

NEW YORK STATE

CAREGIVER GUIDE



Department
of Health

WELCOME

Dear Caregiver,

The New York State Department of Health is excited to share with you the NYS Caregiver Guide. Caregiving, while often truly a labor of love, can be emotionally and physically complex.

Valuable information may be difficult to find. We hope that this guide will support you in caring for yourself and in finding the services that meet the needs of the person you are caring for.

HOWARD A. ZUCKER, MD, JD

Commissioner,
New York State Department of Health



01 INTRODUCTION Pg. 09

Who is a Caregiver?
Impact of Caregiving

02 CAREGIVER EDUCATION Pg. 15

Know your Rights

- NYS Caregiver Advise Record and Enable (CARE) Act
- Family and Medical Leave Act (FMLA)
- New York State Paid Family Leave Act
- New York State Paid Sick Leave

03 CREATING YOUR CARE TEAM Pg. 23

Creating Your Care Team

Get the Family Involved

Services and Programs

Palliative Care and Hospice Care: What's the Difference?

Planning for Care

04 COMMUNICATING WITH HEALTHCARE PROFESSIONALS Pg. 47

HIPAA

05 SAFETY CONCERNS Pg. 53

Medication Management

Medication List

Creating a Safe Environment

Home Modifications and Assistive Technology

06 LEGAL AND FINANCIAL PLANNING Pg. 59

Advance Directives

Medical Orders for Life Sustaining Treatment (MOLST)

Durable Power of Attorney

Financial Planning Resources

Tax Incentives

07 MEDICARE AND MEDICAID Pg. 69

Medicare

Medigap

Medicaid Managed Long Term Care

Independent Consumer Advocacy Network (ICAN)

New York State Health Insurance Information,

Counseling and Assistance Program (HIICAP)

08 PLANNING FOR THE UNEXPECTED Pg. 75

Get and Stay Organized

09 SEEKING SUPPORT Pg. 83

Attend to Your Own Health Needs

Asking for Help

10 RESOURCES Pg. 89

New York State Resources

National Resources

Terms You May Encounter



INTRODUCTION

**CAREGIVERS (YOU)
PLAY AN IMPORTANT
ROLE IN OUR SOCIETY.**

Caregivers (you) play an important role in our society. If you support the needs of someone who is unable to care for themselves due to age-related conditions, illness, injury, or disability, consider this guide your starting place.

Being a caregiver is not always easy, although it can be rewarding. Caregivers must find and accept ways to care for themselves, too.

In this guide, you will find tips and plans that you can use, as well as legal and medical definitions and information about your rights. Perhaps most importantly, you will find a list of resources—not only for the person you support, but also for yourself.

■ Who is a Caregiver?

A caregiver is someone who may do any of the following—and more:

- **Speak up for another person to ensure their rights and wishes are supported.**
- **Help with activities of daily living, such as bathing, eating, or dressing.**
- **Manage medications and talk to care providers.**
- **Manage chores, appointments, shopping, cooking, cleaning, and transportation.**
- **Provide support with legal planning.**
- **Manage bills or provide other forms of financial support.**
- **Offer emotional support and encouragement.**

Caregivers may or may not live with the person they support.

Spouses, partners, adult children, family members, friends, and neighbors all serve as caregivers and may provide care at home, in a facility, or from a distance.

Conditions that often require the help of a caregiver include physical decline, chronic conditions such as arthritis, diabetes or dementia, visual and hearing impairments, sudden medical events such as a heart attack, stroke, or a traumatic brain injury, developmental disabilities, mental health or psychiatric disorders, and addiction. Some situations require temporary care, while others require long-term services and support.

■ Impact of Caregiving

As a caregiver, you are not alone. Across the United States, millions of adults care for others. Taking on this role often affects one's mental and physical health, social life, and interpersonal relationships. Many caregivers report physical or emotional strain from caregiving. Caregivers who provide more hours of care report a higher amount of stress and loneliness.

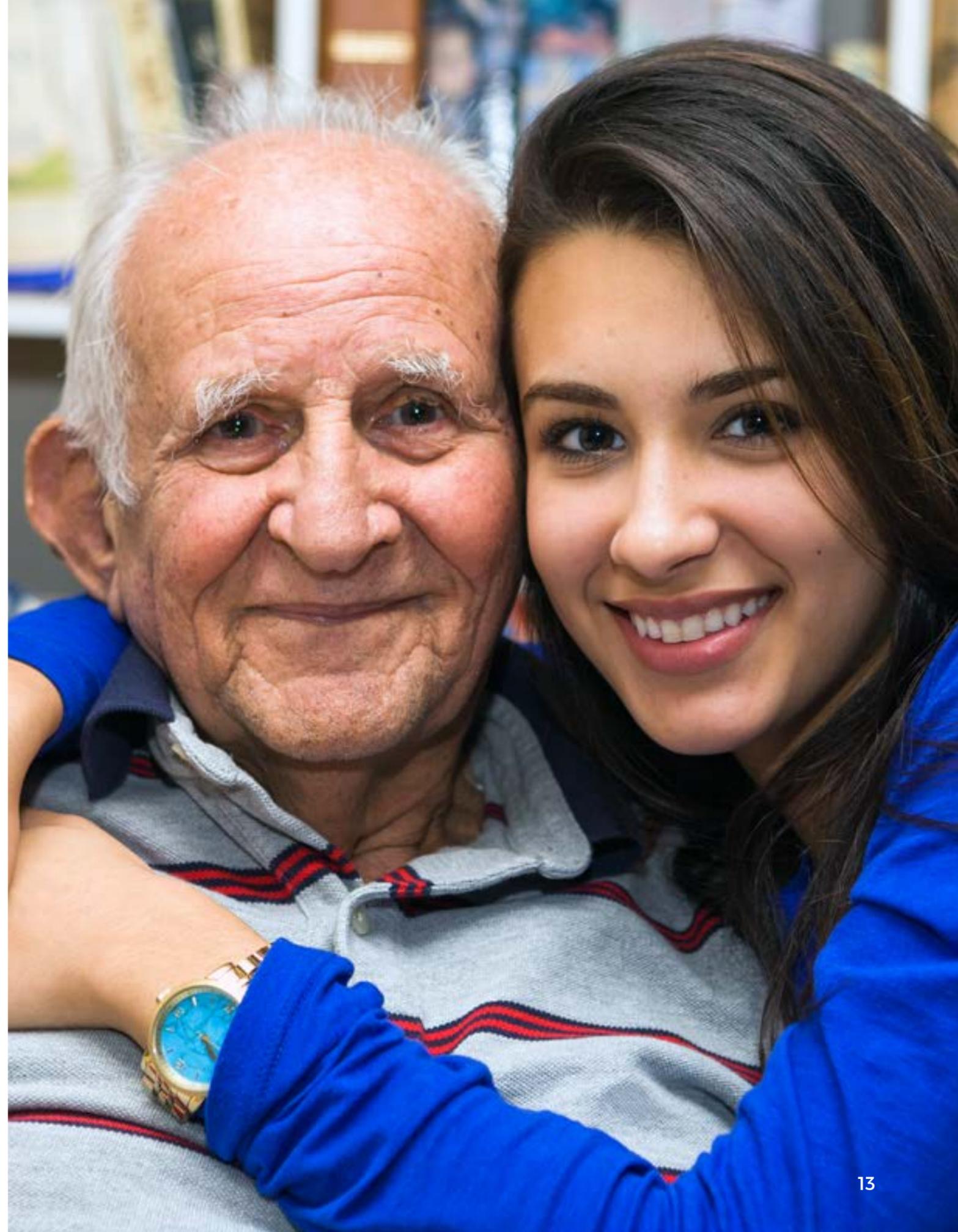
Caregiving can affect personal finances when using paid help, offering monetary support, or due to a change in personal or work life.

