, taxes, and workers compensation insurance?
- What training do the workers receive?
- Will an RN monitor care? Does the RN visit the home regularly or only at the onset of care?
- Are the caregiver employees citizens or legal residents of the US?
- Is the agency contracted with a high quality, local hospital?
- What are the hiring standards of the agency? What about background checks for caregiver employees?
- Is there a person on call 24/7?
- What if I am not comfortable with, or just do not like, the person chosen by the agency?
- Do you have Geriatric Care Managers or Social Workers on staff?

Certified Home Health Aide

Certified Home Health Aides assist clients with activities of daily living, such as getting out of bed or up from a chair, dressing, grooming, bathing, walking, toileting, eating, medication reminders, errands, light housekeeping, going to the doctor, meal preparation, and laundry. Importantly, they are monitored by a Registered Nurse, follow a prescribed plan of care, have taken a state-mandated course in basic medical and personal assistance, and are required to complete continuing education on a yearly basis.

Companion, Homemaker, Personal Care Assistant, or Home Attendant

These titles generally refer to service providers who assist in household tasks, but who do not perform the personal, hands on care tasks performed by Certified Home Health Aides. Staff will typically provide services in the home that relate to daily activities such as dressing, cooking, medication reminders, cleaning, and transportation. These staff positions are not certified, have no education requirements, and are usually not monitored by a registered nurse. Services are paid privately.

Registered Nurse (RN) & Licensed Practical Nurse (LPN)

An RN provides highly skilled level of care for individuals recovering from surgery or an accident, or those with more complex medical needs such as wound care, injections, intravenous therapy, and ventilator care and disease treatment. LPNs have less training than RNs and usually work under RN supervision.

Hospice

Hospice is a program of care for terminally ill patients and their families, which takes place in the home, a nursing home, or dedicated hospice unit. The goal is to provide physical, emotional, and spiritual support with a dignified, peaceful approach to comfort in the final months of life regardless of disease. Hospice care is covered under Medicare, Medicaid, and most private insurance. No one is denied hospice care because of an inability to pay.

- **New Jersey Hospice & Palliative Care Organization**
908.233.0060
www.njhospice.org

- **National Hospice and Palliative Care Organization**
Information on end-of-life issues and state-specific advance directives
703.837.1500
www.nhpco.org

- **Ageing & Disability Resource Connection of New Jersey (ADRC)**
877.222.3737
www.adrcnj.org

Nutrition Programs

Meal Sites

Located throughout New Jersey, sites provide a hot midday meal and the opportunity to socialize with others.

- **Essex County Division of Senior Services – Congregate Program**
Sites in Bloomfield, Newark, and senior housing complexes throughout the county
973.395.8385 or 8367
www.essex-countynj.org

- **Morris County Senior Citizen Nutrition Program**
Sites in Butler, Chatham, Chester, Denville, Dover, Jefferson Township, Long Hill Township, Madison, Montville, Morristown, Mt. Olive Township, Parsippany, Rockaway, and Roxbury
973.285.6856
www.morrishumanservices.org

- **Somerset County Nutrition Program**
Sites in Hillsborough, Manville, Somerset, Raritan, Warren, Bridgewater, and N. Plainfield
908.704.3646
www.co.somerset.nj.us

- **Sussex County Nutrition Programs**
Franklin: **973.827.2973**, Hopatcong: **973.398.2608**
Newton: **973.579.2120**, Vernon: **973.764.5454**
- **Warren County Division of Aging and Disability Services**
Sites in Belvidere, Hackettstown, Phillipsburg, and Washington
908.475.6591
www.co.warren.nj.us
- **All Counties: Aging & Disability Resource Connection of New Jersey (ADRC)**
877.222.3737
www.adrcnj.org

Home Delivered Meals

Nutritious meals can also be delivered to homebound seniors in the following counties:

