



YOUR CARE, YOUR CHOICE:
A GUIDE TO
LONG-TERM CARE





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The transition from a hospital to a nursing home can be confusing and challenging. That's why, through funding provided by the Odd Fellow & Rebekah Benefit Fund, the Center for Elder Law & Justice has developed this guide to help ease the transition.

We hope this guide will serve as a valuable tool while you decide what comes next. The information included in this booklet was drawn from a survey of health care consumers and professionals in Western New York. Our goal was to answer the most common and pressing questions faced by consumers and advocates while navigating through the options for long-term care.

On the next page we list the topics covered within this booklet. Our guide is not meant to be read cover to cover but rather to be used in the order most useful to you in finding answers to your questions.

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The following content is for informational purposes only and does not constitute legal advice.



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THE LEVELS OF LONG-TERM CARE

A nursing home, also known as a rehab facility, is not the only place where you can receive long-term care. There are many options that may be better for your care depending on your unique situation. Before you choose, know your options. Your options for long-term care include:

Nursing Homes/Rehab Facilities: The highest level of post-hospital care. Provide skilled nursing and related services, short-term rehabilitation, and long-term care. Long-term care is health-related care and services (above the level of room and board) needed regularly due to a mental or physical condition.



Adult Homes: Provide long-term residential care, room, board, meals, housekeeping, help with medication, personal care, and supervision.

Enriched Housing: Long-term residential care primarily for those 65 years of age or older in community-integrated settings that resemble independent housing units. Provide room, board, housekeeping, personal care, supervision, help with medication and required to provide one hot meal a day in a group setting.



Assisted Living Residence (ALR): Adult homes or enriched housing programs with additional licenses and responsibilities. For example, ALRs must develop an individualized service plan for each resident and coordinate with service providers chosen by the resident.

Special Needs ALR: Authorized to serve persons with special needs, generally memory care illnesses such as Alzheimer's or other dementias. Required to follow specific training and staffing guidelines.



Medicaid Assisted Living Program (ALP): Provide for case management, home health services, physical, occupational, and speech therapy, medical supplies and equipment, adult day health care, and intermittent nursing care. Designed to allow nursing home-eligible individuals on Medicaid to age in place.

Community Services: Community based long-term care can be informal (provided by friends and family) or formal (paid for privately or through health insurance) and usually occurs at home. If you are a recipient of Medicare, Medicaid, or both, it is important to know what home health services *may* be available if you are eligible.



Medicare Part A or B Community Services *

Does Cover: Part-time or "intermittent" skilled nursing care, physical therapy, occupational therapy, speech language pathology services, medical social services, and part-time or intermittent home health aide services. If you have a Medicare Advantage plan, check with your plan to find out if you have additional coverage.

Does Not Cover: 24-hour care at home, meal delivery, homemaker services when that is all you need, custodial, and personal care when this is all you need.

Medicaid Community Services *

Does Cover: Skilled nursing and therapy services, plus home attendant and personal care services for individuals having difficulty with at least one or more activities of daily life. Individuals who are Medicaid eligible may be able to receive services in the home like: housekeeping, meal preparation, bathing, toileting, and grooming.

Managed Long-Term Care Program: Available for individuals who have been assessed as nursing home eligible. Covers case management, home health aides, home attendant services, and physical therapists.

*In October 2020 significant changes will be made to eligibility requirements for Medicaid Community Services. You may also qualify for extra help through Medicaid waivers or a Medicare Savings Program. If you have questions, contact the Center for Elder Law & Justice at (716) 853-3087. Visit us online for more information and helpful resources:

https://elderjusticeny.org/resources/long-term-care-resources/

CHOOSING A NURSING HOME

If you and your hospital care team decide that the next step in your plan is a nursing home, for short-term rehabilitation services or long-term care, your hospital will be responsible for identifying nursing homes near you that can meet your needs. The most common complaint from patients who experience this transition is that they were not involved in choosing their nursing home. These tools can help.

TIP:

The hospital will work with you to choose an available nursing home. However, if you stay after after you've been offered a nursing home placement, you may become personally responsible for paying for that stay. Researching and suggesting homes to your discharge planner or physician before a choice is made, or even before you are sure you need a home, can help make sure that you find a nursing home that's right for you.

Work With Your Discharge Planner: The earlier you ask to speak to a discharge planner, the better. Hospitals are required to provide you with information about local nursing homes and your discharge planner should be able to provide that information. See page 7 to learn about discharge planning and active participation.