When employed caregivers are trying to balance a caregiving role with their career, many need to modify work schedules by going in late, leaving early, or taking time off. Some caregivers may take a leave of absence, reduce their work hours, or leave their jobs altogether in order to take care of someone.

Although caregiving can be demanding, research shows it can also have a positive effect. Some caregivers find little to no impact on their personal health and well-being, and find meaning in their role as a caregiver. In some cases, connecting with the right resources and support can help make a difference.

> YOU ARE NOT ALONE

ONE IN FIVE AMERICANS SERVES AS A CAREGIVER.



EDUCATION



**CAREGIVER
EDUCATION**

AS A CAREGIVER, INFORMATION WILL HELP YOU.

EDUCATIONAL VIDEOS

The United Hospital Fund

A series of videos that teach you about medication management, home safety and more: www.nextstepincare.org/videos. 

Caregiver Action Network

Watch caregivers sharing their own advice and support, along with videos that teach daily tasks such as bathing: www.caregiveraction.org/resources/videos. 

Home Alone AllianceSM

These “How-To” videos provide instruction to family caregivers on specific medical/nursing tasks. Many are available in both English and Spanish: www.aarp.org/ppi/initiatives/home-alone-alliance/family-caregiving-videos.

TRAINING RESOURCES

At the end of this guide, you will find a list of agencies that can help. You can also visit www.nyconnects.ny.gov to find caregiver training resources near you.



CAREGIVERS HAVE RIGHTS.

- The right to be involved in decision-making including hospital discharge planning and medical treatments.
- The right to be trained in how to provide necessary care.
- The right to learn about the person's condition.
- The right to ask for help and set limits.

■ Know Your Rights

NYS CAREGIVER ADVISE, RECORD AND ENABLE (CARE) ACT

The CARE Act requires that during a hospital stay, patients have the right to designate a caregiver who will help them after they are discharged.

➤ UNDER THE CARE ACT HOSPITALS MUST:

- Provide each patient or their legal guardian with at least one chance to identify at least one caregiver prior to the patient's discharge or transfer.
- Attempt to notify the caregiver of the patient's transfer to another healthcare facility or before the patient returns to their residence.
- Consult with the named caregiver and patient regarding the patient's post-discharge needs at their home and offer the caregiver education in all required post-discharge tasks (while taking into account the capabilities and limitations of the caregiver).
- In the formal discharge plan, identify: the caregiver(s), the recommended post-discharge care, and contact information for community resources to help the caregiver(s) provide care.

FAMILY AND MEDICAL LEAVE ACT (FMLA)

The Family and Medical Leave Act of 1993 (FMLA) is a federal law that allows eligible employees of covered employers to take unpaid, job-protected leave for specific family and medical reasons. Group health insurance coverage is available as if the employee had not taken leave.

For more information contact your employer's human resources department and/or the United States Department of Labor at www.dol.gov/whd/fmla or **866-487-9243**.

► DID YOU KNOW?

The law protects patients from being discharged without having needed services in place: www.health.ny.gov/professionals/patients/patient_rights.



NEW YORK STATE PAID FAMILY LEAVE ACT

Beginning in January 2018, all employees in New York State became eligible for paid leave to take care of a family member with a serious health condition, care for a newborn or adopted/foster child, or any urgent matter regarding a spouse, child, domestic partner, or family member serving in the military. The law covers employees under New York State's temporary disability law and those who have been employed for at least 26 weeks.

As of January 2021, the benefits of this law include a maximum of 12 weeks of paid leave in a 52-week period and wages of up to 67% of the employee's average weekly wage. For more information visit www.ny.gov/programs/new-york-state-paid-family-leave.

NEW YORK STATE PAID SICK LEAVE

Beginning January 1, 2021, all employers in New York State are required to provide annual sick leave to their employees. In most cases, the leave must be paid. Leave may be used for a mental or physical illness, injury or health condition of an employee or an employee's family member.

The term "family member" is defined broadly to include the employee's child, spouse, domestic partner, parent, sibling, grandchild, and grandparent, as well as the child or parent of the employee's spouse or domestic partner.

The amount of leave, and whether it is paid or unpaid, depends on the size the employer. For more information, contact your employer's human resources department.

YOUR CARE TEAM



**CREATING
YOUR CARE TEAM**

■ **Creating Your Care Team**

Teamwork is essential to caregiving. Build a team of people you trust. In addition to you and the person in need, the care team can include family, friends, doctors, social workers, and others whom you trust.

In this section, you will learn about the following care options:

- **Informal Care (family, friends)**
- **Home Care**
- **Consumer Directed Care**
- **Adult Day Care**
- **Respite Care**
- **Transportation**
- **Telehealth**
- **Adult Care Facility**
- **Skilled Nursing Facility**
- **In-Home Services for the Elderly**
- **Palliative and Hospice Care**





WHICH CAREGIVING TASKS DO YOU PROVIDE?

- Transportation
- Grocery shopping
- Housework
- Managing finances /paying bills
- Preparing meals, including food for special diets
- Medication management
- Managing medical services
- Getting in and out of bed and chairs
- Dressing
- Answering the phone or door
- Maintaining equipment (wheelchair etc.)
- Bathing or showering
- Going to the bathroom
- Exercise
- Grooming
- Home repair
- Laundry
- Coordinating paid service
- Engagement or socializing
- Other

■ Get the Family Involved

Family and friends may be able to help with care. If your family is one that tackles issues as a team, you're probably ahead of the game. However, even close families are tested when one of you needs care. Try to plan a family meeting.

Before the meeting, prepare to talk about medical care, living arrangements, dividing caregiving tasks and how to pay for care. Think about ways you might use each other's strengths so you can make specific requests. Review your list of caregiving tasks. Which tasks could you ask others to help with?



TIPS FOR DIFFICULT CONVERSATIONS:

Know your purpose.

Be clear on what you want to accomplish.

Listen.

Allow everyone to share their concerns and express their feelings.

Take your time.

Leave room to discuss further at a later time.

Spend time together.

Plan time after the conversation to help everyone stay connected.

Plan.

Figure out what you want to say ahead of time.

State the issue.

Share the purpose of the conversation and why it's important to you.

Wrap up.

Thank everyone for their time and attention.

■ Services & Programs

HOME CARE

Home care includes a range of services. The goals of home care may be to help someone after an illness or injury, provide services after a hospital stay, or provide long-term support to keep the person as healthy and independent as possible.

Home care services are provided by Certified Home Health Agencies (CHHAs) and Licensed Home Care Service Agencies (LHCSAs). Home care can be paid privately or through Medicare, Medicaid and other insurance programs. Homemakers, personal care aides, and home health aides are some of the home care staff that you might interact with.

Homemakers help with light housekeeping tasks. They can grocery shop, do laundry, and prepare meals. Homemakers cannot provide personal care.

Personal care aides help with personal care such as bathing, grooming, and dressing. They can also prepare meals, grocery shop, and do light housework. Personal care aides are limited in the medical care they can provide. For example, they cannot check blood pressure or give someone their medication.

Home health aides assist with daily living activities, which includes bathing, dressing, and walking. Home health aides can also grocery shop and do household chores. Some home health aides can perform health-related tasks such as taking a temperature or helping with exercises.