- **Essex County Division of Senior Services**
973.395.8375
www.essex-countynj.org
- **Morris County Senior Citizen Nutrition Program**
973.285.6856
www.morrishumanservices.org
- **Somerset County Nutrition Program**
908.704.6346
www.co.somerset.nj.us
- **Sussex County Home Delivered Meal Program**
973.209.0123
www.sussexcountyagingservices.org
- **Warren County Division of Aging and Disability Services**
908.689.4140
www.co.warren.nj.us
- **SAGE Eldercare**
Delivers to Berkeley Heights, Chatham, Chatham Township, Millburn, Mountainside, New Providence, Short Hills, Springfield, and Summit
908.273.5554
www.sageeldercare.org
- **All Counties: Aging & Disability Resource Connection of New Jersey (ADRC)**
877.222.3737
www.adrcnj.org

10. EMPLOYMENT & VOLUNTEERING FOR AGING LOVED ONES

Studies show that remaining active and engaged in a variety of activities has a positive impact on physical and mental health. Your aging loved one may find that volunteering or working, even for relatively small amounts of time each week, provides a sense of independence and an uplifting change of pace.

Employment

Senior Community Service Employment Program (SCSEP)

The Senior Community Service Employment Program (SCSEP) is administered under New Jersey's One Stop Programs and Services known as WorkForce 55+.

The main objective of the Workforce 55+ SCSEP is to bring together the talents of older workers and the unmet needs of communities by providing income and gainful part-time subsidized work activities for low-income, older persons. Contact your local One-Stop Career Center. A listing of all New Jersey Centers is provided on the following website:

- **NJ Department of Labor and Workforce Development**
Division of One Stop Programs and Services
<http://lwd.state.nj.us/labor/wnpjpin/findjob/one'stop/OlderWorker.html>

Volunteering

Various volunteer opportunities are available through local senior centers, and other community organizations. These provide opportunities for older adults to connect with members of the community and share their skills and experiences.

- **Corporation for National and Community Service/Senior Corps**
800.942.2677
www.nationalservice.gov/programs/senior-corps
- **Jersey Cares**
973.424.1091
www.jerseycares.org
- **NORWESCAP/Skylands RSVP & Volunteer Resource Center (Morris, Sussex, and Warren)**
888.387.9830
www.norwescap.org, search on "RSVP"
- **United Way of Northern New Jersey (Morris, North Essex, Somerset, Sussex, and Warren)**
908.253.6503
UnitedWayNNJ.org/BecomeAVolunteer
- **Volunteer Management Center, Inc. (VMC)**
973.538.7200
www.vmcnj.org

11. HOUSING FOR AGING LOVED ONES

Independent Living Options

While many older adults prefer to remain in their own home, often the rising costs and physical maintenance of the home and property make it increasingly difficult. As the numbers of seniors increase, so do the housing options available to them.

Adult retirement communities typically provide social and recreational activities for independent seniors who require no assistance with personal care. Housing options can be single houses, condos or apartments that are usually purchased, although some communities may have rental units available. A manager is usually responsible for general maintenance and upkeep. A monthly fee is generally charged for these services. The resident pays property taxes as well. The usual entrance age for most communities is 55 years or older. Services, like home care, may be brought into the home, the same as they would be for a private residence.

Rooming and Boarding Homes serve populations with diverse backgrounds and needs: the transient construction worker who needs a bed, veterans, persons with disabilities who can function with community support, the older adult who may need some help with activities of daily living. Some homes are specialized, serving those with mental illness, developmental disabilities, Alzheimer's, HIV/AIDS, substance abuse, veterans, or victims of abuse. Boarding homes are licensed by the Department of Community Affairs. There are five classes of licenses:

- Class A: Valid for rooming houses only
- Class B: Valid only for rooming houses and for boarding houses offering no financial services and no personal services other than meals and other food services and laundry
- Class C: Valid for all rooming and boarding houses
- Class D: Valid only for facilities operated under contract with an agency of the State of New Jersey
- Class E: Valid only for alcohol and drug rehabilitation facilities owned and operated by nonprofit religious organizations

Long-Term Care Facilities

Nursing homes, assisted living facilities, and other long-term care centers vary in price, quality, philosophy, and financial security. By doing some research, asking lots of questions, and trusting your own instincts, you and your loved one can find the facility that works best for everyone involved.