Nursing Home Compare: (medicare.gov/nursinghomecompare)

Nursing Home Compare is a website run by the federal government that rates every nursing home in the country on a 5-star scale using data on staffing, quality, and other measures. You can also find information about any history of citations that a home has received from the NYS Department of Health. It can also be helpful to visit the websites of nursing homes you are considering as well as look for reviews online. If you aren't comfortable using the internet, ask for help from family, friends, advocates, or hospital staff.

In-Person Visits: If you are hospitalized you may not be able to visit local nursing homes, but if possible ask your friends, family, or advocates to visit for you. A visit can tell you a lot about the type of care that a home provides. Look for how clean the facility is, how the staff treat residents, and, if possible, speak with staff, visitors, or residents about the nursing home. An in-person visit can sometimes reveal more about a nursing home than other research tools.

THE FIRST 48: WHAT TO EXPECT IN YOUR NEW NURSING HOME

If you decide that a nursing home is your best option for care, then it can be helpful to know what to expect in your first two days. There will be physician's orders (admission orders) for your immediate care. These tell your nursing home what they need to provide your care. You have the right to know what those orders are and to provide corrective statements if there are errors. You can ask to see those orders and should be provided with a copy. It's useful to bring your copy of the hospital discharge packet and your list of medications. It's important to check that your new nursing home has a correct list of medications. See page 9 for more advice on medication safety.

Your nursing home is required to develop a Baseline Care Plan or a Comprehensive Care Plan within your first 48 hours at the facility. Staff are required to provide you with a written summary of this plan that includes: your initial goals, physician's orders, dietary orders, therapy services, and social services. Remember, you decide your goals and objectives, and these should be included in the plan.





The nursing home is required to complete and provide you with a copy of a summary of your Baseline Care Plan within 48 hours of admission, unless they have completed the Comprehensive Care Plan within those 48 hours. Both plans are similar, but the Comprehensive is more detailed. In the first 48 hours you'll want to think about your goals for your care so that they can be included and addressed in the Comprehensive Care Plan. Do you have goals for your health or for leaving the facility? Do you have preferences for your care, daily routine, or activities? It might help to write these goals and preferences down before you have to express them.

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PAYING FOR YOUR HOSPITAL CARE

If you are covered by Medicare there are some important things to know about paying for your hospital stay. If you have private, employer-based, or Medicare Advantage insurance, contact your plan to find out how your stay will be covered. Medicare has four different programs called "parts," that cover different services:

Part A: Inpatient coverage for hospital stays, skilled nursing, hospice, and some home care.

Part B: Outpatient coverage for doctor visits, surgery, lab tests, medical equipment, and preventative exams.

Part C: Medicare Advantage - optional plans that provide more coverage than other parts, but may cost more.

Part D: Prescription drugs - for drugs not covered by Parts A or B.

If you're 65 or older and receive Social Security, you are automatically enrolled in Medicare Part A and Part B by the Social Security Administration. You will typically receive your Medicare card three months before your 65th birthday. Some people will wait to enroll in Part B because it has a monthly premium of \$144.60**. If you wait to enroll in Medicare however, you will have to pay a higher premium as a late enrollment penalty. Some employer-based insurance plans allow you to wait to enroll without a penalty. Ask your insurance plan or employer if you have a "qualifying health plan" to find out if you can wait. If you have a qualifying plan, you have up to 8 months after your employer coverage ends to enroll in Medicare and avoid the penalty. There is also a higher premium if you wait to enroll in Medicare part A. If you don't receive Social Security, you can still enroll in Medicare if you are 65 or older.

Medicare Part A: Hospital Coverage

If you are in the hospital and covered under Medicare Part A, you will use that coverage to pay for the care you receive. It's important to know what deductibles and coinsurance you will have to pay out of pocket. You may also qualify for more than one insurance or for a Medicare Savings Program which can lower your cost of care. Consult with a professional to explore your options.

The deductible for Medicare Part A is \$1,408.00**. This means you will have to pay the first \$1,408.00 that you owe for your care by yourself before Medicare will start contributing.