CONSUMER DIRECTED PERSONAL ASSISTANCE PROGRAM (CDPAP)

New York State's CDPAP allows people with Medicaid choice in who they hire to provide services—including hiring family or friends. This Medicaid program provides services to chronically ill or individuals with physical disabilities who have a medical need for help with activities of daily living (going to the bathroom, bathing, getting dressed, walking, etc.) or professional nursing services.

To be eligible for CDPAP, individuals must qualify for Medicaid.

ADULT DAY CARE

Adult day care provides care outside the home and offers a safe, structured environment that gives care recipients the chance to spend time with other people their age. Some adult day care programs provide health services as well.

Social adult day services programs provide care for adults in a supervised group setting within the community. Services include socialization activities, supervision and monitoring, and nutrition.

Adult Day Health Care offers medically supervised services for individuals who have a physical or mental disability. Services may include nursing evaluation and treatment, physical therapy and other medical care.



RESPIRE CARE

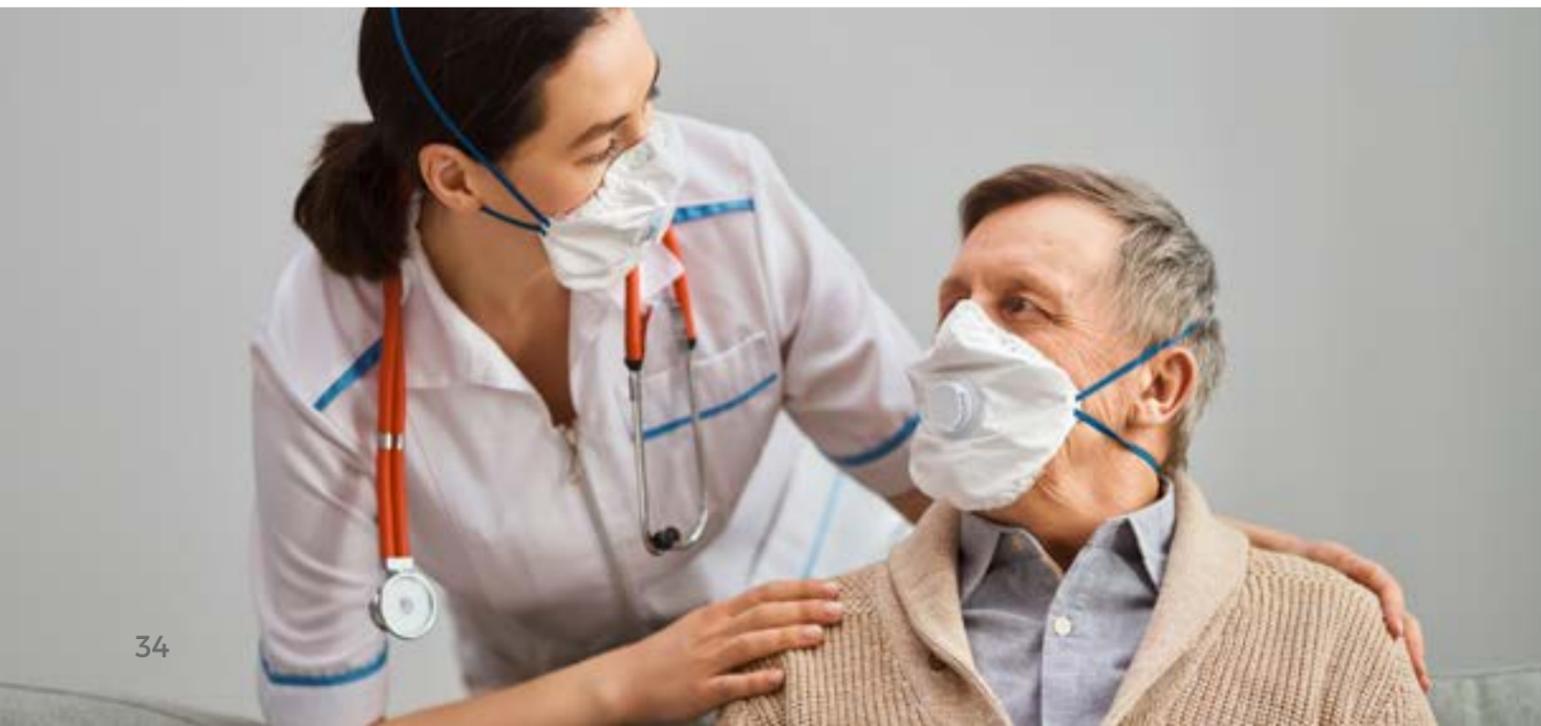
Respite care provides a temporary break from caregiving duties to allow the caregiver to attend to their own needs, participate in community activities, meet friends, go shopping, or just to take a break. This may also be needed in the event you are unable to provide care, such as a medical emergency, surgery or when you are traveling.

Respite may be arranged through caregiver programs operated in your county, through home care agencies or in some instances, certain residential facilities. Friends, family and volunteers may also be able to provide respite for a few hours at a time.

TRANSPORTATION

In some areas, special or discounted transportation services for people with disabilities may be available.

You can learn more about available transportation options local to you by contacting NY Connects at **800-342-9871** or online at www.nyconnects.ny.gov. 



TELEHEALTH

Many providers may offer services through telehealth. Telehealth is the use of electronic technology to deliver health care to patients from a distance. Telehealth may take many forms including a video call with a doctor to discuss symptoms or treatment options or the use of technology to remotely monitor and collect health data for the person you care for. Health and medical data collected remotely may include vital signs, blood pressure, heart rate, or blood oxygen levels.

Telehealth options may be helpful by allowing you to access healthcare from the comfort and safety of home. Telehealth may also help avoid transportation issues and allow long-distance caregivers to be a part of healthcare visits. For more information about telehealth, ask the healthcare provider or insurance company about your options.



ADULT CARE FACILITIES

Adult care facilities are licensed and may be referred to as adult homes, enriched housing programs, assisted living residences or assisted living programs. All of these facilities provide residential care along with different types of services and supports. For instance, adult homes provide meals, housekeeping, supervision, and care management while enriched housing programs offer community settings that are like independent housing units.

SKILLED NURSING FACILITIES

Nursing homes primarily provide three types of services:

- **Skilled nursing or medical care and related services.**
- **Short-term rehabilitation due to injury, disability or illness.**
- **Health-related long term care needed regularly due to a mental or physical condition.**

EXPANDED IN-HOME SERVICES FOR THE ELDERLY PROGRAM (EISEP)

New York State's EISEP provides non-medical services to adults age 60 and older who are not eligible for Medicaid and require help with activities of daily living such as going to the bathroom, bathing, getting dressed, walking, and instrumental activities of daily living such as grocery shopping, paying bills and cooking.

➤ DID YOU KNOW?

EISEP also offers respite services, which give temporary breaks from caregiving duties.





WORKING WITH HOME CARE STAFF

HELPFUL TIPS:

-
- ▶ **Describe each team member's role.** Every care situation is different. Clearly defining needs and responsibilities can help.
-
- ▶ **Create a back-up plan in case staff, volunteers, or service providers do not arrive on time or have to cancel.** Ask the home health agency about their rules for coverage if staff do not show up. If you hire a private individual, talk with that person about your expectations if he or she has to cancel.
-
- ▶ **Show home care staff your list of emergency contacts.** Put the list where it is easy to access.
-
- ▶ **Home care staff should go through full criminal background checks.** Ask the agency if staff have had a criminal background check before they come into the home.
-
- ▶ **Make sure the home care staff is a good fit for you and the person you support.** The first few days can be treated as a test period. For example, pay attention to how the person speaks and interacts with the person you support. If you do not live with the person you care for, consider dropping in unannounced while staff is present.
-

■ Palliative Care and Hospice Care: What's the Difference?