The best advice when considering a long-term care facility for your loved one is to start planning early! Begin to visit well before you think your loved one will need to move. Make a list of facilities in your area; proximity to your home may be very important to you. Plan to visit more than one or two. Visit a facility you are considering more than once at different times of day, evening, or weekend. When visiting, ask ALL your questions! None are too basic or trivial. Trust your instincts about the facility, but also do a background check. Ask for references from other families with loved ones at the facility. Be sure to read contracts carefully. Ask about fees, about what is covered, and what would be extra.

When visiting any facility, look for all the things you would want for any loved one. Observe if it is well lit, free of clutter, looks and smells clean, prepares meals that look and smell appetizing, has well marked exits and other safety measures in place, etc. Observe if the residents are clean and groomed and appropriately dressed, are engaged, and seem content. You will want to ask many questions.

Do not stop your vigilance once your loved one has moved in. Visit often, get to know the staff, continue to ask questions, and advocate for your loved one's needs.

Assisted Living Facilities

Assisted living provides a combination of residential housing, personalized supportive services, and health care designed for the individual needs of those requiring help with activities of daily living, but who do NOT require the medical attention offered at a nursing home. Some assisted living communities may have specialized units for those with cognitive impairment, like dementia. Assisted living generally offers the resident more autonomy, privacy, and participation in care decisions than do nursing homes. Most communities provide daily activities, meals, laundry, housekeeping services, and 24-hour staff. Units are offered in various sizes and prices to meet individual budgets and needs. Methods of payment include private pay and, in limited instances, Medicaid. Most assisted living facilities require 18-24 months of private pay before potentially considering Medicaid.

Sample Suggested Questions When Visiting an Assisted Living Facility

- Is the facility licensed?
- How long has the facility been in operation?
- What are staffing practices? (Educational and training requirements, supervision)
- Is there a health and wellness program? (Exercise, social interaction, nutrition)
- What kind of contract is required? (Facility should disclose in advance all fees, timing of payments, cost of additional services, fees to hold the bed if the resident is transferred to a medical facility, etc.)

Residential Health Care Facilities (RHCF)

Residential health care facilities provide health maintenance and monitoring services under the direction of a professional nurse. They provide a room, meals, linens, housekeeping, personal assistance, personal laundry, 24-hour security, financial management, and recreation activities, as well as supervision of medication and limited health services. Rooms and baths may be shared or private. Most services are included in the rent, but some may be purchased separately. These facilities provide a home-like atmosphere and services while encouraging independence and assuring safety. These facilities are licensed, regulated, and inspected by the NJ Department of Community Affairs.

Continuing Care Retirement Communities (CCRC)

Continuing care retirement communities, also known as life care communities, are residential campuses that provide a continuum of care from independent units to assisted living to full nursing care, all in one location. They guarantee the senior lifelong residence, allowing him or her to progress through the stages of care as needed. There is often a large down payment required for entrance into the CCRC and, depending on the level of assistance needed, monthly fees may be charged.

Sample Suggested Questions When Visiting a CCRC

- Is the organization's most recent annual financial report available for review?
- Are the statements of financial position, operation, and cash flow included?
- Does the organization have a positive net worth? If not, how does it believe its long-term financial health is affected?
- In the past few years, have operating revenues exceeded expenses?
- Does the organization rely on non-operating income from donations, endowments, and investments?
- Does the organization have the necessary financial resources to ensure the ability to provide services now and in the future?
- Does the organization have an endowment? If so, what is its size and how is it used and managed?
- Is there a resident assistance fund? How can residents qualify?
- Does the organization have a formal risk-management program?
- What type of insurance does the organization have?
- Are the residents involved in strategic and financial planning and decision-making?

