

SECTION D

INFORMATION FOR ALL CAREGIVERS OF LOVED ONES WITH ISSUES OF AGING, DISABILITY, OR MENTAL ILLNESS

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1. MEDICAL MATTERS FOR ALL CAREGIVERS

Affordable Care Act

On March 23, 2010, President Obama signed the Patient Protection and Affordable Care Act, commonly known as the Affordable Care Act or ACA. The law put into place comprehensive health insurance reforms that have been and continue to be rolled out to ensure that all Americans have access to affordable health insurance options. For key features of the ACA see:
<http://www.hhs.gov/healthcare/facts/timeline/timeline-text.html>.

Beginning October 1, 2013, most people will be eligible for health coverage through the Health Insurance Marketplace. The Marketplace allows individuals and small businesses to compare health plans on a level playing field. Middle and low-income families will get tax credits that cover a significant portion of the cost of coverage.

If you live in New Jersey, this website should be used to apply for coverage, compare plans, and enroll.

➤ **HealthCare.gov**

You may want assistance with the application and enrollment process and there are many resources available to help you understand your health coverage options and select a plan that meets your needs. There are people in each community trained and certified to help you. They are known by different names, depending on who provides the service and where they are located, but all provide similar kinds of help. To locate “navigators” in your area that can help explain your options:

➤ <http://localhelp.healthcare.gov/>

Note: The Marketplace will not have an effect on an individual’s Medicare coverage. In fact, it is illegal for someone to sell a Marketplace plan to an individual with Medicare if they are aware the individual has Medicare coverage.

Understanding HIPAA

HIPAA – the federal Health Insurance Portability and Accountability Act – provides protections for patients’ privacy rights. The Act was passed to protect individual patient medical records from being disclosed to anyone who asked to see their content. At the same time, the privacy rule is balanced so that it permits disclosure of health information needed for patient care and other important purposes.

It is a common misconception that HIPAA stops communication between medical professionals and family caregivers. On the contrary, HIPAA requires it and can be an important part of any caregiver’s plans as they care for a loved one. There are many resources on the Internet that explain HIPAA in further detail. One good source of information is:

➤ www.nextstepincare.org/uploads/File/NSIC_HIPAA_4.24.pdf

Organizing Medical Information

As a caregiver, it is important to try to keep your loved one's medical information well organized and up-to-date. The benefits of doing so are very much worth all the effort! Be sure to inform other family members or close friends where key documents and files can be located.

Create lists of your loved one's doctors and contact information, medications, diagnoses, tests, vaccinations, and surgeries. It is very useful to create a summary sheet of this information and make a few copies to bring to doctor appointments, especially with new doctors. It makes it much easier to complete all medical forms.

Consider creating a health care binder, beginning a new one each year if necessary. Some caregivers use encrypted online programs to maintain medical information. Whatever the platform, suggested sections include:

Contact Information for Health Care Providers

A complete list of all medical service providers, dentists, eye doctors, and clinics where lab tests are performed. Include provider's name, specialty, address, phone, and fax numbers.

List of Prescriptions, Over the Counter Medications & Supplements

Include everything that is regularly taken: name of the medication, dosage, dates taken, reason for taking, and any side effect or problems. Include vitamins, herbal supplements, or any homeopathic remedies taken regularly, as they can interfere with certain prescribed medications.

Summary of Doctor Visits

A chronology of visits for easy reference with date, doctor's name, and a few words about the visit. Take notes during visits if possible. If not possible, write a summary right after the visit.

Copies of Medical Tests

Most doctors send copies of medical test results. If not, contact the doctor's office for a copy. Keep test results in chronological order.

Billing & Insurance Papers

As insurance papers come in, collate them with the corresponding bill and mark them as paid or pending. Compare the bills against the summary of office visits to protect against billing errors.

IMPORTANT! Be Prepared!

Caregivers should prepare a "Go To" document that summarizes their loved one's medications and key health facts for use in an emergency. Consider using the free **Vial of Life** system. The Vial organizes important medical information to assist medical personnel in giving proper medical treatment. The Vial is stored on the refrigerator and emergency personnel can access its information even if you are not at home.

➤ www.vialoflife.com

Critical Medical Documents

There are several important documents to have on hand in case of a medical emergency or admittance to a medical facility. These documents sometimes require conversations that can be difficult or upsetting. Reassure your loved one that your intent is only, and always, to be able to carry out their plans and wishes – that you both share these common goals. An attorney can ensure that documents are properly executed according to your loved one's wishes.

Important Note: Capacity

Executing legal documents requires capacity, meaning your loved one has the ability, level of judgment, and decision-making needed to create legally binding documents. Capacity is a legal term, not a medical one. Should capacity be called into question, a lawyer and a judge must determine if legal capacity exists. A doctor's opinion may be solicited as part of the legal process. For more information about capacity, consult an attorney.

The following documents are important to have. They are described in more detail in **Sections A, B, and C: Chapter 8: Legal Matters & Important Papers**.

- **Power of attorney**
- **Power of attorney for health care/medical decisions (also known as health care proxy)**
- **Living will**
- **Will**

Additionally, it is a good idea for you and your loved one to become familiar with and, when appropriate, discuss such documents as:

Do Not Resuscitate Orders (known as DNR)

Unlike a living will or health care power of attorney, a DNR order is a medical order that must be written by a physician or other authorized person. A DNR tells medical professionals not to perform emergency CPR if a patient's breathing or heartbeat stops. A DNR order does not relate to any other treatment.

There are two types of DNR orders and it's important to understand the difference.

In-Hospital DNR: When admitted to a hospital, your loved one or their health care proxy will be asked if they want to execute a DNR. An in-hospital DNR is only for in-hospital.

Out-of-Hospital/First Responders DNR: If your loved one is at home and wishes to have a DNR in place that would be in effect in the home, there is a need for an out-of-hospital DNR. This DNR order ensures that all first responders and emergency medical services will comply with this request. For an example:

- www.state.nj.us/health/ems/documents/dnr.pdf

National POLST (Physician Orders for Life-Sustaining Treatment Paradigm)

The National POLST Paradigm is an approach to end-of-life planning for people over 18 based on conversations between patients, loved ones, and medical providers. POLST is a medical order that is filled out with a physician or advance practice nurse and details your personal wishes regarding end-of-life care. The POLST is designed for those nearing the end of life and outlines goals of care, such as personal goals or family milestones you want to reach. The POLST also outlines preferences for resuscitation, ventilation, and the scope of medical interventions. The POLST is unique because it is transferable across all settings, including hospital, health care facility, and home. For information:

- In New Jersey, POLST is implemented by Goals of Care: www.goalsofcare.org
- National site: www.polst.org

Other Advance Directives

Many can be found online, but one well-regarded resource is called **Five Wishes**. Five Wishes is a document designed to promote better care for those near the end of life. It lets family and doctors know what a loved one wants or doesn't want medically, how they want to be treated, etc.

- www.agingwithdignity.org

Psychiatric Advance Directive (PAD) (For Loved Ones with Mental Illness)

A PAD is a legal document that allows an individual with mental illness to direct who will make health care decisions for them and to state their wishes for mental health treatment if they become unable to make decisions for themselves in the future. The psychiatric advance directive may be used to accept or refuse any procedure or treatment. Like advance directives for end-of-life care, PADs are either instructional (living will) and/or agent driven (durable power of attorney). PADs offer an approach to personal empowerment and crisis prevention that is not widely used as of yet. Speak with your mental health provider for more information.

Medications Management Organization

Keep everyone's medications in his or her own place. Keep a medication master list, including which doctor ordered the medicine. Use a pill organizer carefully (the large ones work best over time). Store medication according to instructions. Set reminder alarms!

Many people have multiple physicians and prescribers so it is important to tell every provider about all your loved one's prescriptions, over-the-counter medications, and vitamins/supplements.

Interactions

Always ask the doctor or pharmacist about what interactions, if any, the medication may have with food or drink or other medications.

Generic Alternatives

Be sure to discuss with your health care provider any barriers your loved one may have to taking their medications, such as non-coverage of a drug under their insurance plan or out-of-pocket cost. Ask about generic alternatives, as they can be less costly.

Disposing of Medications

Leftover medicine is a danger. Flushed down the drain, it pollutes lakes, rivers, and our drinking water. Kept at home, it can be taken by your loved one by mistake. It's also a poison risk for small children and teens. It is important to properly dispose of medication no longer needed. For pharmacies near you that will dispose of medication:

➤ www.disposemy meds.org

The Value of a Geriatrician

If you provide care for an aging loved one, you might consider having them seen by a geriatrician. A geriatrician can conduct a comprehensive geriatric assessment, which will review such things as your loved one's functional capacity, fall risk, cognition, medication management, nutrition, etc. The outcome of the assessment can be a coordinated plan to maximize overall health and aging that may involve a core team consisting of a physician, nurse, and social worker. The cost of the service may be covered in part by Medicare or other insurances.

Communicating Effectively with Doctors

It is your right to expect full attention from any doctor during a visit, but it also your responsibility to be properly prepared before you and your loved one walk into any appointment. Remember, doctors are busy people, but the time you've reserved is your time and you should use it wisely. Here are a few tips on how to establish good communication with your loved one's doctors.