Palliative care provides treatment meant to help someone with a serious or chronic illness feel better physically, emotionally, and spiritually. This type of care helps control symptoms and may include pain relief, counseling, and treatment for sleep problems. This is provided while the medical team also treats the illness. Palliative care can be provided at any time during a serious illness and can be provided in any setting.

Hospice care is a type of palliative care for people who are near the end of life. The goal of hospice care is to help provide comfort and prepare the patient and their family for the end of life. In most cases, hospice care is used when the doctor believes the patient has between six months to a year to live. Hospice care can be given in the home, in a hospice residence or in a facility, such as a hospital or nursing home. Hospice care is provided through a team-based approach with doctors, nurses, social workers and other dedicated health professionals.



■ Planning for Care

Having read about the various care options, take a moment to think about which might be helpful for your situation, both now and in the future.

Even if you're not quite ready to use the care options listed here, planning for the future can help lessen many of the difficult caregiving situations that arise. It's never too soon to start looking at available options.

As you research, local agencies can provide you with more information on options in your community. Use the list at the end of this guide to see what agencies are available to you.



WHICH OF THESE OPTIONS ARE RIGHT FOR YOU?

- **Informal Care (family, friends)**
- **Home Care**
- **Consumer Directed Care**
- **Adult Day Care**
- **Respite Care**
- **Transportation**
- **Telehealth**
- **Adult Care Facility**
- **Skilled Nursing Facility**
- **In-Home Services for the Elderly**
- **Palliative and Hospice Care**

COMMUNICATION



COMMUNICATING WITH HEALTHCARE PROFESSIONALS

BE PREPARED TO SHARE INFORMATION.

Be prepared to share important information and ask key questions when you speak with your doctor or specialist. Community agencies specific to the disease or disability can also help you learn about a medical condition or disability. They can also help you with common questions to ask when meeting with the health care team.



TIPS TO EFFECTIVELY COMMUNICATE WITH YOUR CARE TEAM:

- **Pick a doctor or team of health providers that you feel comfortable talking to so that it is easier for you and the person you assist.**
- **Prepare ahead of time for each doctor visit. Make a list of specific issues and questions that you need to talk about with your doctor.**
- **Make notes describing the key changes in your health or the care recipient's medical condition so your doctor has a clear picture of your needs during the visit.**
- **Keep a list of current medications —name of drug, what the strength is, how often it is taken, when refills are needed—and take it with you to your appointments. Be ready to tell the doctor exactly what you need as the result of each appointment (information, referrals to care, refills or new drug prescriptions, etc.).**
- **Learn about the disease or disability, treatments, and the likely result, including clear definitions of the words that the health care team uses.**
- **Ask questions until you understand. Ask about what the treatment options are, including the pros and cons of each.**

■ HIPAA

You might hear “I can’t tell you that because of HIPAA.” HIPAA (Health Insurance Portability and Accountability Act) is a federal law that established rules for sharing and protecting personal medical information.

Health care professionals can share medical information with caregivers and others directly involved in a person’s care if the patient has a reasonable understanding of the situation and has an opportunity to say no.

In some situations, caregivers need medical information to have a clear understanding of what care is needed so they can decide and prepare for next steps in treatment. HIPAA allows people directly involved in one’s care or payment for such care to get this information.

HIPAA does not require written consent, though some health care facilities do ask for the patient’s signature.

If you as the caregiver have problems getting the medical information you need, talk with the medical provider or facility’s social worker, patient representative or privacy officer.



SAFETY

**SAFETY
CONCERNS**

■ Medication Management

Managing medications is often part of being a caregiver. You may have to make sure that the person you care for is taking the correct amount of medication at the right time. People sometimes take several medications and your role may involve watching for side effects with multiple medications. Reading and understanding medication labels can help you. Be aware of the expiration date and safely get rid of any expired medication.

■ Medication List

Doctors and other medical staff need to know the complete list of medications that their patients are taking. Keep a current list of medications and any known allergies. The list should include all prescription drugs, over-the-counter medications, and supplements that the person takes.

Printable medication lists are available online or you can ask your insurance provider or local pharmacists for a blank form you can fill out.

- ▶ **Place the list in a safe place where you find it in case of an emergency. Take it with you to medical appointments. Also consider creating a reminder system for medications to help ensure doses aren't missed.**



■ Creating a Safe Environment

The New York State Department of Health developed a downloadable Home Safety Checklist you can use to check for safety and health hazards in the home where you're going to be providing care. The Checklist is available online and includes tips to help you rid the home of things that might jeopardize one's personal safety or health. Many falls can be prevented by making changes within the home.



HOME SAFETY CHECKLIST

www.health.ny.gov/publications/3106.pdf



PREVENTING FALLS CHECKLIST

www.health.ny.gov/publications/0640

■ Home Modifications and Assistive Technology

In some cases, devices designed to help with medications, bathing, or other care tasks may help. In New York State, the Technology Related Assistance for Individuals with Disabilities (TRAID) program loans assistive devices to caregivers and people of all ages and disabilities. Many of the devices help with being able to move, medications, bathing, and other care tasks.

For more information on assistive devices, contact The Justice Center at **800-624-4143** or online at www.justicecenter.ny.gov/traid-program.



LEGAL + FINANANCIAL

A man and a woman are sitting at a table, looking at a document together. The woman is on the left, and the man is on the right. They appear to be in a professional or business setting. The image is overlaid with a green tint.

**LEGAL AND FINANCIAL
PLANNING**

HONOR A PERSON'S WISHES.

■ Advance Directives

The best way to make sure that a person's health care wishes are known and honored is to use one or more of the following legal documents, sometimes referred to as "Advance Directives."

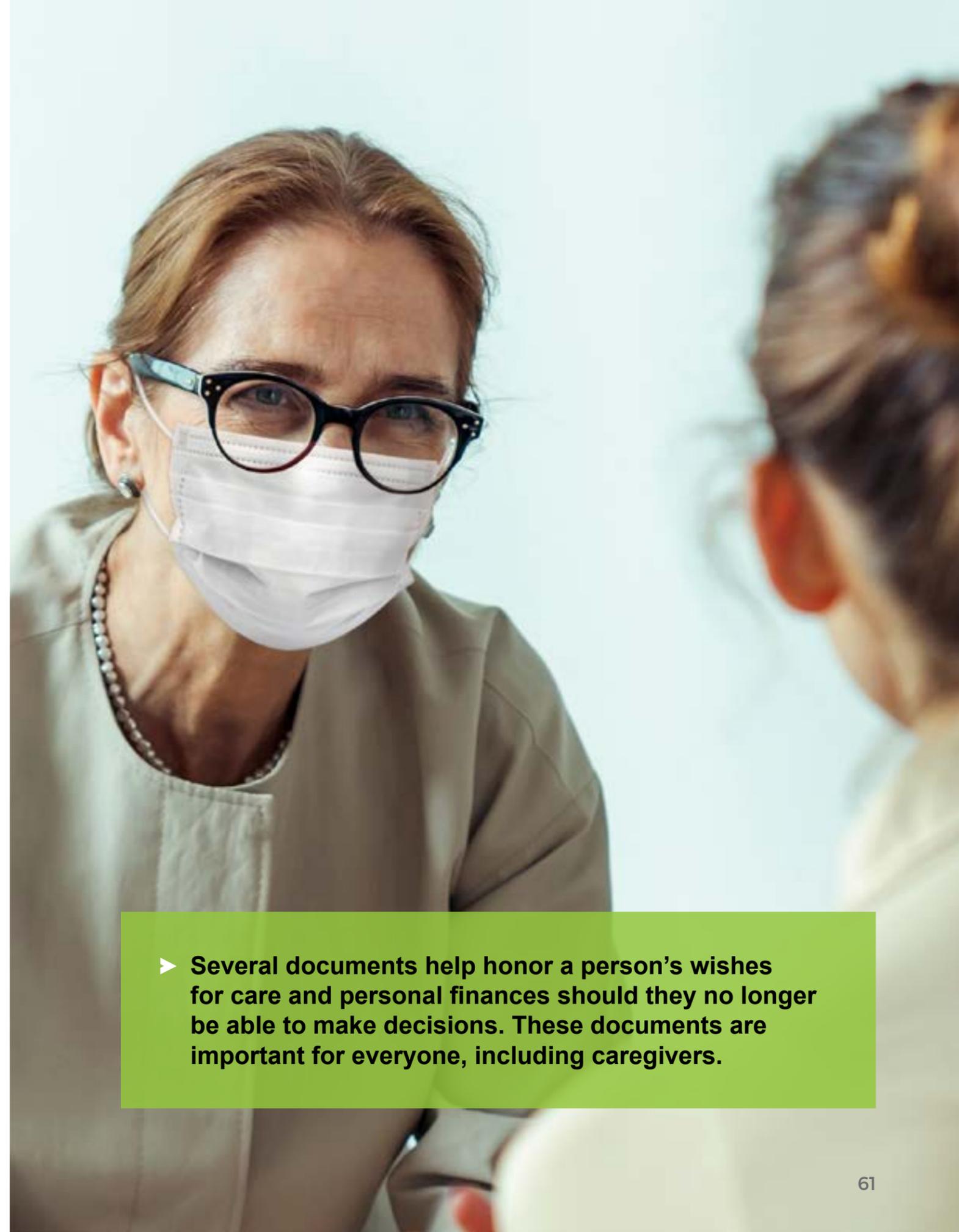
In New York State, there are three types of Advance Directives:

- ▶ **Health Care Proxy:** A Health Care Proxy lets a person name a health care agent they trust to make health care decisions on their behalf.
- ▶ **Living Will:** A Living Will allows a person to leave written instructions that explain their health care wishes, especially about end-of-life care.
- ▶ **Do Not Resuscitate Order (DNR):** A DNR can be arranged with a doctor or provider before an emergency occurs, and expresses a person's wish to do without cardiopulmonary resuscitation (CPR) or other lifesaving emergency treatment.



FORMS 

www.health.ny.gov/professionals/patients/patient_rights



▶ **Several documents help honor a person's wishes for care and personal finances should they no longer be able to make decisions. These documents are important for everyone, including caregivers.**



■ Medical Orders for Life Sustaining Treatment (MOLST)

The MOLST tool is used to help physicians and other health care providers discuss and honor a person's preferences for treatments such as cardiopulmonary resuscitation (CPR) or artificial nutrition.

More information is available online at www.health.ny.gov/professionals/patients/patient_rights/molst.



■ Durable Power of Attorney

This legal document allows someone to name another person to act on their behalf in specific personal or business matters. It cannot be used for health care decisions. If the person you're providing care for needs help with money matters like banking or paying bills, you may need to ask the person to consider naming someone to act on their behalf in regard to the bank or credit account(s) through a durable power of attorney. A lawyer can help complete the form.

■ Financial Planning Resources

Financial resources may be available to you. Use the following checklist to help you figure out what sources of financial support may be available to you or the person needing care.

○ Personal Assets

Including investments and savings. Retirement benefits may include individual retirement accounts (IRAs) or annuities.

○ Employee Benefits

May apply if the person is still working and has access to sick leave, short-term disability, and other health-related resources such as health savings or flexible spending accounts. Review the employer's handbook and check with the employer to understand what is available to you or the person in need of care. Military Service Benefits may be available for those who served in the military, their spouses, and others who qualify through the Veterans Administration or the Department of Defense.

○ Supplemental Security Income (SSI)

Is a government assistance program that provides a minimum monthly income for people who are 65 or older, who have a disability, and have limited income and assets.

○ Social Security Disability Insurance (SSDI)

Is a government program that provides a minimum monthly income to those younger than 65 who have a disability and have accumulated enough work credits throughout their working life.

○ Community Services

Some caregiver support services, including respite, support groups, and care consultations, are offered through community organizations and may be available locally at low or no cost.

○ Home Energy Assistance Program (HEAP)

Helps low-income people pay for the cost of heating their homes.

○ Supplemental Nutrition Assistance Program (SNAP)

Issues electronic benefits that can be used like cash to purchase food.

○ Insurance

Including long-term care insurance, private health care or disability insurance, and life insurance may help provide a source of funds for care. Be sure to contact the provider to understand the coverage and benefits.

○ Other

As you plan for your financial future, you might want to think about working with an independent, professional financial planner who will understand your individual situation.

■ Tax Incentives

To help New York State caregivers save on the costs of providing care, New York has made many common medical supplies exempt from Sales and Use Tax.

For more information about tax-exempt products visit www.tax.ny.gov/pubs_and_bulls/tg_bulletins/st/quick_reference_guide_for_taxable_and_exempt_property_and_services.htm.



INSURANCE



**MEDICARE
AND MEDICAID**

■ Medicare



Medicare is the federal medical insurance program for people age 65 and over, certain younger persons with disabilities, and people with certain disabilities or diseases.

Medicare enrollment, covered benefits, provider network, and related information can be reviewed at: www.medicare.gov.

■ Medigap

Medicare Supplemental Insurance (Medigap) policies are sold by private insurance companies and can help pay some of the health care costs that original Medicare doesn't cover, like copayments, coinsurance and deductibles.

To buy a Medigap policy, one must be enrolled in Medicare Part A and Part B. For more information, visit: www.medicare.gov/supplements-other-insurance/whats-medicare-supplement-insurance-medigap. 

■ Medicaid Managed Long Term Care

Managed Long Term Care Plans help provide services and support to people with a long-lasting health problem or disability. These Plans are approved by the New York State Department of Health to provide Medicaid managed long term care. A Plan can provide your Medicaid home care and other long term care benefits.

More information about Managed Long Term Care Plans is available online at www.health.ny.gov/health_care/medicaid/redesign/docs/mltc_guide_e.pdf. 



■ Independent Consumer Advocacy Network (ICAN)

ICAN is the New York State Ombudsman Program for people with Medicaid who need long-term care services. The program assists New Yorkers with enrolling in and using managed care plans that cover long-term care services, such as home attendant services or nursing home care.

For questions or assistance, call ICAN at **844-614-8800** or visit www.icannys.org.

■ New York State Health Insurance Information, Counseling and Assistance Program (HIICAP)

The New York State Health Insurance Information, Counseling and Assistance Program (HIICAP) provides free and unbiased health insurance counseling on Medicare, Medigap, private health insurance, low-income subsidy programs and other health insurance information.

To contact a HIICAP counselor near you, please call **800-701-0501** or visit www.aging.ny.gov/health-insurance-information-counseling-and-assistance-program-hiicap.



PLANNING



**PLANNING FOR
THE UNEXPECTED**



- ▶ **Unexpected care needs can arise for the person you support or for yourself. Preparing for these situations ensures that the person you support still receives the care they need.**

Keep a written journal of current care needs.