Skilled Nursing Facilities/Nursing Homes

Skilled nursing facilities are also known as nursing homes, nursing centers, and long-term care facilities. They provide room and board, protection, supervision, and 24-hour medical care. There are three types of nursing care: basic care, skilled care, and sub-acute care (after hospitalization, short term medical care). Facilities are licensed and regulated by the NJ Department of Health, and accept a variety of payment options including Medicare, Medicaid, private insurance, and private funds.

Sample Suggested Questions When Visiting a Nursing Home

- Is the nursing home accepting new patients? Is there a waiting period for admission?
- Is the nursing home Medicare certified? Medicaid certified?
- What is the expected length of private pay residence before one can apply to Long-Term Medicaid as the source of payment?
- Is the licensing and certification current?
- Does the nursing home have any specialty care units?
- What is the monthly or daily base rate and what services does it cover?
- What services are not covered by the base rate, such as telephone, toiletries, salon, activities, and what are the costs for these?
- What is the procedure to pay for the add-on charges?
- Are residents able to make choices about their daily routines?
- Can residents have personal articles and furniture in their rooms?
- Are residents offered food choices at mealtimes? Are nutritious snacks offered?
- Can residents continue to see their personal physicians?
- How are residents encouraged to interact, socialize?
- Does the nursing home have a variety of activities? An outdoor area? Volunteer groups?
- Are care plan meetings held at times that are convenient for residents and family members?
- Does the facility have a disaster plan in place in case of emergency?

Finding Facilities, Licensing & Performance Information

There are many online resources with information about facilities in your county as well as performance reviews about a facility you may be considering. Here are just a few good places to begin:

Medicare

Compare skilled nursing facilities online based on health inspection results, staff data, quality measures, and fire safety inspection results.

- **800.MEDICARE (800.633.4227)**
www.medicare.gov/nursinghomecompare

NJ Division of Health Facilities and Licensing

The NJ Department of Health, Division of Health Facilities and Licensing regulates a wide range of health care settings for quality of care, such as hospitals, nursing homes, assisted living residences, home health care, and others. It also shares “report card” information, and investigates complaints received from consumers and other state and federal agencies. You can locate facilities by county, as well as facility performance information.

- <http://www.state.nj.us/health/healthfacilities/>

Legal Services of Northwest Jersey provides free civil legal services, including addressing landlord and tenant rights to low-income residents, seniors, and more: www.lsnj.org/lsnwj/

The **Community Health Law Project** offers legal, consumer protection, and advocacy services for seniors and people with disabilities: www.chlp.org/

Affordable Housing

There are various housing options available for your aging loved one. A good starting place may be the New Jersey Housing Resource Center (NJHRC). The NJHRC is a partnership between the NJ Department of Community Affairs, the NJ Department of Human Services, Division of Disability Services, and the New Jersey Housing and Mortgage Finance Agency. They provide an online tool to assist people in finding affordable housing.

- **New Jersey Housing Resource Center (NJHRC)**
877.428.8844
www.njhrc.gov

The largest group of affordable units is public housing. Housing authorities administer this federal program. New Jersey has about 100 housing authorities.

Housing authorities get federal funds to build and run public housing developments. Most have rental units, but some have houses for sale. Rents and sale prices depend on household income and can be no more than 30 percent of adjusted earnings. People who live in public housing typically earn less than 80 percent of the median family income. Federal rules require housing authorities to keep a certain percentage of these units for very low income households, earning 50 percent or less than median family income. Some housing authorities must reserve units for extremely low income households with earnings at or below 30 percent of median family income. Use federal income standards to determine eligibility. All rental units must be within Fair Market Rent.

Housing authorities often have waiting lists, depending on local conditions. Public housing authorities may give priority to people who live or work in the communities they serve. The people who operate these authorities are an excellent resource. They know the local housing market and are aware of other programs and opportunities that might be available.

Call your municipality or your local ADRC to put you in contact with the public housing authority in your community.