When Calling the Doctor's Office

Before calling, write down what you want to discuss. While it may be tempting to use the time on the phone to complain about a non-medical caregiving issue, that isn't an appropriate time for such a conversation. Keep the call focused on the medical or psychiatric issue about which you have questions.

Prepare for Each Office Visit

Many people walk into an examining room with their loved one with nothing more concrete than vague complaints about not feeling well. To make the best use of the appointment, write down and prioritize all your concerns beforehand, from most urgent to least, and take the list along with you.

In addition, jot down anything related to your loved one's health that has happened since the last visit. If this is a new doctor, come prepared with notes on any disease that runs in your loved one's family or past treatments they've had. Bring medical records and X-rays from the former doctor. If the office won't release them to you, have records sent directly to the new doctor before the first visit.

If you are seeing a new mental health provider, bring previous psychiatric evaluations and lab work related to psychiatric medications.

Be Honest, Even if Some Topics Embarrass You or Your Loved One

Some people find it difficult to talk to doctors about what causes their loved one the most distress, such as incontinence, or even problems that put them in danger, such as self-neglect. But your doctor has probably heard similar concerns many times before. Physicians are trained to help with issues you wouldn't want to discuss with anyone else. Be candid and honest.

Additional information is available online with advice about communicating with doctors. Search online for "*communication with doctors.*"

Explore Alternatives

Alternative medicine is becoming more common. Treatments such as acupuncture, massage, guided imagery, relaxation training, therapeutic touch, T'ai Chi, and yoga are now used in clinics and hospitals alongside conventional treatments. Asking your doctor about alternative treatments is something that you and your loved one might want to consider.

Assessing Hospitals

There are consumer-oriented websites that provide information on how well hospitals provide recommended care to patients throughout the country. Medicare and Medicaid host the following:

- **Medicare Hospital Compare**
Compare the quality of care at Medicare-certified hospitals
www.medicare.gov/hospitalcompare
- **Centers for Medicare & Medicaid Services**
Compare the quality of care at Medicare & Medicaid facilities
www.cms.gov, Search on "*hospital compare*"

When an Ambulance is Required

Should your loved one have a medical emergency requiring ambulance transport to a hospital, he or she has the right to request which hospital they prefer. Of course, in some cases the closest hospital may be the only sensible choice, negating discussion. Remember to be prepared in advanced with your "Go To" document with your loved one's medications and health history.

Questions to Ask Before Tests, Screenings & Scans

Each medical situation is individualized. Consult the Internet for a list of questions according to your loved one's specific needs. Search on "*questions to ask about medical tests.*" Be sure to ask the doctor why the test is necessary and what will it tell you that you don't currently know. Ask if the results will significantly alter treatment plans. Ask how and when you will receive results – will you be called or should you call the doctor?

Questions & Checklists Before Surgery

Again, there are many good and comprehensive lists of questions to be found on the Internet. Search on “*questions to ask before surgery.*” Additionally, always ask the staff about insurance precertification requirements well before any surgery is scheduled. Check out the “Family Caregiver’s Guide to Surgery for Older Adults,” which is helpful for any caregiver:

- http://nextstepincare.org/Caregiver_Home/Elective_Surgery

Transitions of Care

Caring for a loved one often involves navigating their care through multiple transitions. Whether it be managing transitions between the hospital, facilities, or home, caregivers often are faced with coordinating their loved one’s care between settings.

Facilitating communication with all providers who are caring for your loved one is an important part of managing transitions of care. Make sure that all medical and insurance records are transferred from each setting to the next and that your loved one’s primary care physician gets records of all procedures, tests, medications, and therapy done in the hospital or rehabilitation facility.

After surgery, or even an acute illness, your loved one may not go straight home from the hospital, but may instead go to some sort of inpatient rehabilitation facility for physical, occupational, or speech therapy. A social worker or discharge staff member at the hospital will help you understand your loved one’s needs, insurance coverage, and all available options.

Rehabilitation care is often provided in either an “acute” or “sub-acute” setting. Acute rehabilitation facilities specialize in providing intense therapy (usually three or more hours per day of therapy) and are usually intended for those recovering from major surgery or a serious accident. Sub-acute rehabilitation is usually provided in skilled nursing facilities and is for those who need therapy to help recover from an illness or surgery, but cannot tolerate the intense therapy provided in acute rehabilitation facilities.

For information about what rehabilitation care is covered by Medicare:

- **800.MEDICARE**
www.medicare.gov

Assistive Devices, Technologies & Durable Medical Equipment

A doctor may suggest that your loved one use what are called “assistive devices,” special technologies, or durable medical equipment. Such items help people maintain their independence, aid in mobility, or increase their safety. Items include: walkers, wheelchairs, devices for use in the bathroom and bedroom, vision and hearing aids, safety aids in the kitchen, a special computer keyboard, or a TTY/text telephone.

Note that such devices should be tailored to your loved one’s specific needs. Borrowing another person’s walker may sound like a great idea, but could, in fact, cause problems for your loved one. In many cases, an actual assessment is needed to ensure the device or technology is properly chosen and fitted.

Your doctor may be able to suggest local resources for such devices. Three other places to start are:

Advancing Opportunities (AO)

AO provides assessments and also has a free lending library with excellent resource information.

- **888.322.1918, TTY: 609.882.4182**
www.assistivetechologycenter.org

Goodwill Home Medical Equipment (Ewing, NJ)

Recycles and fits used equipment, some of which may be covered by Medicare.

- **609.396.1513**
www.goodwillhomemedical.org

Richard West Assistive Technology Advocacy Center (ATAC)

The ATAC of Disability Rights New Jersey (DRNJ) serves as the state's federally funded assistive technology project through a sub-contract with the NJ Department of Labor and Workforce Development. Its purpose is to assist individuals in overcoming barriers in the system and to make assistive technology more accessible to individuals with disabilities.

- **800.922.7233**
609.292.9742 (TTY 609.633.7106)
<http://www.drnj.org/atac/>

2. KEEPING LOVED ONES SAFE

Abuse Issues

There are different kinds of abuse to consider when talking about older adults, vulnerable adults, or children: mistreatment and neglect. Mistreatment refers to any harmful conduct that is willfully inflicted on a vulnerable person, including physical, sexual, emotional, or financial abuse and exploitation. Signs of maltreatment and abuse include, but are not limited to, frequent visits to the emergency room, unexplained bruises or wounds, and depression, fear, or anxiety on the part of the person receiving care.

Neglect can either be inflicted by another or self-imposed. Behavior is considered neglect when the responsible individual (i.e., caregiver, guardian, etc.) confines, isolates, or fails to provide essential services to prevent or lessen physical harm or mental anguish. Behaviors are considered self-neglect when an individual makes unnecessary or unsafe decisions or is taking part in unsafe activities. Signs of neglect include malnutrition or dehydration, unsafe or unsanitary living conditions, missing or broken eyeglasses, hearing aids or dentures, and the withholding of medical care, among others.

Adult Protective Services (APS)

APS investigates reports of suspected abuse, neglect, and exploitation of an elder or of a vulnerable adult age 18 or older living in the community. A person is considered vulnerable if they are unable to act on their own behalf. Reports may be made by anyone. When a report is received, APS investigates. If the report is confirmed and the person is willing to accept help, APS will identify and put in place services that can help the person. If you suspect a vulnerable adult is being abused or neglected, contact:

- **Adult Protective Services**
609.341.5567 or 800.792.8820
www.state.nj.us/humanservices/doas/home/adultpsp.html
- **Essex: FOCUS, Hispanic Center for Human Development, Inc.**
973.624.2528, x134, after hours call 911, local police, first aid, or hospital
- **Morris County: Morris County Division on Aging, Disabilities, and Veterans**
973.326.7282, after hours call 911, or 973.285.2900
www.morrishumanservices.org
- **Somerset County: Somerset County Board of Social Services**
908.526.8800, after hours call 800.287.3607
www.co.somerset.nj.us
- **Sussex County: Sussex County Division of Social Services**
973.383.3600, after hours call 911, or local police department
www.sussex.nj.us

- **Warren County: Warren County Division of Social Services**
908.475.6591, after hours call 911 or local police
www.co.warren.nj.us/humanservices/TASS/social_services.html
- **All counties: Aging & Disability Resource Connection of New Jersey (ADRC)**
877.222.3737
www.adrcnj.org

NJ Division of Child Protection and Permanency (DCP&P)

Anyone who has reasonable cause to believe that a child is being abused or neglected has a legal responsibility to report it. The contact is:

- **Child Abuse Hotline**
877.NJABUSE (877.652.2873)
800.835.5510 (TTY/TDD for the deaf)
www.state.nj.us/dcf/reporting/how/index.html

Disability Rights New Jersey

A New Jersey nonprofit that protects, advocates for, and advances the rights of persons with disabilities.

- **www.drnj.org**

Office of the Public Guardian

This office works to ensure the rights of seniors in the community. The Office serves as a guardian or conservator of last resort for those individuals aged 60 or older who have no willing or responsible family member or friend to act in that capacity.

- **609.588.6500**

The Prevention of Domestic Violence Act

This Act provides protection from abuse to older adults and people with disabilities. The Act authorizes the issuance of a restraining order using the criminal code to define abuse. A caregiver or any person who has reasonable cause to believe that an older person or a person with a disability is subject to abuse, neglect, or exploitation should report such information to the police. All counties have organizations that include emergency shelter and transitional housing.