When kept up to date, this journal can benefit you as the caregiver, others who may need to step in to help with care, and the medical team involved in emergency care.

Back up support.

Though you may not receive the support of others on a regular basis, having a backup plan in the event of emergency is essential. Think about enlisting a care agency before an emergency arises, even if you only use it once in a while. Starting the process can take time, and this way you will already have them enrolled in a program and can increase hours of care as needed. Talk about a backup plan with family or friends who are willing to provide care or other assistance during an emergency.

Know your options.

Because care needs can change, sometimes suddenly, research a number of care options before you need them. If possible, involve the person you care for in choosing options for the future. Having this knowledge before a crisis will help him or her receive the best quality care available and will help lower your own stress in an already stressful situation.

Prepare for common emergencies.

Depending on the disability or health issue of the person you support, ask the health care team about likely emergency situations and make a plan for what to do if these common issues happen.

Keep an information folder in a safe and known place.

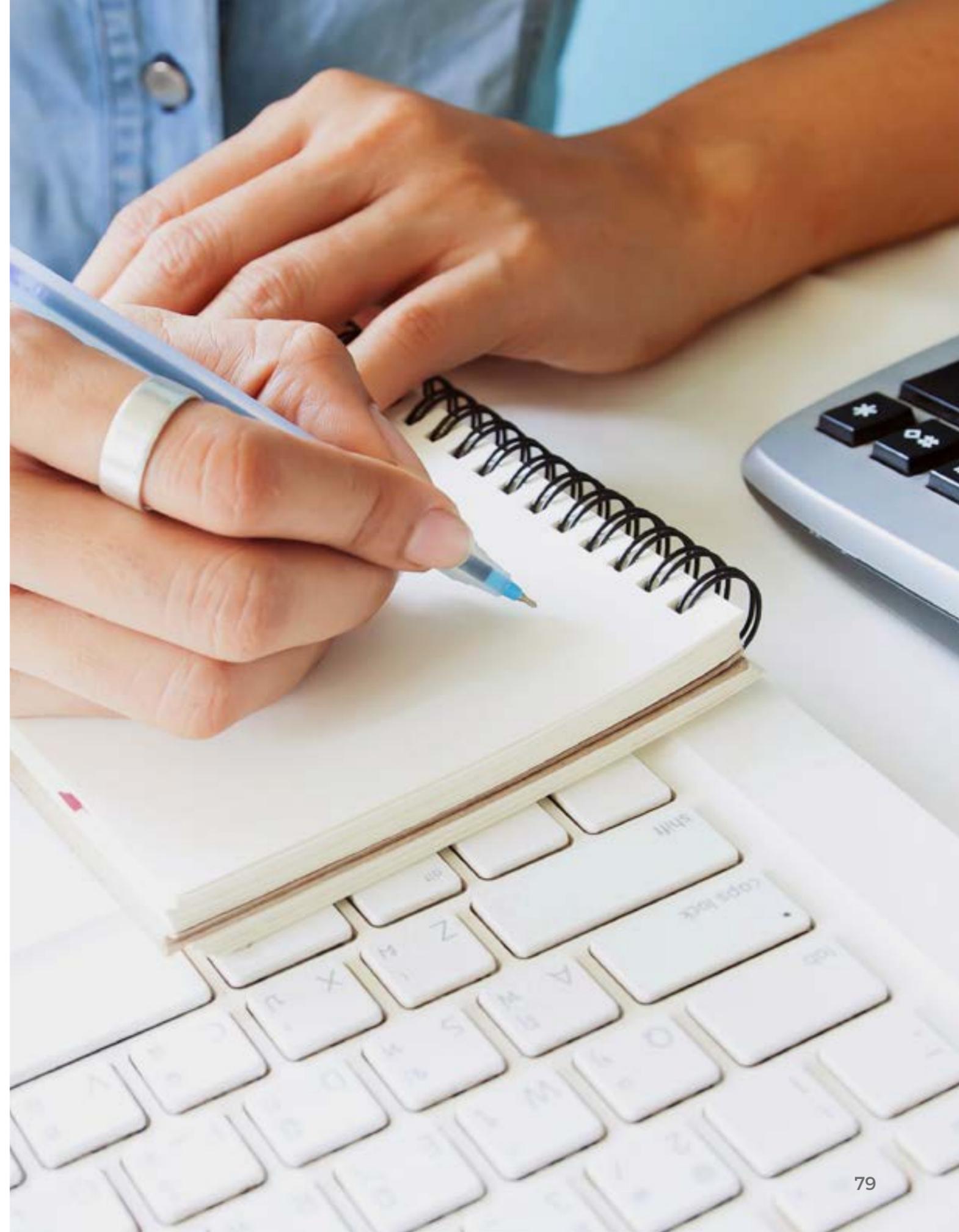
Make sure the information on the following pages is readily available to first responders and to you. It's important to have a file for both the person you support and yourself.

■ Get and Stay Organized

Many caregivers find that being organized helps lower their stress in the event of an emergency or a sudden change to the current care needs. You can download an organization application for your smartphone or tablet; or use a three-ring binder to collect printed materials and notes. Whatever you find that works for you, use it!

Create a file of important information about the individual you are caring for. Keep this information in any form that works for you (e.g., a folder, binder, or other type of organizational tool). Select a place to store the file where you can grab it quickly in an emergency. Always store this file in the same place and update it as often as possible.

**FIND AN
ORGANIZATION
SYSTEM THAT
WORKS FOR YOU.**



TIPS FOR STAYING ORGANIZED:

➤ Phone Numbers

Keep important numbers by the telephone, including numbers for emergency services as well as a list of the involved relatives and family, doctors, pharmacy, insurance companies, case manager, nurse, or other service providers involved in direct care. Another list of phone numbers could be the “help list”—contact information for anyone who has offered to lend a hand (e.g., friends or neighbors).

➤ Calendars and Schedules

Think about keeping a shared calendar with family and friends helping with care. This can be a great way to keep everyone up to date and make sure that care needs are covered. These calendars would be a good place to list appointments, as well, so that everyone involved is aware of critical dates.

➤ Medications

Keep a list of all the medications you and the person you support are taking, including drug name, strength, and how often it is taken. Products such as pill containers that divide medications by date and time, as well as automatic dispensers, can help keep medications organized and help you remember when they need to be taken.

➤ Important Documents (Patient’s Medical File)

Personal data and medical information, including test results, surgery dates, immunization records, and allergies.

➤ Insurance Information

Include copies of insurance cards for commercial insurance or Medicare/Medicaid/VA benefits, prescription drug coverage, dental insurance, vision insurance, and/or long-term care insurance.

➤ Legal Information and Documents

Living Will, Health Care Proxy, Power of Attorney, name and contact of lawyer, contact information for relatives and close friends to be immediately notified in an emergency, and other legal documents.

➤ Organ Donor Authorization

SUPPORT



**SEEKING
SUPPORT**

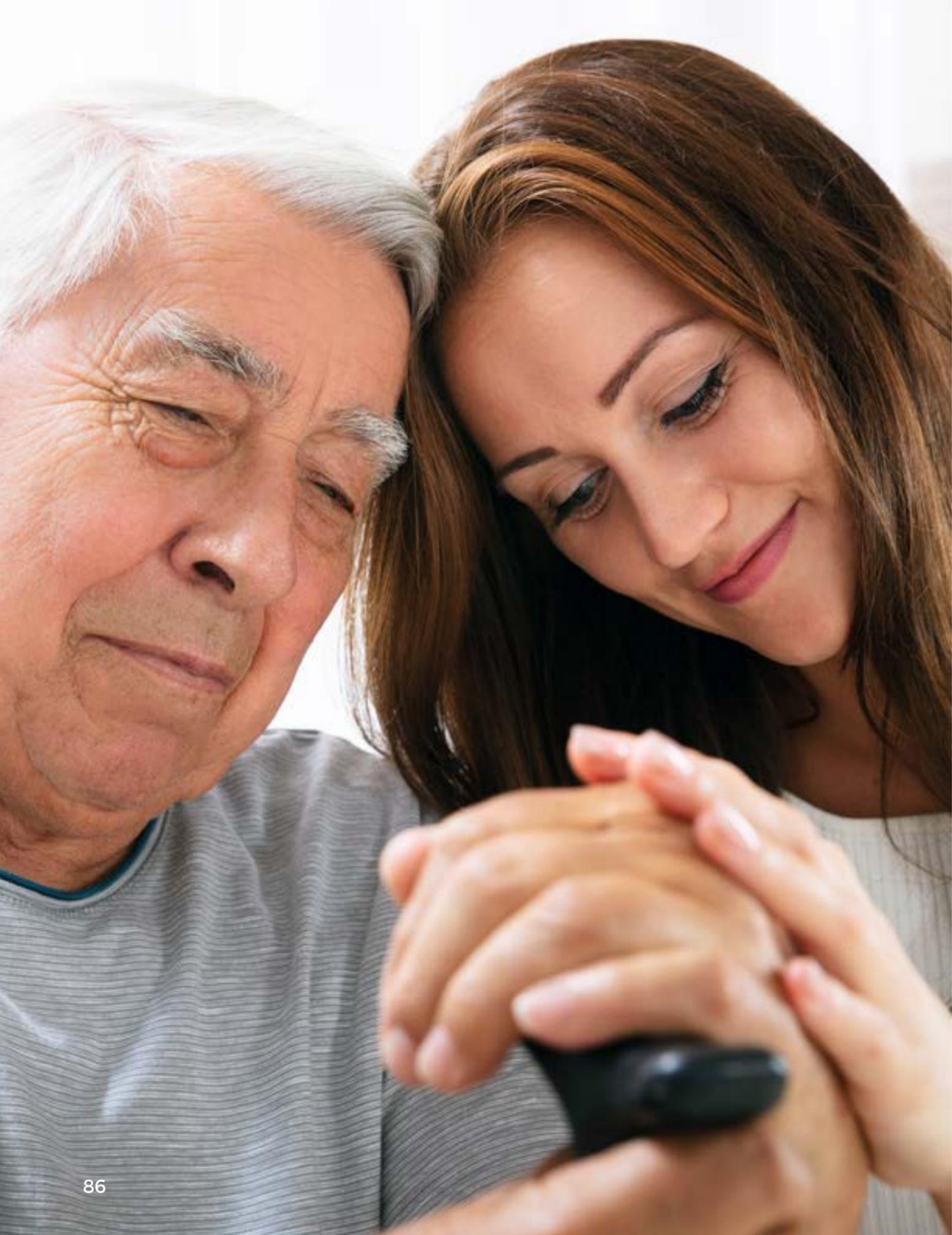
■ Attend to Your Own Health Needs

Caregiver stress can take an emotional and physical toll. When you fly on a plane, you're told to put your oxygen mask on first before helping others. The same is true in caregiving—your needs should come first. Take a moment to think about taking a break and how to make it happen.

WHICH OF THE FOLLOWING WOULD HELP YOU?



- See your primary care doctor and stay current with check-ups and yearly exams, and speak openly about your emotional and physical needs.
- Exercise.
- Eat a balanced, healthy diet.
- Get 7-8 hours of sleep.
- Try taking yoga classes or other courses designed to reduce stress.
- Take part in religious or spiritual activities.
- Attend a community event.
- Enjoy a hobby.
- Spend time with friends.
- Allow yourself space and the right to get angry, sad, and cry.
- Join a support group.



■ Asking for Help

Be willing to accept offers of help.

When others are willing to help, try to be open to accepting that help. Caregiving can be a full-time responsibility, often leading to stress and health concerns for the caregiver. Don't be shy about letting others pitch in.

Speak up and spread the responsibility.

Sometimes friends and family may not know what you need. Be clear about ways they might be able to help. Try to get as many family members involved as possible, even ones who live far away. For example, you might divide caregiving tasks so that one person takes care of medical responsibilities, another helps with money and bills, and another helps with groceries and errands. The more specific your request, the more likely you are to get what you need.

Differing opinions about care.

Though others offer help, you may not agree with how they provide care. It is okay to allow for different styles, as long as no one's well-being is at risk. In other situations, you may find that the person offering help may do better with more training or education related to caregiving. You might gently offer up information.

If you have concerns that the person providing care or the person in need of care is being mistreated or neglected, contact your local Adult Protective Services (APS). APS workers develop service plans for eligible clients to address abuse, neglect, financial exploitation, or unmet essential needs of adults.

RESOURCES



RESOURCES

■ New York State Resources

**Department of Health,
Alzheimer’s Disease Program**
Email: alz@health.ny.gov 
www.health.ny.gov/diseases/conditions/dementia

**Department of Health,
Adult Care and Assisted Living
Complaint Line**
866-893-6772

**Department of Health,
Home Safety Checklist**
www.health.ny.gov/publications/3106.pdf

**Department of Health,
Hospital Patient Care Issue Line**
800-804-5447

**Department of Health, Medical Orders
for Life-Sustaining Treatment (MOLST)**
www.health.ny.gov/professionals/patients/patient_rights/molst 

**Department of Health,
Medicaid Program**
www.health.ny.gov/health_care/medicaid

**Department of Health,
Nursing Home Patient Care Line**
888-201-4563

Department of Health, Patient Rights 
www.health.ny.gov/professionals/patients/patient_rights

**Health Insurance Information,
Counseling and Assistance Program
(HIICAP)**
800-701-0501

Home Care and Hospice Information
800-628-5972

**Hospice & Palliative Care Association
of New York State**
www.hpcanys.org

**Local Offices for the Aging
throughout NYS**
www.aging.ny.gov/local-offices

**Medicaid Managed Care
Managed Long Term Care** 
www.health.ny.gov/health_care/managed_care

Medicare General Information Line
800-633-4227

Medicare Rights Line
800-333-4114

**Mental Health Association
of New York State**
www.mhanys.org

NY Association for Independent Living
www.ilny.us

New York State Bar Association
www.nysba.org

**New York State Caregiving
and Respite Coalition**
www.nyscr.org

New York Connects
800-342-9871
www.nyconnects.ny.gov

**New York State Division
of Veterans’ Affairs**
888-838-7697
www.veterans.ny.gov

New York State Homecare Registry 
https://apps.health.ny.gov/professionals/home_care/registry/home.action

**New York State Homes
and Community Renewal**
www.nyshcr.org

New York State Office for the Aging 
1-844-NYSOFA1 or 1-844-697-6321
www.aging.ny.gov/programs/caring-loved-one

New York State Unified Court System 
www.nycourts.gov/forms/surrogates/guardianship.shtml

Office of Children and Family Services
518-473-7793
www.ocfs.ny.gov

Office of Mental Health
800-597-8481
www.omh.ny.gov

**Office for People with
Developmental Disabilities**
866-946-9733
www.opwdd.ny.gov

■ National Resources

Administration on Aging, US Department of Health & Human Services
www.aoa.gov

Alzheimer’s Association
800-272-3900
Email: info@alz.org

American Association of Caregiving Youth
www.aacy.org

American Cancer Society
800-227-2345
www.cancer.org

CHAMPVA Insurance
www.va.gov/health

Family Caregiver Alliance
800-445-8106
Email: info@caregiver.org
www.caregiver.org