The next important thing to consider is the coinsurance for your stay. The coinsurance is the cost that you must share with Medicare for daily care depending on the numbers of days spent in the hospital. These are:

Days 1-60: \$0
Days 61-90: \$352 per day
Days 91 and beyond: \$704 per day

It's important to note that Medicare covers hospital stays in "benefit periods." A benefit period starts when you enter a hospital or nursing home and ends when you haven't received inpatient care for 60 days in a row. This means you can leave your hospital/nursing home and return during the same benefit period and owe a higher daily coinsurance. You also owe the \$1,408.00 deductible for every new benefit period.

Medicare will only cover your care for 90 days per benefit period. However, it also provides 60 "lifetime reserve days" that can be added to any benefit period. If you need care on day 91 or beyond, you will have to use your reserve days. For any day that uses a lifetime reserve day, the coinsurance is \$704.00. If the cost of care is lower or not much higher than \$704.00, some beneficiaries choose to pay in full and save their reserve days for later.

If you and your doctor have decided your next step is nursing home care, Medicare will cover as many as 100 days, but possibly fewer, of care in a nursing home. The first 20 days are covered in full but the last 80 have a \$176.00 daily coinsurance. However, in order to qualify for any days of coverage, you must enter your nursing home within 30 days of a hospital stay that lasted at least 3 days and the nursing home care must be for the same condition for which you received treatment at the hospital. Finally, those 3 days must be considered inpatient care. Sometimes, hospital patients will be admitted under "observation status," which involves less direct care.

You can ask your nurse, doctor, or any other staff if you are considered inpatient or observation status. You may also want to contact your patient advocate (see page 11) who can help determine your status. For questions about Medicaid or Medicare, visit our website:



https://elderjusticeny.org/resources/

^{**}All Premiums and deductibles listed are for 2020. These numbers are adjusted on a yearly basis.

DISCHARGE PLANNING AND PARTICIPATION

From the moment you enter a hospital to the moment you leave, it's important to be involved in your care. If you don't play an active role, you may not get the results best-suited to your care. Here are some tips to help make sure that your care is your choice.

Deciding where you go after your hospital stay is called "discharge planning," and hospitals are required to focus on your goals of care and treatment preferences during the process. Social workers or discharge planners typically are in charge of creating your discharge plan.

TIP:

If you haven't been provided options or discharge planning information, ask a staff member to provide them or to connect you with a discharge planner.

Hospitals are also required to provide you with data about the quality of facilities you are considering. That same data should be personalized for your care needs. For example, if you and your hospital have decided that you need nursing home level of care, your hospital should provide data about the quality of local nursing homes. If you were at high risk of falling, that data might include the percentage of residents that experience falls at local nursing homes.

Additionally, when it is time to move to your chosen facility, the hospital must send your medical information to the new facility and other providers who will be involved in your care. This information might include, but is not limited to: current course of illness and treatment, post-discharge goals of care, and treatment preferences.

TIP:

It's important to make sure that your medical information goes to your new facility. Ask your doctor or other staff if your medical information, including medications, will be sent by the hospital. See page 9 for more tips on Medication Safety.

While discharge planners are normally experts on care settings, it is important to remember that you are an expert about yourself. You know your physical and financial limitations and the extent to which your loved ones can provide care. If you don't speak up with important information, your discharge planner may not consider those factors.

If you disagree with your hospital about the timing or location of your discharge, try to explain why. If the disagreement persists, you may want to file an appeal of your discharge (see page 13).

Be it discharge planning or your care while at the hospital, it is important to learn how to actively participate in your healthcare decision-making and planning. A good place to start is having the right questions to ask. Here are some of the most relevant questions you may need to ask during a hospital visit:

General Questions

- What is my status or illness? What can I expect?
- What kind of care do I need? (Grooming, diet, medication, special equipment, etc.)
- What follow up appointments will I need? Have those appointments been made?
- How will my doctor learn about my current status?
- What medications am I taking and why? Will my medications interact with other medications? What problems might I experience with my medications? When should I report those problems? If you're not sure, it's always better to report an issue to your doctor.

Questions for Discharge to your Home:

- Will I need a ramp, handrails, or grab bars?
- Will I need special equipment at home and who will pay for it?
- Will I get home care, including a nurse or therapist?
- Will Medicare/Medicaid pay for these services?
- Are there care techniques I need to learn, such as changing dressings?
- How and when will I be trained in these care techniques? Can I start now?

Questions for Discharge to a New Healthcare Facility:

- Do you have ratings for my facility options?
- How long will I stay?
- How will my new facility get my medical information including medications?
- Is there a social worker at my new facility that I can work with?
- If needed, are there special services available for dementia patients?