- **New Jersey Coalition for Battered Women**
800.572.7233 or 609.584.8107
www.njcbw.org (Click on “Get Help”)

Personal Emergency Response Systems (PERS)

A PERS lets your loved one call for help in an emergency by pushing a button on a lightweight, battery-powered device they wear around their neck, on a wristband, on a belt, or in their pocket. When they need help, they press a button that generates a call to an emergency response center. The center will find out the nature of the emergency, review your loved one's medical history, and check who should be notified.

You can purchase, rent, or lease a PERS. Medicare, Medicaid, and most insurance companies typically don't pay for the equipment. The few that pay require a doctor's recommendation. Some hospitals and social service agencies may subsidize the device for low-income users. If you buy a PERS, expect to pay an installation fee and a monthly monitoring charge. Your local ADRC may be able to tell you what systems are available in your area. See if friends, neighbors, or relatives have recommendations.

Safety in the Home

Caregivers and loved ones with issues of aging or disability should safeguard themselves with simple at-home injury prevention. There are many easy, common sense things that can be done to improve home safety, especially as loved ones age or become less mobile. The Internet has many wonderful ideas. To begin, search on "*home safety tips for seniors*" and "*home safety tips for people with disabilities*."

Communicate with Local Police, Fire & Emergency Departments

As a caregiver, you should notify your local police if you think they should be aware of your loved one's illness, disability, or condition for any reason. For example, your loved one may be a wanderer or might have difficulty leaving the house in an emergency. In some cases, police departments automatically share this sort of information with fire and emergency health departments. When you call the local police, ask if they do so and, if not, contact those departments yourself.

Keeping Track of Your Loved One

There are many resources that can help you keep your loved one safe if they wander or become confused while out of the home.

Project Lifesaver

This program provides a tracking device for individuals at risk of wandering due to Alzheimer's disease, dementia, autism, or other condition. Each county's sheriff's department coordinates the program. If a person goes missing, the sheriff's department can activate the tracker, which assists local search teams and helps reduce the time the person is lost and at risk. County sheriff department contact information can be found online.

- www.projectlifesaver.org
- **Sheriff's Association of New Jersey**
856.225.5514
www.njsheriff.org

MedicAlert Foundation

MedicAlert is a 24/7 medical identification and information network. Services protect people of all ages and varying medical conditions and include communicating health information, storing care wishes, and reuniting loved ones in an emergency.

- **888.633.4298**
www.medicalert.org

MedicAlert Foundation + Alzheimer's Association Safe Return

MedicAlert + Safe Return provides a specialized 24/7 emergency response service for those with Alzheimer's or related dementia who wander or have a medical emergency. If the individual wanders, MedicAlert Foundation works with you, your local Alzheimer's Association chapter, and local law enforcement to provide safe return of your loved one.

- **888.572.8566**
www.alz.org

Alzheimer's Association Comfort Zone & Comfort Zone Check-In

The Association offers two GPS location management services that help families monitor a person with Alzheimer's or dementia. A small tracking device can be easily carried in a pocket, purse, or be installed in a vehicle. Families receive alerts if the person wanders from a preset safety perimeter.

- **877.259.4850**
www.alz.org

Local Police Departments & Silver Alerts

Should your loved one go missing, call your local police department to let them know. They may determine that the situation warrants contacting New Jersey state police who may then issue a Silver Alert. A Silver Alert is a public notification system that broadcasts information on commercial radio stations and TV stations about missing persons – especially seniors with Alzheimer's, dementia, or other mental disabilities – to aid in their return. Silver Alerts also use electronic message signs on roadways. In general, the decision to issue a Silver Alert is made by the law enforcement agency investigating the report of a missing person.

Identification for Your Loved One

An official photo ID is a good idea for everyone. A non-driver photo ID can be acquired at age 17; six points of identification are required, just as for a driver's license.

- **NJ Motor Vehicle Commission**
609.292.6500 or 888.486.3339
www.state.nj.us/mvc

At any age, a photo ID can be acquired at some county clerk's offices. This ID can include medical alert information. Sussex, Warren, and Somerset county clerks no longer do resident IDs.

- **Essex County Clerk**
973.621.4921
www.essexclerk.com/identification_resident.html

- **Morris County Clerk**
973.285.6160
www.morriscountyclerk.org

Driving Safety

There are critical indications that someone may be losing the judgment or ability to drive:

- Incompetent driving at night, even if competent during the day
- Drastically reduced peripheral vision, even if 20/20 with corrective lenses
- Struggling to drive at high speed even if they drive well locally at slow speeds
- Erratic driving: abrupt lane changes, braking or acceleration, hitting curbs
- Getting lost, even while driving on familiar roads
- Frequently startled, claiming cars or pedestrians seem to appear out of nowhere
- More frequent near-crashes or dents on car, mailboxes, garage doors
- Failing to use turn signals; drifting into other lane
- Range-of-motion issues, such as failing to look over the shoulder
- Increased traffic tickets or "warnings" by traffic or law enforcement officers

Talking to your loved about the need to stop driving is one of the most difficult discussions you may ever face. However, it's better if it comes as advice from you or someone they know rather than by an order from a judge or the DMV. Be empathetic. It helps to involve other family members in the discussion for assistance, but not to confront. Keep the conversation non-accusatory, honest, and between "adults," not "child and parent." Say things like, "We're concerned," "We care," or "We don't want you to get hurt or to hurt others."

Some caregivers enlist the help of their loved one's doctor who may be able to write a prescription for a driving evaluation. There are programs that offer behind-the-wheel driving evaluations, as well as evaluations of physical abilities, vision, reaction time, and perceptual-cognitive capacities. These programs, while valuable, can also be costly. Search the Internet for "*Driving Evaluations New Jersey*."

If the decision is to stop driving, continue to support your loved one in ways beyond just offering rides. Help your loved one make a schedule and plan activities and trips on days when a caregiver can drive. If appropriate, explore other transportation options to help your loved one maintain their independence.

3. CAREGIVING FOR A VETERAN

If you are a spouse, parent, sibling, child, or a friend caring for a veteran with issues of aging, disability or mental illness, there are additional resources available to support both you and your loved one. The US Department of Veterans Affairs and NJ Department of Military and Veterans Affairs fully recognize the valuable role caregivers play in supporting veterans, and view caregivers as “partners” with the VA in providing care.

Reaching out for help and accessing all available resources available to your veteran loved one (and to you) will help you maintain your own health and well-being and support you in your caregiving role.

Veterans Crisis Line

The Veterans Crisis Line is a free, confidential resource for veterans, family members, and caregivers. It is accessible 24/7 and 365 days a year through the VA New Jersey health care system.

- **800.273.8255, Press 1**

NJ Vet2Vet Hotline

This is a free and confidential helpline available 24/7 for veterans and their families through Rutgers University Behavioral HealthCare. The helpline features peer counseling, clinical assessments, and assistance to family members.

- **866.VETS.NJ4 (866.838.7654)**
www.njveteranshelpline.org

Resources for Caregivers of Veterans

VA's National Caregiver Support

A primary resource/referral center to assist caregivers of veterans seeking educational resources and help caregivers navigate the VA health care system. VA licensed clinical social workers provide information on VA community caregiver support resources and “warm” referral to dedicated caregiver support coordinators in local VA medical centers. Emotional support of caregivers is an integral component of this service.

The VA also hosts a website for caregivers with a wide range of resources and tools. The website has **Family Caregiver Program** applications (VA CG 10-10) which enables post-9/11 veterans and service members who elect to receive their care in a home setting to designate a primary family caregiver and secondary family caregivers if needed. Caregiver support coordinators assist with the application process. Caregiver support and educational resources are also available.

- **855.260.3274** (Monday through Friday, 8:00am-11:00pm; Saturday, 10:30am-6:00pm)
www.caregiver.va.gov

VA New Jersey Health Care System/Caregiver Support: Caring for Those Who Care

The Veterans Administration in New Jersey offers two main campuses in East Orange and Lyons. Additional outpatient health clinics include Elizabeth, Hackensack, Hamilton, Brick, Jersey City, Morristown, Paterson, Piscataway, and Tinton Falls. Social workers are connected to the VA medical team managing a veteran's care at the VA. Caregiver services can be accessed via website and a local Caregiver Support Coordinator.

- **East Orange campus: 973.676.1000, x3085**
Lyons campus: 908.647.0180, x4003
www.newjersey.va.gov/services/caregiver/index.asp

If you are not enrolled in the VA health care system, you can contact **877.222.VETS (877.222.8387)** regarding eligibility and assistance with completing the application (VA 10-10EZ) for enrollment.

VA New Jersey Home-Based Primary Care Program (HBPC)

Provides interdisciplinary primary care services in veterans' homes who are experiencing difficulties accessing primary care due to geographic, physical, functional, or psychosocial limitations, or complex conditions for which routine clinic-based care is not effective.

- **Program Manager, Rural Health/HBPC**
908.647.0180, x4151
- **Social Work Supervisor**
908.647.0180, x4440

VA “Healthy Caregiving” QuickSeries Booklet & Smartphone App

“Healthy Caregiving” outlines how caregivers can access services and benefits, provides tips on daily life, preventing stress, caring for trauma survivors, and more. Also available as an eGuide for smart phones.

- www.quickseries.com

VA New Jersey Mental Health Services

Mental Health Services can be accessed via the website or phone.

- **East Orange campus: 973.676.1000, x1421**
Lyons campus: 908.647.0180, x4596
www.mentalhealth.va.gov

Coaching Into Care

A national clinical VA program that works with family members or friends who become aware of a veteran's post-deployment difficulties and supports efforts to find them help.

- **888.823.7458**
www.military.com/veterans-report/coaching-into-care

Veterans Benefits & Services

Veterans of the United States Armed Forces are entitled to benefits and support from the US Department of Veterans Affairs. Those who served in the NJ Army National Guard or the NJ Air National Guard are entitled to benefits and support from the NJ Department of Military and Veterans Affairs. Both agencies provide patient care and benefits to veterans and their dependents.

US Department of Veterans Affairs

The VA operates the nation's largest integrated health care system (hospitals, clinics, readjustment counseling centers, etc.) and administers benefits and services that provide financial and other forms of assistance to service members, veterans, their dependents, and survivors.

- www.va.gov
- www.benefits.va.gov/benefits/
- www.va.gov/opa/publications/benefits_book.asp

VA Health Care Benefits

Veterans enrolled with VA completely satisfy their requirement to have health care coverage under the new Affordable Health Care Act. To learn more about your loved one's VA health care benefits, there are many links on the Internet. Two good starting points are:

- <http://hbexplorer.vacloud.us/>
- <http://www.va.gov/healthbenefits/online>

NJ Department of Military and Veterans Affairs

This Department offers a range of benefits, including housing, financial assistance, employment, education, and more for those who served in the NJ Army National Guard and NJ Air National Guard.

- **888.8NJ.VETS**
www.nj.gov/military/

NJ Veterans Benefits Guide

- www.nj.gov/military/veterans/njguide
- www.military.com/benefits/veteran-state-benefits/new-jersey-state-veterans-benefits.html

Northern New Jersey County Support for Veterans

- **Essex County Veterans Bureau, East Orange**
973.395.8394
- **Morris County Human Services: Aging, Disabilities & Veterans**
973.285.6868
www.morrishumanservices.org/adv/

- **Somerset County Veterans Services**
908.704.6329
<http://www.co.somerset.nj.us/hservicesveterans/index.html>
- **Sussex County Internment Officer, Stanhope**
973.347.8333
- **Warren County Internment Officer, Belvidere**
908.475.2413

Local Vet Centers

Vet Centers offer broad readjustment services for combat veterans: counseling for military traumas, employment and family problems, referral services for VA benefits, substance abuse, referral, and job counseling.

- **800.905.4675 or 973.748.0980**
Bloomfield Vet Center: 2 Broad Street, Bloomfield, NJ 07003

Aid & Attendance Pension Benefit

The VA offers Aid & Attendance (A&A) as part of an “Improved Pension” Benefit that allows for veterans and surviving spouses who require the regular attendance of another person to assist in eating, bathing, dressing, medication dosing, etc. to receive additional monetary benefits. It also includes individuals who are blind or a patient in a nursing home because of mental or physical incapacity. Care in an assisted living facility also qualifies. This is a “Pension Benefit” and IS NOT dependent upon service-related injuries for compensation. A&A can help pay for care in the home, nursing home, or assisted living facility. Caregivers are encouraged to speak with a VA benefits representative or a veteran service office about the application process and assistance with expediting claims for seniors.

- www.veteranaid.org

VA Health Care Benefits for Operation Iraqi Freedom/Enduring Freedom Veterans

Veterans are provided five years of free health care beginning on the date of separations for all illnesses and injuries unless clearly unrelated to military service.

- **877.222.8387**

The Post-9/11 GI Bill

This bill provides financial support for education and housing to veterans with at least 90 days aggregate service after Sept. 10, 2001 or veterans with a service-connected disability after 30 days.

- www.gibill.va.gov/benefits/post_911_gibill/

Prescription Assistance/Savings Programs

VA offers cost effective medications and refills and will mail medications directly to the home.

- www.newjersey.va.gov/services/pharmacy.asp

Education Opportunities for Veterans

There are many programs that support education opportunities for veterans. Two good places to start are:

- www.state.nj.us/military/veterans/programs.html
- www.onlinedegrees.org/returning-troops-the-transition-back-to-school/

Employment Support for Veterans

This site is a good starting point with regard to job assistance and training.

- <http://www.dol.gov/vets/>

Support for Veterans with Mental Health Issues

In addition to the suggestions below, caregivers can find helpful advice and access to services for veterans through many mental health agencies throughout northern New Jersey.

- **National Alliance on Mental Illness**
www.nami.org/Content/NavigationMenu/Find_Support/Veterans_Resources/Veterans_Resource_Center.htm
- **New Jersey Association of Mental Health and Addiction Agencies**
www.njamhaa.org

NJ Vet2Vet Helpline (Rutgers University Behavioral HealthCare)

This 24/7 helpline features peer counseling, clinical assessments, and assistance to family members, and access to a comprehensive support network of mental health professionals who specialize in issues specific to veterans returning to civilian life.

- **866.838.7654**
ubhc.rutgers.edu/vet2vet/program.htm

Post Traumatic Stress Disorder (PTSD)

This New Jersey program offers treatment to combat veterans of all war periods with PTSD. Treatment is extended to family members affected by the veteran's affliction.

- **888.8NJ.VETS (888.865.8387)**

Suicide Prevention

If your loved one is talking about death or dying, exhibits self destructive behaviors, exhibits mood swings, anxiety, sleeplessness, anger, an increase in alcohol or drug abuse, or a withdrawal from family and friends, a trained VA professional is on call 24/7.

- **Toll Free: 800.237.TALK (800.237.8255)**

Supportive Services for Veteran Families (SSVF)

A program in 11 counties in northern New Jersey designed to assist low-income, single veterans or veteran families at risk of homelessness to maintain their housing and to rapidly re-house veteran families who have recently become homeless. All veterans participating in the SSVF program must be engaged in a sustainable housing plan.

- **855.483.8466**
www.communityhope-nj.org

New Jersey Veterans Memorial Homes

Three state-of-the-art facilities that provide long- and short-term care.

- **Memorial Home at Paramus**
1 Veterans Drive, PO Box 608, Paramus, NJ 07653
201.634.8200
- **Memorial Home at Menlo Park**
132 Evergreen Road, Edison, NJ 08818
732.452.4102
- **Memorial Home at Vineland**
524 North West Blvd., Vineland, NJ 08360
856.405.4200

Social Security Information for Veterans

- **Expediting Disability Benefits for Wounded Warriors** (online publication)
www.socialsecurity.gov/pubs/EN-05-10030.pdf
- **Armed Forces Veteran Planning for Retirement** (online publication)
www.socialsecurity.gov/pubs/EN-05-10017.pdf
- **Social Security Administration Retirement Planner for Veterans**
www.socialsecurity.gov/retire2/veterans.htm

NJ Transportation Programs for Veterans

For veterans in need of transportation to VA medical centers and clinics, other hospitals, private physicians, and the VA regional office, contact your local veterans service office.

Death, Burial & Related Benefits

Free interment and perpetual care is available to veteran residents of New Jersey, their spouses, and dependent children. Pre-registration is encouraged.

- **Federal VA Burial & Death Benefits**
800.827.1000
- **NJ Veterans Benefits Hotline**
888.8NJ.VETS

4. EMERGENCY PREPAREDNESS FOR CAREGIVERS

Planning for an emergency is a vital activity to be taken seriously by everyone so that personal safety and recovery is maximized and direct and indirect loss is minimized. Being prepared for natural disasters like hurricanes, winter storms, floods, and man-made disasters like fires and terrorist attacks can greatly reduce the danger and distress you and your loved ones may experience.

Having a plan is one of the most important steps you can take in disaster preparedness. Knowing what to do and how to do it can help your family and friends manage disasters with less worry, fear, and uncertainty. There are many local organizations and online resources that can help you develop a comprehensive emergency plan. Once your plan is complete, it really will be comforting to have it all in place! So, dive in. Create a disaster plan for you and your loved one and feel fully prepared for any emergency.

National Resources

Federal Emergency Management Administration (FEMA)

Preparedness information for people with disabilities and other special needs.

- www.ready.gov

Administration on Aging (AoA)

Resources for families and caregivers, including a comprehensive Disaster Preparedness Toolkit. The focus is on seniors, but information is applicable for all caregivers.

- www.aoa.gov/aoaroot/Preparedness/Resources_Individuals/index.aspx

Another useful planning document can be downloaded at:

- http://www.aoa.gov/AoA_Programs/HCLTC/Caregiver/docs/Just_in_Case030706_links.pdf

National Red Cross

The American Red Cross provides extensive information on emergency preparedness. Also search on “*Emergency Prep for Seniors*,” “*Emergency Prep for People with Disabilities*,” “*Power Outage Checklist*,” “*Hurricane Safety Checklist*,” “*Winter Storm Checklist*,” and “*Food Safety Checklist*.”

You can also register with the Red Cross to receive the latest north Jersey region news, event updates, and disaster alerts. Search the site for “*Email Mailing List New Jersey*.”

- www.redcross.org
- www.redcross.org/prepare/disaster

Post-Disaster Assistance

Access to disaster planning resources, as well as forms and instructions to apply for disaster assistance:

- www.disasterassistance.gov

New Jersey Resources

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. It is also an essential component of homeland security and can help communities rebuild after terrorist attacks or natural disasters. In the event of a community emergency, 2-1-1 acts as a critical communication link between emergency management professionals and the public-at-large. It is staffed 24/7.

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

New Jersey Red Cross Chapters

Local chapters provide lots of information, including where to find shelters in an emergency. Search these sites on “*get assistance.*”

- **American Red Cross of Northern New Jersey**
973.797.3300
www.redcross.org/nj/fairfield
- **American Red Cross of Central New Jersey**
609.951.8550
www.redcross.org/nj/princeton

NJ Office of Emergency Management State Police Division Headquarters

The NJ Office of Emergency Management also has a Facebook page where residents can connect and share up-to-the minute information.

- **609.882.2000**
www.registerready.nj.gov
www.facebook.com/READYNEWJERSEY

NJ Office of Homeland Security and Preparedness

- www.njhomelandsecurity.gov

NJ Special Needs Registry

Registration allows residents with special needs and their families, friends, and associates an opportunity to provide information to emergency response agencies so emergency responders can better plan to serve them in an emergency. Information is kept confidential.

- www.registerready.nj.gov

Local Emergency Alert Systems

Contact your community's town hall or police department to register for local emergency alerts via phone messages, emails, and text messages. Many towns use Nixle for this alert service.

- <https://local.nixle.com/register/>
To receive alerts on your mobile phone, text your zip code to 888777

In addition, most towns have an Office of Emergency Management where any special circumstances you have can be registered so that your needs can be anticipated by emergency responders. You can also call local police and ask about how to register seniors and people with disabilities with law enforcement and emergency services.

Caregivers Library

This site has emergency preparedness resources for caregivers of loved ones with disabilities and aging issues, including Alzheimer's.

- www.caregiverslibrary.org/caregiving-ministries/ministry-home/disaster-preparedness-article.aspx

Create a Support Network

Determine who your support network consists of: family members, neighbors, and friends. Communicate your plans with them. Share copies of important papers with them, including evacuation plans, contact information, lists and locations of prescription medications, and where you keep supplies. Exchange important keys. Agree on contact plans that do not depend on land phone lines. Before a storm arrives, initiate your plans for checking in on each other.

Post-Disaster Scams

Natural disasters attract con artists who take advantage of people who have been devastated. Protect yourself and your loved one from scams by staying alert and cautious. Search "*post disaster scams*" online for more specific information. The most common post-disaster scams include home repair frauds, fake charities, and identity theft.

The Hidden Impact of Disasters

Everyone is impacted by disaster, some more than others. Vulnerable family members – seniors, those with disabilities, or mental illness – are at greater risk of disaster-related stress that can interfere with the normal ebb and flow of our emotions and abilities. They are often slower to register for disaster assistance and once they are registered may not follow through and complete the necessary applications to obtain assistance. In the aftermath of a disaster, they may be at higher nutritional risk or may forget to take necessary medications. They are often targeted by con artists who try to financially exploit them after a disaster. Families may be susceptible to physical and mental abuse as stresses increase in later stages of a disaster.

If you or your loved one is struggling post-disaster, reach out to others and take advantage of resources to keep you and your loved one safe and healthy. Remember, you need not be alone as you cope with caregiving issues post-disaster.

5. BENEFIT PROGRAMS & SAVINGS/ASSISTANCE PROGRAMS FOR LOVED ONES WITH ISSUES OF AGING, DISABILITY, OR MENTAL ILLNESS

See **Sections A, B, or C, Chapter 7** for information on Social Security, Medicare, and Medicaid.

General Financial Planning

Durable Power of Attorney for Financial Matters

It is very important for caregivers and their loved ones to draw up a durable power of attorney for financial matters. By creating a power of attorney, your loved one can designate someone to assist with finances now and/or act on their behalf should they become incapacitated. A power of attorney can give your loved one peace of mind knowing that someone they trust will have the authority to make financial decisions for them when they are no longer capable.

A power of attorney is a written document in which your loved one appoints someone else (an “agent”) to act for him or her under certain circumstances. The power of attorney needs to be “durable,” meaning it begins when it is signed and it remains in effect throughout your loved one’s lifetime. Your loved one can continue to manage their finances even after signing a power of attorney, but if they become incapacitated, then the named agent will step in.

It is important to review each institution’s specific requirements for power of attorney documents as early as possible. Some strictly require their own power of attorney form or “authorization from the loved one” before a caregiver can even inquire on their loved one’s behalf about a power of attorney with that institution.

Financial Planners

Professional financial planners look at a person’s long-term financial goals and analyze assets, income, investments, and personal concerns. The financial planner will provide advice and plans on how to maximize returns and minimize expenses through investments and reinvestments. To find a planner:

- **AARP**
888.687.2277
www.aarp.org

- **Financial Planning Association**
800.322.4237
www.fpanet.org

- **National Association of Personal Financial Advisors**
888.333.6659
www.napfa.org

Bill Paying Services

If your loved one is no longer capable of handling his or her own finances, sometimes an option is to hire a professional to pay all of the bills. A bill paying service will submit a report to the power of attorney. This report will include all of the money necessary to pay the bills for that month as well as the service fee.

American Association of Daily Money Managers (AADMM)

AADMM is a membership organization comprised of individuals who provide money management services. For a listing of money managers by geographic area:

- **877.326.5991**
www.aadmm.com

If your loved one is also a senior, additional resources are available:

Essex County: Friend Advocate Program

This program offered by Jewish Family Service of MetroWest has trained and supervised volunteers who provide assistance with bill paying, budgeting, and organizing paperwork.

- **973.765.9050**
www.jfsmetrowest.org

Morris County: Senior Cents

Senior Cents is a money management and advocacy program for seniors and people with disabilities in Morris County that uses trained volunteers to enable the older adult to control their finances and remain independent. The program is offered through Cornerstone Family Programs.

- **973.538.5260**
www.cornerstonefamilyprograms.org

Somerset & Warren counties: Money Management Assistance Program (Money MAP)

The Money Management Assistance Program (Money MAP) uses trained, supervised, and screened volunteers to provide money management and bill payer assistance to older adults in Somerset and Warren counties who are either unable to manage their own financial affairs or who just need some help keeping track of financial matters and paying routine bills.

- **Somerset County Office of Volunteer Services**
908.704.6358
www.co.somerset.nj.us
- **Warren County Division of Aging & Disability Services**
908.475.6591
www.co.warren.nj.us

Financial & Tax Assistance/Savings Programs

AARP Tax Aide

Program offers free tax assistance and preparation services to taxpayers who are 60 and older with low-to moderate-incomes. Call or visit website to find a site near you.

- **888.227.7669**
www.aarp.org

WorkFirst NJ (Temporary Assistance for Needy Families/General Assistance)

WorkFirst NJ (WFNJ) is the state's welfare reform program. It provides financial, medical, and other support services to families who meet certain criteria, depending on family size, monthly income, and assets and resources through the Temporary Assistance for Needy Families (TANF) program. Under the supervision of the NJ Division of Family Development (DFD), the 21 county welfare agencies administer the TANF program.

Cash benefits and other support services are provided to individuals and couples with no dependent children through the WorkFirst NJ General Assistance (GA) program. While most WorkFirst NJ GA programs are administered through the county welfare agencies, about one-third of New Jersey's 566 municipalities maintain their own welfare offices to serve those clients.

It is important to note that people who are permanently disabled, sole caregivers of a dependent who is disabled, chronically unemployable, over age 60, or victims of family violence are exempt from the five-year time limit on WFNJ.

- **NJ Division of Family Development, WorkFirst NJ**
800.792.9773
www.state.nj.us/humanservices/dfd/programs/workfirstnj/

New Jersey's Homestead Property Relief Program

The Homestead Credit/Rebate Program provides credits or rebates for homeowners and tenants who occupied their principal residence in New Jersey on October 1 of the year for which the credit applies, paid property taxes on that dwelling either directly or through rent, and whose gross income for the entire year does not exceed certain limits.

- **877.658.2972**
www.state.nj.us/treasury/taxation/homestead/geninf.shtml

New Jersey's Property Tax Reimbursement Program (Also Known as the "Senior Freeze")

This program reimburses eligible senior citizens and people with disabilities for property tax increases. The amount of the reimbursement is the difference between the amount of property taxes that were due and paid in the "base year" (the first year that all eligibility requirements are met) and the amount due and paid in the current year for which the reimbursement is being claimed, provided the amount paid in the current year was greater.

The applicant must meet all the eligibility requirements for the base year and for each succeeding year, up to and including the current year, to qualify for the reimbursement.

- **800.882.6597**
www.state.nj.us/treasury/taxation/ptr/index.shtml

Tax Benefits for Caregivers

If you support an aging parent, a family member with a disability, or a family member with a mental illness, you might qualify for some tax benefits that reward you for your caregiving efforts. These tax benefits may include claiming your loved one as a dependent on your tax return or deducting the contributions you made towards their medical expenses and care. For eligibility requirements and information, search the Internet on “*tax tips for caregivers of people with disability, 2013.*” (Note: always include the current year in your search request, as requirements can change.)