Hospice Foundation of America
800-854-3402
Email: haoffice@hospicefoundation.org
www.hospicefoundation.org

Medicare
www.medicare.gov

National Alliance for Caregiving
Email: info@caregiving.org
www.caregiving.org

Sage National LGBT Elder Hotline
1-877-360-5428

National Alliance for the Mentally Ill
800-950-6264
www.nami.org

National Council on the Aging
Email: info@ncoa.org
www.ncoa.org

National Hospice & Palliative Care Organization
800-658-8898
www.nhpco.org

National Institute on Aging
800-222-2225
www.nia.nih.gov

National Mental Health Association
800-969-6642
www.nmha.org

United Hospital Fund, Next Step in Care
www.nextstepincare.org



United States Department of Labor, Family and Medical Leave Act
www.dol.gov/whd/fmla



■ Terms You May Encounter

Activities of Daily Living (ADL): Basic self-care tasks such as feeding, toileting, dressing, and grooming.

Adult Day Health Care: A program that offers medically supervised services for individuals with physical or mental impairment. Services may include nursing evaluation and treatment, physical therapy, speech pathology, nutrition assessment, occupational therapy, social work, psychosocial assessment, coordination of referrals, transportation, and socialization activities.

Advance Directive: A document that outlines to health care professionals the various types of care that a person wants or does not want in case they are unable to relate the information themselves.

Assisted Living Residence: A residence that provides care such as meals, housekeeping, supervision, and case management.

Assisted Living Program: A residence that includes home care services and that may accept Medicaid.

Care Plan: A written plan for one's care that describes the services an individual will receive in order to be as physically, mentally, and socially healthy as possible.

Care Recipient: A person who receives needed care.

Care Team: A group of trusted individuals who can help one make decisions about a loved one's care. This team may include formal supports (primary and specialty care doctors, local agencies, social workers, mental health counselors) and informal supports (family members, friends and members of your religious or spiritual community).

Caregiver Advise, Record and Enable (CARE) Act: The CARE Act requires that general hospital inpatients be given an opportunity to formally identify a caregiver (i.e., a relative, partner, spouse, friend, or neighbor) who would provide post-discharge assistance.

Certified Financial Planner: A person who has passed examinations accredited by the Certified Financial Planner Board of Standards, showing that the person is able to manage a client's banking, estate, insurance, investment, and tax affairs.

The Civilian Health and Medical Program of the Department of Veterans Affairs (CHAMPVA): A health benefits program in which the Department of Veterans Affairs shares the cost of certain health care services and supplies with eligible beneficiaries.

Consumer Directed Personal Assistance Program (CDPAP): A statewide Medicaid program that provides an alternative way of receiving home care services, in which the individual or a person acting on the individual's behalf assumes full responsibility for hiring, training, supervising, and terminating the employment of persons providing the services.

Department of Veterans Affairs (VA): A United States department that provides patient care, veterans' benefits, and other services to veterans of the U.S. armed forces and their families.

Do Not Resuscitate Order (DNR): A DNR can be arranged with a doctor or provider before an emergency occurs, and expresses a person's wish to do without cardiopulmonary resuscitation (CPR) or other lifesaving emergency treatment.

Durable Power of Attorney: A legal document that allows a person to designate someone to act on their behalf in specific personal or business matters.

Family and Medical Leave Act (FMLA): The Family and Medical Leave Act of 1993 is a federal law that entitles eligible employees of covered employers to take unpaid, job-protected leave for specific family and medical reasons. Group health insurance coverage is available as if the employee had not taken leave.

Health Care Proxy: A form that designates an individual to make health care decisions on a person's behalf in situations where the person is unable to communicate the information.

Health Insurance Portability and Accountability Act (HIPAA): A federal law that restricts access to individuals' private medical information.

Home Care: The term used for a range of health services that are offered in one's own home. The overall goal of these services is to keep the person as healthy and independent as possible.

Home Health Aides: Individuals who assist with daily living activities. They can also help with personal care, shopping, and household chores. Some home health aides can assist with health-related tasks such as taking a temperature or helping with exercises.

Homemakers: Individuals who help with light house-keeping tasks. They can grocery shop, do laundry, and prepare meals. Homemakers cannot provide personal care.

Hospice Care: Medical services, emotional support, and spiritual resources for people who are in the last stages of a serious illness either at home, in nursing homes or in the hospital. Hospice care also helps family members manage the practical details and emotional challenges of caring for loved one at end of life.

Instrumental Activities of Daily Living (IADL): Activities including preparing meals, paying bills, shopping for groceries or personal items, doing housework or laundry, or using a telephone, among others.

ICAN: A program that assists New Yorkers with enrolling in and using managed care plans that cover long-term care services.

Medicare: The federal medical insurance program for individuals age 65 and older and those with certain disabilities:

- Medicare Part A covers hospital care
- Medicare Part B covers physicians and medical care
- Medicare Part C refers to a Medicare Advantage Plan
- Medicare Part D covers prescription drugs

Medigap: Additional health insurance purchased from a private company to help pay for services and supports not covered by the person's original Medicare plan.

Medical Orders for Life Sustaining Treatment (MOLST): The MOLST tool is used to help physicians and other health care providers discuss and honor a person's preferences for treatments such as cardiopulmonary resuscitation (CPR) or artificial nutrition.

NY Connects: A statewide resource that provides information and assistance; screening for available long term services and supports for all individuals, regardless of age, diagnosis, disability, or payment source; options counseling/ person centered counseling; application assistance for public benefits and facilitated connection to community services.

New York State Health Insurance Information, Counseling and Assistance Program (HIICAP): Provides free, and unbiased health insurance counseling on Medicare, Medigap, private health insurance, low-income subsidy programs, and other health insurance information.

Over-the-counter Medications: Medicine that can be bought without a prescription.

Over-the-counter Medications: Medicine that can be bought without a prescription.

Palliative Care: Special care for people who have serious illnesses. Care is focused on improving quality of life. Sometimes palliative care is combined with curative treatment.

Prescription Medication: Medication that must be ordered by a physician or other professional who is licensed in the U.S. to write prescriptions for medicine.

Personal Care Aides/Assistant: Individuals who help with personal care such as bathing, grooming, and dressing. They can also prepare meals, grocery shop, and do light housework. Personal care aides are limited in the medical care they can provide.

Respite Care: Care that provides temporary relief from caring for an ill individual. This temporary care can be provided in the home or in a facility.

Short-term Rehabilitation: Therapy for individuals recovering from a surgery, illness, or accident that helps patients achieve their maximum functional capacity and get back to their homes and community in the shortest time possible.

Skilled Nursing Facility: A healthcare facility recognized by the Centers for Medicare and Medicaid that provides long-term health care for individuals.

Social Day Program: A program that offers recreation, music, meals, and other activities. Some programs are also able to provide medical assistance.

Technology-Related Assistance for Individuals with Disabilities (TRAD): A program that loans assistive technologies to New Yorkers of all ages and disabilities.

TRICARE: A health insurance plan that provides coverage to current and retired members of all branches of the U.S. armed forces and their dependents.

Urgent Care: A walk-in clinic that provides immediate medical service outside of an emergency room. This setting offers treatment for acute and chronic illness and injuries that are not serious enough to require an emergency visit.