It's important to ask questions and be involved in your care. Asking more questions will likely improve your health outcomes and help you learn more about your health status. It can help to write down what you plan to ask before a meeting with a physician or discharge planner and to keep notes of the answers they give.

If you feel as though you are having trouble being involved in your own care and planning, you may want to contact your hospital's patient advocate (see page 11).

MEDICATION SAFETY

Many adults take more than one medication, and many medications have side effects. It is important you know what medications you are taking, when they should be taken, and potential side effects. Here are some tips to protect yourself and to avoid medication mistakes:

Know the medications you are taking and the ones you shouldn't take

The most important thing you can do to protect yourself from medication errors is to know what medications you take and to make sure your healthcare providers also know. The best way to do this is to make a list of medications that you take and to get all the information you need to update that list from your doctor when you are adding or removing medications from your treatment plan. During a hospital stay, always know what pills and I.V.'s you are given, and make sure that the medications you receive are for you and not a different patient. Some information that you should keep about every medication you take includes:



- Brand and generic names
- Intended effects and possible side effects
- What you should do if side effects occur
- How each of your meds might interact with other meds

- The dose you take
- What to do if you miss a dose or take more than recommended
- Any medications, foods, drinks, or activities you should avoid because you take a med
- Medications you CAN'T take due to allergies or past issues

Use "Medication Reconciliation"

Medication reconciliation is when a patient compares their own list of medications with the one that their healthcare provider has. This is the best way to catch medication errors before they cause harm and the best way to inform your healthcare providers. It's helpful to keep copies of your medication list and to give copies to your loved ones.

REMEMBER THIS

Medication errors happen most often during healthcare transitions. This means you should use medication reconciliation after every change in your healthcare. This includes every time your medications change and **especially** if you are moving to a nursing home or any other new healthcare facility.

Learn the Vocabulary

Finally, you can help avoid medication errors by learning the difference between how you speak about medication and how your doctor does. This is helpful when you are discussing changing your current medication regimen and while carrying out medication reconciliation.



One important concept to learn is "Never Meds." These are medications that you can never take. If your doctor tells you never to take a medication because you are allergic, it's unsafe to take with your other meds, or for any other reason, that medication is a Never Med. It can help to add any Never Meds you have to a list of your allergies, even if you aren't allergic. This can help ensure hospitals and other providers don't accidentally give you a Never Med. Be sure to let your other doctors and pharmacist know if you have a new Never Med.

What I say:	What my doctors says:
Never Meds!I can't take this med	Absolute contraindicationSevere allergic reactionLife threatening side effect
 I have some side effects I notice that when I take this med 	 Relative contraindications Previous intolerance or adverse reaction Side effects
 I'm considering this med I haven't taken this before 	 No known contraindications No known intolerance or adverse drug reaction in patient history

HOSPITAL PATIENT ADVOCATE

Hospitals may have one or multiple patient advocates (also called representatives) that can help with issues you encounter while at the hospital. Advocates are intended to help patients make informed decisions while navigating their health care journey. They are not involved in delivering the care you receive while at the hospital but instead act as a "go-between," between you and your healthcare providers while at the hospital.

Speaking with a patient advocate might connect you with resources that you didn't previously know were available and might help to resolve an issue that you otherwise have not been able to address. Some of the ways that a hospital patient advocate might be able to assist include:



- Advocating for increased patient participation in care
- Making sure you know all the facts about your condition and care
- Helping you get copies of your medical records
- Connecting you with resources useful to you while staying at the hospital or that will be useful to you in the future
- Helping understand your hospital bills and insurance

Although most hospitals offer patient advocates, some do not. While uncommon, some insurance providers will cover patient advocate services. Additionally, if no patient advocate is available to you, you may be able to get information and resources from the Patient Advocate Foundation by calling 800-432-5247.

To be connected with a patient advocate, you can let a nurse or any staff member know that you would like the contact information for, or to be connected with, the hospital patient advocate. On the next page please find contact information for patient advocates or similar roles in some of the hospitals in Western New York.