Medical Costs

Catastrophic Illness in Children Relief Fund

A catastrophic illness is any illness or condition, acute or chronic, for which expenses are incurred that are not fully covered by insurance, state, and federal programs, or other sources and exceed the program’s eligibility threshold. The child must have been 21 years or younger when the medical expenses were incurred. Any illness can be considered “catastrophic” based on the amount of uncovered eligible medical expenses and the family’s income over the prior 12-month time period. The following incurred expenses will be considered and may be eligible for payment/reimbursement if found reasonable. The categories include, but are not limited to:

- Specialized pediatric ambulatory care
- Addictions/mental health services
- Acute or specialized hospital care, both in and outpatient
- Physician care in all settings
- Medical equipment or disposable medical supplies
- Pharmaceuticals
- Medically related home modifications and medical transportation
- Home health care
- Experimental medical treatment or pharmaceuticals following special review

- **NJ Department of Human Services – Catastrophic Illness in Children Relief Fund**
609.292.0600 or 800.335.FUND
www.state.nj.us/humanservices/cicrf/home/index.html

NJ Hospital Care Payment Assistance Program (Charity Care Assistance)

This program offers free or reduced charge care to patients who receive inpatient and outpatient services at acute care hospitals throughout New Jersey. Hospital assistance and reduced charge care are available only for necessary hospital care. Some services such as physician fees, anesthesiology fees, radiology interpretation, and outpatient prescriptions are separate from hospital charges and may not be eligible for reduction. Hospital care payment assistance is available to residents who:

- Have no health coverage or have coverage that pays only for part of the bill
- Are ineligible for any private or government sponsored coverage (such as Medicaid)
- Meet both income and assets eligibility criteria

For information on eligibility and on how to apply:

- **NJ Department of Health & Human Services**
866.588.5696
www.state.nj.us/health/cc/

Prescription Assistance/Savings Programs

Pharmaceutical Assistance to the Aging and Disabled (PAAD)

New Jersey's PAAD program provides pharmaceutical assistance to residents 65 years of age or older or 18 years of age and older if receiving Social Security Disability benefits. This is a means-based program. Single adults with annual income of less than \$25,743 and married couples with annual income less than \$31,563 in 2013 are eligible. Income eligibility changes annually.

The PAAD copayment will be \$5 for each PAAD covered generic drug prescription and \$7 for each PAAD covered brand name drug prescription. PAAD beneficiaries may pay less for generic drugs if their Medicare prescription drug plan charges them less than the \$5 PAAD copayment for generics. People eligible for PAAD are usually eligible for the Lifeline Program and the Hearing Aid Assistance to the Aging and Disabled Program (HAAAD).

Medicare-eligible PAAD beneficiaries are also required to enroll in a Medicare Part D Prescription Drug Plan. PAAD will pay the monthly premium for certain standard basic Part D plans with a monthly premium at or below the regional benchmark or standard basic plans or enhanced plans up to \$5 above the benchmark amount that has no deductible. These plans will cover medically necessary prescription medications under Part D. The federal Medicare Plan and/or PAAD will pay any costs above the PAAD copayment of \$5 for each covered generic drug or \$7 for each covered brand name drug, including premiums. However, if a Medicare Part D plan does not pay for a medication because the drug is not on its formulary, PAAD beneficiaries will have to switch to a drug on their Part D plan's formulary or their doctor will have to request an exception due to medical necessity directly to their Part D plan. Medicare Advantage participants must add a prescription benefit to their coverage and PAAD will contribute up to the regional benchmark amount towards the prescription portion of their total premium. To find out which basic Part D plans in New Jersey PAAD pays the monthly premium:

- **NJ Department of Human Services, Division of Aging Services**
800.792.9745
www.state.nj.us/humanservices/doas/paad

Senior Gold

This state-funded prescription program for New Jersey residents 65 years of age or older or 18 years of age or older and receiving Social Security Disability has a different copayment structure and higher income eligibility requirements than PAAD. For 2013, single adults with an annual income between \$25,743 and \$35,743 and married couples with an annual income between \$31,562 and \$41,563 are eligible. Income eligibility changes annually.

Members pay a copayment of \$15 plus 50 percent of the remaining cost of each covered prescription until they reach annual out-of-pocket expenses exceeding \$2,000 for single persons or \$3,000 for married couples. When they have exceeded their annual out-of-pocket expense, they pay only the flat \$15 copayment per prescription for the rest of the year. There are other restrictions and coordination with other insurance benefits or Medicare Part D. All Medicare-eligible Senior Gold beneficiaries are also required to enroll in a Medicare Part D Prescription Drug Plan of their choice. They will be responsible for paying the monthly premium directly to the Medicare Part D plan, as well as for paying any late enrollment penalty imposed by Medicare for each month they were eligible to enroll in Medicare Part D but did not enroll.

- **NJ Department of Human Services, Division of Aging Services**
800.792.9745
www.state.nj.us/humanservices/doas/home/seniorgold.html

FamilyWize Prescription Drug Discount Card

FamilyWize, in partnership with United Way, offers a free prescription drug discount card that can offer immediate savings on prescription drugs at participating pharmacies for people with no health insurance, during deductible periods, and for prescription medicine not covered by health insurance, Medicare, or other benefit plans. It is not insurance nor is it intended to replace insurance. It can save an average of up to 30 percent or more off the pharmacy's usual and customary retail price of prescription drugs, with the highest savings on generic drugs. The cost will be the discount price with the FamilyWize card or the pharmacy's usual and customary retail price, whichever is lower. For information or to receive a card:

- **United Way of Northern New Jersey**
973.993.1160, x112
UnitedWayNNJ.org/RXSavings

NeedyMeds

NeedyMeds is a 501(c)(3) nonprofit information resource devoted to helping people in need find assistance programs to help them afford their medications and costs related to health care.

- **www.needymeds.org**
800.503.6897

Partnership for Prescription Assistance

The Partnership for Prescription Assistance helps qualifying patients without prescription drug coverage get the medicines they need for free or nearly free.

- **888.477.2669**
www.pparx.org

Resident Prescription Savings Programs

Many New Jersey counties provide residents not currently covered through any government sponsored or employer-based prescription insurance program with drug discount cards that provide savings up to 50 percent on prescription medications. Some cards are free; others have an annual, non-refundable membership fee. Typically there are no age, income, pre-existing condition exclusions, deductibles, or limits on quantities, and no forms to complete except for initial application. Call your county's ADRC.

- **Aging and Disabilities Resource Connection (ADRC)**
877.222.3737
www.adrcnj.org

Rx4NJ

Rx4NJ is a website designed to help low-income, uninsured New Jersey residents get free or discounted brand name medicines. State agencies and community organizations worked with pharmaceutical companies to develop Rx4NJ. If you have a hard time paying for your medications, you may be eligible for help in paying for your prescriptions. Rx4NJ makes it easy to find out if you or a loved one qualifies for assistance. Once you provide the website with basic information related to prescriptions, income, and current prescription medicine coverage, Rx4NJ will be able to tell you what patient assistance programs you may be eligible for. If eligible, you will receive an application print out that you return directly to the drug manufacturer for final approval after your doctor has signed it. For information:

- **888.793.6765**
www.rx4nj.org

RxCut Plus

This is a free prescription savings program that provides discounts on generic medications when the cost is greater than \$10 for individuals with health insurance and a discount for individuals with no insurance.

- **800.808.1213**
www.rxcut.com

Individual Pharmaceutical Companies

Individuals who have no insurance coverage or funds to pay for medications can apply for assistance directly from pharmaceutical companies for brand name medications. Applications for available assistance programs can be found on the website of the company that manufactures the medication.

Check with your pharmacy, wholesale club, and food and retail stores with pharmacies as they often have discounts on drugs. Talk to your health care provider. Ask for generics or for samples. Shop pharmacies to make sure you are getting the best price.

Other Assistance/Savings Programs

Hearing Aid Assistance to the Aged and Disabled (HAAAD)

HAAAD provides a \$100 reimbursement to eligible persons who purchase a hearing aid. Persons must meet the PAAD eligibility requirements or currently be enrolled in PAAD.

- **NJ Department of Health and Senior Services**
800.792.9745
www.state.nj.us/humanservices/doas/home/services.html

New Jersey's Supplemental Assistance Nutrition Program (NJ SNAP)

NJ SNAP, formerly Food Stamps, is the new name for the nutrition assistance program to help low-income individuals and families buy the groceries needed to eat healthy. You may be eligible for NJ SNAP even if you own your own home, work, or have money in the bank.

- **NJ Division of Family Development, NJ SNAP**
800.687.9512
www.nj.gov/humanservices/dfd/programs/njsnap/

Personal Assistance Services Program (PASP)

PASP provides non-medical, consumer-directed home health care for persons with disabilities between the ages of 18 and 66 who are either in school, working, or volunteering in the community. To determine eligibility or for information call your county's ADRC.

- **Aging and Disabilities Resource Connection (ADRC)**
877.222.3737
www.adrcnj.org

Telephone Assistance

Lifeline Program

The Lifeline Program is a federal program which provides support to telecommunications companies that in turn offer discounts to eligible consumers. Consumers can apply for these discounts through their telecommunications company. Additional state support may be available. For eligibility requirements and companies in your state:

- www.lifelinesupport.org

NJ SHARES

NJ Shares partners with Verizon New Jersey to offer two assistance programs for phone service for people with low incomes. Through **Link Up America**, eligible new customers receive a 50 percent discount on the initial phone connection charge, with the remaining 50 percent paid in 12 monthly installments. Through **Communications Lifeline**, existing Verizon residential customers may be eligible to receive discounted local telephone service. Communications Lifeline makes local telephone service available to people who might not be able to afford phone service. To see if you are eligible for either program:

- **888.337.3339**
www.njshares.org

Utilities Assistance

Low Income Home Energy Assistance Program (LIHEAP) & Universal Service Fund (USF)

LIHEAP is designed to help low-income families and individuals meet home heating and medically necessary cooling costs. Applications are usually accepted between October 1 and April 30. To apply for LIHEAP, you need to contact the authorized local community action agency or community-based organization in your area. To be eligible for LIHEAP benefits the applicant household must be responsible for home heating or cooling costs, either directly or included in the rent, and have gross income at or below 200 percent of the federal poverty level. Persons who live in public housing and/or receive rental assistance are not eligible unless they pay for their own heating/cooling costs directly to the fuel supplier. The amount of the LIHEAP heating benefit is determined by income, household size, fuel type, and heating region. See website noted below to find LIHEAP income eligibility levels.

- **LIHEAP information or to locate the nearest application agency**
800.510.3102
www.energyassistance.nj.gov
www.state.nj.us/dca/divisions/dhcr/offices/heaushincomefact.html

Note: The LIHEAP application is also an application for the Universal Service Fund Program (USF). You apply for two benefit programs at the same time using one application.

USF is a program created by New Jersey to help make natural gas and electric bills more affordable for low-income households. If you are eligible, USF can lower the amount you pay for gas and electricity. To be eligible, a household gross income must be at or below 175 percent of the Federal Poverty Level and pay more than 3 percent of its annual income for electric or more than 3 percent for natural gas. If a household has electric heat, it must spend more than 6 percent of its annual income on electricity to be eligible.

- **USF Information**
866.240.1347

Lifeline Utility Assistance

Lifeline is a utility assistance program that offers a \$225 credit on electric and gas utility bills for persons who meet the PAAD eligibility requirements or who receive SSI.

- **NJ Department of Health and Senior Services**
800.792.9745
www.state.nj.us/humanservices/doas/home/lifelinedetail.html

Temporary Relief for Utility Expenses (TRUE) Program

The TRUE Program provides one-time relief for gas and electric bills to moderate-income households who are experiencing a temporary financial crisis. One requirement for a TRUE grant is that you must not currently be receiving or have received within the past year any benefit through the USF or LIHEAP program.

- **732.982.8710**
www.state.nj.us/bpu/assistance/programs/#nbr1

NJ SHARES

A statewide, nonprofit 501(c)(3) organization which provides grants to pay utility bills of households in need through a statewide network of more than 270 community-based agencies. For information:

- **866.NJSHARES (866.657.4273)**
www.njshares.org

Weatherization Assistance Program (WAP)

The New Jersey WAP provides income-qualified residents with services that reduce household energy use and costs by improving the energy efficiency of their homes while ensuring their health and safety. For eligibility requirements and information, contact the NJ Department of Community Affairs.

- **800.510.3102 or 609.984.3301**
www.state.nj.us

Home Modifications/Repairs

If your loved one has a physical disability, home modifications may be helpful. Typical home modifications, such as building a ramp, widening doors, installing grab bars in the bathroom, or lowering countertops, can be very costly. While some home modifications are within the capacity of most do-it-yourselfers (such as changing door hardware from knobs to levers), other projects may require the aid of professional contractors. There are many different programs that can help pay for home modifications for people with disabilities. The Assistive Technology Advocacy Center (ATAC) of New Jersey publishes a home modification guide highlighting many of these programs. This guide is available online at the Disability Rights New Jersey (DRNJ) website:

- **www.drnj.org**

Long-Term Care Insurance

About 44 percent of all people age 65 and older will need nursing home care at some point in their lives. The average age for entering a nursing home is 83. One-third of those who enter a nursing home will stay three months or less and 20 percent will stay about a year. The balance of older adults, or about one half, will remain in a nursing home more than a year at a current cost of about \$100,000 per year.

Private insurance can play a vital role in protecting against what, for some, can become an economic catastrophe. Often, at the point when caregiving is necessary, the opportunity to insure for long-term coverage to help cover nursing home costs has passed and the person needing care is deemed “uninsurable.”

As a caregiver, you should become aware of the conditions of coverage of the insurance carried by the person you care for. A periodic review of all insurance coverages is always recommended.

Key concerns to watch for:

- Waiting periods
- Policy requirements for Medicare approval
- What, if any, limits exist on daily medical benefits
- What are benefit coverages for: Alzheimer’s, respite care, and skilled, intermediate, or custodial care
- Types of care facilities covered or not covered
- Whether in-home services are covered
- Coverages for assisted living or community senior center
- Ability to use benefit for care within a nursing home or facility
- Benefits for personal grooming
- Ability to upgrade to higher benefits or less restrictive coverage, protection against inflation

National Clearinghouse for Long-Term Care Information

Information from the US Department of Health and Human Services and the Administration on Aging.

➤ **202.619.0724**

www.longtermcare.gov

Veterans

An individual with a disability who is a veteran or whose parent or spouse is or was a veteran, may be eligible for monthly cash payments, assistance with educational costs, medical care, vocational assistance, rehabilitation, or other benefits. In addition, a person with a disability who is a veteran may be eligible for grants for specifically adapted housing. Please turn to **Section D, Chapter 3** for more information for caregivers of veterans.

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.

6. TRANSPORTATION INFORMATION FOR LOVED ONES WITH ISSUES OF AGING, DISABILITY, OR MENTAL ILLNESS

For many individuals, transportation is a vital link for maintaining independence in the community, accessing service, and/or participating in the work environment. There are a variety of options for aging loved ones and loved ones with a disability or mental illness. (For information regarding School Transportation for a Child with Disability, see **Section B, Chapter 4.**)

Aging & Disability Resource Connection of New Jersey (ADRC)

The ADRC is New Jersey's doorway to information and assistance for older persons, adults with physical or mental disability, caregivers, and professionals looking for services and programs. The ADRC is an excellent portal to a wide variety of resources, including transportation. 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 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.

- **Dial 2.1.1 or 800.435.7555**
www.NJ211.org

NJ Find a Ride

A directory of transportation options for people with disabilities who do not have access to accessible and reliable transportation, including public and private transportation services, feeder services that provide service to and from fixed bus stops and train stations, community shuttle buses, paratransit services, and on-call or pre-arranged services. Information is easily sorted by county.

- **www.njfindaride.com**

NJ Transit

NJ Transit provides reduced fares for senior citizens and those with a permanent disability. Seniors and passengers with disabilities can travel on-board NJ Transit trains, buses, and light rail vehicles at a reduced fare of one-half the regular one-way fare or lower. Seniors and passengers with disabilities must present a NJ Transit Reduced Fare ID or Medicare Card to obtain the reduced fare ticket.

To receive discounted fares, a NJ Transit Reduced Fare Card/Reduced Fare ID application must be submitted, as well as a Social Security Card and proof of age (birth certificate or driver's license).

Applications can be found at most local banks, savings and loan associations, county Offices on Aging, and the NJ Transit Customer Service offices at Newark Penn Station, New York Penn Station, Hoboken Terminal, and the Port Authority Bus Terminal. An application can also be mailed to you.

➤ **NJ Transit Reduced Fare Office**
973.491.7112

www.njtransit.com/sf/sf_servlet.srv?hdnPageAction=ReducedFareTo

Access Link

NJ Transit also provides paratransit services, called Access Link, for those people who have a disability that prevents them from using the local fixed route bus service. Cost of this service is the cost of the usual bus fare to your destination. Eligibility is determined using the three categories provided in the Americans with Disabilities Act. Your loved one may be eligible for Access Link if:

- If he or she cannot get on or off a bus or ride in an accessible bus due to a disability
- If his or her disability prevents him/her from getting to a bus stop
- If accessible bus service is not available in his or her area

Access Link is comparable to public bus service in that it is a curb-to-curb service, runs on the same schedule, and costs the same as the usual bus fare to the desired destination. Access Link shadows the fixed bus route and must pick up/drop off within a three-quarters of a mile radius of an established bus route.

To apply, an assessment interview is necessary. Transportation can be provided. To arrange an assessment:

➤ **NJ Transit**
800.955.2321 (TTY 800.955.6765)

www.njtransit.com/tm/tm_servlet.srv?hdnPageAction=AccessibleServicesTo

Community (County-Based) Paratransit Services

Services may vary by county, but most offer transportation for things like: non-emergency medical appointments, dialysis, physical and mental therapies, employment, grocery shopping, nutrition sites, post-secondary education, Medicaid services, veteran's services, social and recreational activities, and personal business such as hairdresser, banking, etc. Some paratransit services are open to the general public; others may be restricted to seniors, people with disabilities, or social services clients. Paratransit providers use smaller lift equipped vans and may operate route deviation, curb-to-curb, and sometimes door-to-door. Some providers require advance reservations from one to 14 days before. Most counties provide services on weekdays, with limited evening and weekend service. Out of county transportation may be limited.

➤ **Essex County Transportation**
973.395.5858

www.essex-countynj.org

➤ **Morris County Transportation (MAPS)**

This program is for Morris County residents aged 60 or older or with a physical or mental disability that includes functional limitations. You must notify in advance if the caregiver will be traveling with the resident.

888.282.MAPS (6277) or 973.829.8103

www.co.morris.nj.us

➤ **Somerset County Transportation**

908.231.7115 or 800.246.0527

www.co.somerset.nj.us

➤ **Sussex County Skylands Ride**

973.579.0483

www.sussex.nj.us

➤ **Warren County Transportation**

908.454.4044 or 866.594.4044

<http://warren.nj.us/humanservices/transportation.html>

Municipal Transportation Services

Many municipalities also offer their own transportation services to older adults and people with disabilities. Please check with your municipality to learn what services they may provide.

Other Resources – Public/Nonprofit/Private

American Red Cross of Northwest NJ

The Red Cross provides transportation for veterans to medical appointments and VA hospitals.

➤ **973.538.2160**

Easton Coach Company

Easton Coach Company operates paratransit transport for senior citizens, Medicaid recipients, and individuals with disabilities. Primarily in Pennsylvania and New Jersey. Needs four days notice.

➤ **908.454.4044 or 866.594.4044**

www.eastoncoach.com

LogistiCare – Non-Emergency Medical Transportation

LogistiCare is New Jersey's medical transportation broker in all counties for individuals on Medicaid and is responsible for arranging non-emergency medical transportation through its provider network.

➤ **866.527.9933**

www.state.nj.us/humanservices/dmahs/home/logisticare.html

Community Rides

Mental Health Association of Morris County facilitates independent living for Morris County residents who have been discharged from psychiatric hospitals by helping them to meet their needs, including running errands, shopping, and visiting family and friends.

- **973.334.3496**
www.mhamorris.org

Morris on the Move (M.O.M.)

M.O.M. provides transportation for up to 18 passengers and two wheelchairs. Priority given to public assistance and other low-income residents commuting to or from work or work-related activities. Operates a shuttle from Dover to Mt. Olive; service is limited service.

- **973.829.8501**

New Jersey Council on Special Transportation (NJ COST)

A statewide advocacy organization that provides information and promotes activities to enhance the coordination of transportation services. It also offers contact information for the state's 21 county coordinated transportation programs, as well as some information on available municipal transportation services.

- **973.251.2242**
www.njcost.com

Transportation Management Associations (TMA)

TMA's assist commuters, businesses, and local municipalities in New Jersey to provide transportation for residents by offering commuter information and services such as organizing car/van pools.

- **TransOptions (Essex, Morris, Sussex, and Warren counties)**
973.267.7600
www.transoptions.org
- **Ridewise (Somerset County)**
908.704.1011
www.ridewise.org

Way2Go Transportation to Greystone Psychiatric Hospital

Free transportation for Warren County residents to Greystone Psychiatric Hospital to visit ill family members who are receiving inpatient treatment. Transportation is provided by Family Guidance Center of Warren County Intensive Family Support Services program and is available on Tuesdays and Saturdays.

- **908.689.1000, x331 or x330**

Other Private Resources

There are numerous private companies that provide transportation services. Search the Internet on “private transport NJ,” “private non-medical transport NJ,” and “private medical transport NJ.”

Additional Transportation Information

Accessible Parking Privileges: Disability Plates & Placards

Disability parking privileges are available for drivers who have lost the use of one or more limbs, are permanently disabled and cannot move without an assistive device, or those who transport individuals with such disabilities on a regular basis.

Effective August 1, 2013, certification by a medical professional is required as part of the application process. Recertification is required every three years. Applications are available at your local motor vehicle agency or may be downloaded from the New Jersey state website:

- **NJ Motor Vehicle Commission**
609.292.6500
www.state.nj.us/mvc/Vehicle/HandicappedPlates.htm
www.state.nj.us/mvc/pdf/Vehicles/HDC_Placard_Application.pdf

Adaptive Driving & Vehicle Modification for Individuals with Disabilities

Individuals who have a disability that impacts their ability to drive may want to obtain an evaluation from a qualified driver evaluator. This assessment will assist the individual to determine what equipment and modifications may be necessary to safely operate a motor vehicle. Caregivers may also want to research motor vehicle modifications to ensure safe travel for their loved ones. For information on how to find a qualified evaluator and available modifications visit the National Highway and Transportation Safety Administration site and click on the brochure titled “*Adapting Motor Vehicles for People with Disabilities.*”

- www.nhtsa.gov/cars/rules/adaptive
- **Kessler Institute – Driver Rehabilitation Program**
www.kessler-rehab.com/programs/outpatient-services/driver-rehab/Default.aspx
- **JFK Johnson Rehabilitation Institute – Driver Evaluation and Training**
www.njrehab.org/adult-programs/adult

Some hospitals, medical providers, and other services provide transportation for their patients or consumers. Please check with your provider when making an appointment to see if transportation is available.

7. LIFE TRANSITIONS FOR CAREGIVERS

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, friend, or even child were used to doing independently can generate a range of emotions for you both. Being informed about and understanding your loved one's particular illness or disability 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 and/or your loved one are 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.

The Reality of Loss

Loss comes in many forms. Should the person you care for become increasingly dependent, losing more and more of their abilities, this is a real and meaningful loss and a natural reaction is to grieve – for both the caregiver and the care recipient. If you care for a child or young adult, the loss of your dreams and hopes for them is also very real and will likely bring grief. Such feelings of loss often go unspoken. Friends and family may not understand or even be aware of such losses and the accompanying grief. But that does not minimize the reality of them.

For caregivers, whose losses are sustained over a long period of time, grieving itself can become a long-term process. Experts say there are many stages of grief, which can recur or even appear simultaneously. For illnesses that keep changing this is especially true. The grieving process is highly personal, but however it occurs it is normal and unavoidable.

Ultimately, as a caregivers you may face a double sorrow. You may lose the person you have provided care for and experience all the grief that is associated with the loss of a loved one. But you may also experience a natural sense of loss when the caregiving role itself comes to an end.

Caregiving responsibilities gave each day a direction, a purpose. While it may have been consuming and stressful, caregiving had a sense of reward and, in any case, it was what you did. With the sudden loss of your caregiving job you may temporarily feel lonely or useless. The loss of such a meaningful role can also be the cause of grief.

Bereavement Support for Caregivers

Bereavement is a normal response to the loss of a loved one. Grieving is a very individual experience and is impacted by a number of factors such as the intensity of the relationship with the person who has died, your age, personality and coping style, the circumstances around the death, previous experiences with loss and death, cultural and religious beliefs, etc. Losing someone you care about can be very difficult and often brings about a range of emotions and even physical symptoms. Your response to the loss you are experiencing will vary over time. Whatever you are feeling remember to be patient with yourself. There is no set timeline for healing.

You do not have to meet the challenges of loss and of major life transitions alone. Reach out to those around you for support. There are a number of professional organizations and support groups available within the community to help you through this difficult time.

AARP: Caregiving Resource Center

Click on *Caregiving Resource Center*, then *Grief and Loss*.

➤ www.aarp.org

Compassionate Friends

This program provides comfort, hope, and support for families experiencing the death of a child, son or daughter, brother or sister, or grandchild, and those providing support to a grieving family.

➤ www.compassionatefriends.org

Good Grief

This program offers education and support for families, teens, and children coping with loss.

➤ www.good-grief.org

Griefnet

This site provides access to email support groups and websites.

➤ www.griefnet.org

Interregnum, Inc.

This organization provides grief support, education, and outreach. This site offers a listing of support groups, educational workshops, and educational materials for individuals, groups, and professionals.

➤ www.interregnum.org

National Cancer Institute at the National Institutes of Health

This site explains the normal grieving process, types of grief reactions, and treatment of grief.

➤ www.cancer.gov/cancertopics/pdq/supportivecare/bereavement/Patient/page2

Beginning Your Next Chapter

You may have been a caregiver for a very long time. You may have even forgotten how to fill your day or what your interests used to be. Begin by asking yourself what activities sustained you before you took on a caregiving role. Are there any new interests you might want to explore? What about friends and family – what possibilities exist there? Were you active in any faith-based communities or organizations? Would you like to return to activities with those groups? What do you wish to do with your time and what do you want your life to be?

Remember that no caregiver ever really goes back to the old “normal.” Time has passed and you have grown and changed as an individual. You must find a new sense of routine in this new phase of life – a new “normal.”

There are no easy answers. Give yourself time to rediscover and even reinvent yourself. Use resources – caregiver support groups and counselors may be helpful as you explore new opportunities. This stage of transition, while it may be difficult, promises new things for you.

Finally, always remember that your caregiving has been a gift to your loved one – one of the greatest gifts you can ever give, a gift to be proud of and to cherish.