Affordable Senior Housing is typically age-restricted, multi-unit housing with self-contained living units for older adults who are able to care for themselves. Renters must meet age and income requirements, with the rental cost determined by the household income. Usually no additional services such as meals or transportation are provided. Many municipalities in New Jersey have subsidized senior housing buildings for older adults and people with disabilities. There is usually a waiting list. Lists of senior citizen, subsidized housing in each county can be obtained by contacting your local ADRC or your local housing authority.

- **Ageing & Disability Resource Connection of New Jersey (ADRC)**
877.222.3737
www.adrcnj.org

New Jersey Low & Moderate Income Program/Mount Laurel (MtL)

Individuals looking to rent an apartment, or buy a house or condominium in New Jersey may consider a Mount Laurel unit. Mount Laurel units can be for the elderly, families, or those with special needs. All MtL developments have income restrictions and must be affordable to low- and moderate-income households as defined by Federal rule or by State regulation, depending on how the developments were funded. The list of units created by the Council on Affordable Housing (COAH) can be found at:

- <http://www.state.nj.us/dca/affiliates/coah/reports/units.pdf>

Subsidized Housing/Rental Vouchers

Rental vouchers are available to individuals and families who are low or very low income. To determine whether your loved one meets these income criteria, consult the HUD website. The income limits change every year. Search on "*Income Limits*."

- www.huduser.org/datasets/il.html

Some New Jersey programs use income limits published by the Council on Affordable Housing (COAH). These numbers are similar to HUD, but slightly different:

- http://www.nj.gov/dca/services/lps/hss/admin_files/incomelimits.pdf

Some voucher programs have “set-asides” for those who are considered low or moderate income (below 80 percent of the area median income), those who have special needs (such as a mental illness), and those over age 62. If your loved one falls into any of these categories, ask for information on programs specific to that group(s).

There are two types of rental vouchers: **tenant-based** and **project-based**.

Tenant-based vouchers are provided directly to the tenant and allow the tenant to pay a portion of their income toward rent. The amounts vary by program, but typically the tenant pays 30 percent to 40 percent of the monthly household income toward rent and utilities – the remaining rent is paid directly to the landlord from the subsidy provider. When the tenant moves, the voucher can be transferred to another rental unit. Agencies often have waiting lists for vouchers. Depending on the length of the lists, the agency may “close” the list until the number falls beneath a certain threshold. Assuming that you will be placed on a waiting list, it is advised that you contact as many of the agencies that you can. There is no penalty for being on more than one list (but ultimately, you can only accept one voucher). Each agency may represent a different geography and/or type of housing.

Project-based vouchers are attached to the property, which means a tenant is entitled to the rental subsidy for as long as they live in that unit. When a tenant moves, the voucher is given to the next tenant in that unit. Tenants pay 25 percent to 40 percent of monthly household income toward rent and utilities, depending on the subsidy program attached to the project.

Be prepared that most have waiting lists, and consider having your loved one place his or her name on as many agency lists as appropriate, based on geography and housing type desired.

Contact your local housing authority or:

- **NJ Department of Community Affairs**
609.292.4080
www.state.nj.us/dca/divisions/dhcr/offices/srap.html
- **US Department of Housing and Urban Development**
Local Office – One Newark Center, 1085 Raymond Blvd, Newark, NJ 07102
973.622.7900
www.hud.gov

Other Housing Programs & Information

Homelessness Prevention Program

This program provides limited financial assistance to low- and moderate-income tenants and homeowners in imminent danger of eviction or foreclosure due to temporary financial problems beyond their control. Funds are used to disburse payments in the forms of loans and grants to landlords and mortgage companies on behalf of eligible households in danger of homelessness.

- **NJ Department of Community Affairs**
866.889.6270
www.state.nj.us/dca/divisions/dhcr/offices/ha.html

Home Improvement Programs

Some counties offer loans to homeowners to make improvements to their homes. There are typically income guidelines and other requirements.

- **Essex County Home Improvement Program**
973.655.0200
<http://www.essex-countynj.org/index.php?section=pr/print/2705a>
- **Morris County Home Improvement Program**
973.285.6060
www.morrisplanning.org/divisions/community
- **Warren County Home Improvement/Rehab Program**
908.475.3989
http://warren.nj.us/Humanservices/local_resources.html

Housing Rehabilitation Programs

Housing Rehabilitation Program funds provide rehabilitation assistance to income-eligible owner-occupants of single family homes, townhouses, condominiums, and multi-family units. The assistance is governed by federal regulations and county guidelines. Funds are typically used to improve insulation, correct code violations, renovate substandard heating, electrical, and plumbing systems, and for structural repairs and major systems failures, e.g., failing septic, furnace, inferior roof.

- **Morris County Department of Human Services**
973.285.6030 (TDD: 800.852.7897)
<http://morrishumanservices.org/behavioral/community.asp>
- **Somerset County Community Development**
908.541.5756
www.co.somerset.nj.us/hservices/comdevelopment/housingrehab.html

- **Warren County Department of Human Services**
908.475.3989
http://warren.nj.us/Humanservices/local_resources.html

New Jersey Housing and Mortgage Finance Agency (HMFA)

The New Jersey Housing and Mortgage Finance Agency (HMFA) has many housing programs funded from the sale of bonds. Some provide mortgage assistance and closing costs to homebuyers. Others help homeowners repair the houses they already own.

Those looking to buy a house or condominium should consider calling HMFA to see about the availability of homebuyer assistance programs. For information on HMFA programs:

- **800.NJHOUSE (800.654.6873)**
www.state.nj.us/dca/hmfa/

US Department of Housing and Urban Development (HUD)

In addition to finding information on local affordable housing units, access HUD for information about reverse mortgages, links to homeless resources, and rental assistance programs.

- **Local Office – One Newark Center, 1085 Raymond Blvd, Newark, NJ 07102**
973.622.7900
www.hud.gov

12. ADVOCACY FOR AGING LOVED ONES

Self-Advocacy

Self-advocacy is when an individual knows his or her rights and responsibilities, stands up for them, and makes choices about his or her life. As a caregiver of a loved one with issues of aging you may be in many instances your loved one's best advocate. However, it is also important to encourage your loved one to learn how to advocate on his or her behalf whenever possible. Self-advocacy is promoted when as a caregiver you ensure your loved one is made aware of and informed about available services and is involved in any planning processes.

Keys to Successful Advocacy on Behalf of Your Loved One

Communicating effectively with professionals and learning how to navigate the system are important skills for any caregiver to learn and develop. These can be acquired through help from other caregivers, caregiver coalitions, or other advocacy groups.

Be Patient

Most government and private agencies are not able to offer enough services to help everyone needing assistance, so people usually have to apply for services. This is sometimes referred to as an eligibility-based system. Depending on the organization, services or other assistance could be distributed on a first-come, first-served basis to those who need the service the most or to those who meet the financial eligibility requirements. It is up to you to know how the organization you are trying to work with makes these decisions and plan accordingly. Sometimes, there may even be long waiting lists for services. You may not know how long it takes to get to the top of the waiting list and get what you need, but one certainty is that if you do not apply and get on the list, you will not get the needed services.

Stay on People's Good Side

Find the line between advocacy and aggression. A successful advocate lets the system work for them. You want to stay on top of things, but don't turn into a pest and make it harder for the professionals to do their jobs. Smile when you are talking to people...even if you are on the phone, your smile will come through in your tone of voice. Professionals are people too, and words like "please" and "thank you" will go a long way toward developing a strong working relationship.

You Just Might Be the Expert in the Room

Be prepared to assist professionals who may have limited experience with your loved one's exact needs. Your family doctor may be wonderful, but he or she may have little or no experience writing prescriptions for wheelchairs or accessibility devices. Share your expertise by discussing your loved one's needs, giving as much detail as possible about what you are looking for. You may want to speak with agencies about equipment and service evaluations before approaching a doctor for authorization.

Keep Accurate Notes

Record keeping may seem like a hassle at first, but saves a great deal of time down the road. Whenever you have a conversation with any professional, it's a good idea to write it down. Some caregivers keep a notebook just for this purpose. Include all contact names, phone numbers, dates of calls, and a quick summary of the discussion.

Know What You Need; Do your Research

When advocating for equipment or services, make sure to collect all the details and product information ahead of time. If insurance is being used for payment, ask both the insurance company and the

equipment provider if there are pre-set guidelines or other information that will be needed. This will save a lot of time later on in the process.

Understand your Insurance Benefits

Do not be afraid to ask questions when you are unsure of something about your insurance. Review the terms of each program and policy. Know when referrals or pre-certifications are necessary. Pay careful attention to copays, service limits, and equipment ownership and replacement responsibilities. These issues are especially important for those whose functional abilities may change with time. Remember, you can always appeal an insurance company's decision in the event of a denial, no matter what type of plan you are on.

Systems Advocacy

Systems Advocacy is a process by which organized groups or individuals come together to advocate for positive change to programs, services, and legislation. Advocacy for changes in policy or service delivery may be most effective when there is a united voice that speaks on behalf of issues. There are numerous organizations that advocate regarding issues, policies, disabilities, and diseases on local, state, and national levels.

AARP

AARP's mission is to enhance older quality of life for all as we age. AARP works on issues that are important to Americans age 50 and older, including health and financial security.

- **AARP Washington, D.C.**
888.687.2277
www.aarp.org

- **AARP New Jersey**
866.542.8165
www.aarp.org/states/nj/

NJ Office of the Ombudsman for the Institutionalized Elderly (OOIE)

The NJ Office of the Ombudsman for the Institutionalized Elderly (OIEE) is part of a national resident-focused advocacy program that seeks to protect the health, safety, welfare, and civil and human rights of older individuals in institutions. Staff and volunteers work with individual residents to help them address the challenges they face. OIEE investigates, resolves, and/or refers complaints to the appropriate agency. In addition to individual advocacy, OIEE advocates to bring about change to systems on local, state, and federal levels.

- **609.826.5090 or 877.582.6995**
www.nj.gov/ooie/

United Way *Caregivers Coalition*

United Way *Caregivers Coalition's* work on behalf of caregivers includes advocacy at the local, state, and national level. Your ideas and experiences could help direct the *Coalition's* advocacy efforts. Please contact the *Coalition* if you are interested in joining advocacy efforts on behalf of caregivers.

- **888.33UWCARES (888.338.9227)**
UnitedWayNNJ.org/CaregiversCoalition

13. KEY NUMBERS AT A GLANCE

Aging & Disability Resource Connection of New Jersey (ADRC)	877.222.3737
NJ 2-1-1	Dial 2-1-1 or 800.435.7555
<u>AARP</u> Washington, D.C. New Jersey	888.687.2277 866.542.8165
Alzheimer's Association, Greater New Jersey Chapter 24-Hour Helpline	973.586.4300 800.272.3900
<u>Benefits</u> US Medicare New Jersey Medicaid US Social Security Administration	800.MEDICARE or 800.633.4227 800.356.1561 800.772.1213
<u>County Caregiver Coordinators & Support Programs</u> Essex County Morris County Sussex County Warren County	973.395.8389 800.564.4656 973.579.0555, x1225 908.475.6591
Mental Health Association in New Jersey, Inc.	800.367.8850
National Association of Professional Geriatric Care Managers	520.881.8008
<u>State Health Insurance Program (SHIP)</u> Essex County – Newark Day Center Morris County – NORWESCAP, Inc. Somerset County – Aging & Disability Services Sussex County – Division of Senior Services Warren County – Aging & Disabilities Resource Connection	800.792.8820 973.643.5710 973.784.4900, x208 or SHIP, x3501 908.704.6319 973.579.0555, x1223 908.475.6591
United Way of Northern New Jersey Volunteer Coordinator	908.253.6503
United Way Caregivers Coalition	888.33UWCARES (888.338.9227)