Erie County Medical Center: (716) 898-4155

Buffalo General Medical Center: (716) 859-3515

Kenmore Mercy Hospital: (716) 447-6914

Mercy Hospital Buffalo: (716) 828-2044

Millard Fillmore Suburban Hospital: (716) 568-3569

Roswell Park Cancer Institute: (716) 845-1365

or (716) 845-2981

Sisters of Charity Hospital: (716) 862-1390

Sisters St. Joseph Campus: (716) 891-2689

Mercy Hospital Orchard Park: (716) 862-17900

Degraff Memorial Hospital: (716) 568-3569

Eastern Niagara Hospital Lockport: (716) 514-554

Eastern Niagara Hospital Newfane: (716) 514-554

Niagara Falls Memorial Medical Center: (716) 278-4352

Bertrand Chaffee Hospital: (716) 592-2871 ext. 1203

Brooks Memorial Hospital: (716) 363-3977

UPMC Chautauqua: (716) 664-8271

Westfield Memorial Hospital: (814) 452-7081

Women's Christian Association Hospital: (716) 664-8271

Olean General Hospital: (716) 375-6162

Mount St. Mary's Hospital: (716) 298-2017



HOSPITAL DISCHARGE APPEAL

As a patient, you may disagree with your hospital about when to leave and where to go. You may need more care or not have a safe place to go. Sometimes this disagreement can be addressed by speaking with your doctor or discharge planner and explaining why you disagree. In extreme cases, when discussion is not enough, you may consider appealing your discharge.

TIP:

Your primary physician or community doctor may be able to provide valuable input on why it's too soon for you to leave.

If you have Medicare, when you are first admitted for a hospital stay you should be provided with a document called, "Important Message from Medicare," that you must sign and return. This document explains your rights, including the discharge appeal process. For those not on Medicare, your hospital is required to issue you a discharge notice at least **24 hours** before you leave that includes the date of

your discharge and the process to follow to appeal. You must call to start your appeal no later than your discharge date, otherwise losing your appeal will mean that you have to pay for your continued hospital stay.

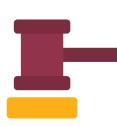


For those on Medicare, this appeal is called a fast appeal because it happens on a faster timeline than most others. If you have decided that a fast appeal is right for you, start by calling your local Quality Improvement Organization (QIO). QIOs handle fast appeals and other Medicare matters. The New York State QIO is called **Livanta** and can be reached by calling 1-866-815-5400 or 1-866-868-2289 (TTY).

It's important to contact your QIO right away. When you call you should explain or leave a message explaining that you want to file a fast appeal of a pending hospital discharge. If your family member or caregiver calls for you, they may need to fill out a form stating they can act as your representative later in the process.

While the QIO reviews your appeal you cannot be transferred from the hospital. During this time however, normal coinsurance and deductible payments will apply. The QIO typically takes about 2 days to review a fast appeal and will look at a copy of your records and contact you to discuss your concerns. You can see the records that the hospital provides the QIO by request.

If the QIO determines that the hospital was right to ask you to leave, you will be allowed to stay until noon the next day at no extra charge (if you started your appeal no later than your **original** discharge date). After that time, the hospital can start charging you for the time that you stay. If the QIO agrees with you that you need more time in the hospital, you will be allowed to stay until a new discharge is proposed by the hospital.



In the event your QIO agrees with the hospital, you will have an opportunity to ask it to reconsider its decision, which it must do within **72 hours**. The appeals process can continue beyond the QIO, including having your discharge reviewed by what is called an Administrative Law Judge, but this is less common and comes with additional risks. If you are considering an appeal and are a resident of Western New York, call the Center for Elder Law & Justice at: (716) 853-3087.

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LONG-TERM CARE RESOURCES

We hope that this guide has given you useful information, but long-term care planning is a difficult process and this guide may not be enough. Here are some other resources that may be useful while you plan the next step in your care journey.

<u>Center for Elder Law & Justice:</u> Our organization has more informational materials available online to help guide your care planning. In some cases we can offer Medicare and Medicaid advice to Western New Yorkers. Call our free Legal Advice Helpline for a brief attorney consultation and visit our website to learn if you qualify for other free civil legal services.

Call: 716-853-3087

Legal Advice Helpline: 1-844-481-0973

Online: https://elderjusticeny.org/resources/long-term-care-resources/

<u>NY Connects:</u> Helps identify the best available long-term care options for you or your loved one as well as provides informational resources that help you decide.

Call: 1-800-342-9871

Online: https://www.nyconnects.ny.gov/

<u>Western New York Independent Living Center:</u> Provides tools, resources, and supports for people with disabilities to allow them to live as independently as possible. Can assist nursing home residents with disabilities looking to return to the community.

Call: 716-836-0822

Online: http://wnyil.org/Independent-Living

MY NOTES: