The transition 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 for nursing home residents. 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 residents and advocates.

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.
WHAT ARE MY RIGHTS?

Nursing home residents have rights that are guaranteed by federal, state, and local law. It’s important to know those rights to make sure they are honored. Here are some of the most important rights to know:

Right to a Dignified Existence
- Be treated with consideration, respect, and dignity
- Quality of life is maintained or improved
- Security of possessions
- Homelike environment
- Exercise rights without interference, coercion, discrimination, or reprisal
- Freedom from physical or chemical restraints
- Freedom from abuse, neglect, and exploitation

Right to Self-Determination
- Choice of activities, schedules (when to wake/sleep), health care, and providers, including physician (see page 13)
- Reasonable accommodation of needs and preferences
- Participate in your assessment, care planning, and treatment (see page 5)
- Organize and participate in resident and family groups (see page 10)
- Request, refuse, and/or discontinue treatment

Right to be Fully Informed
- Of care to be provided and the risks and benefits of treatment (see page 11)
- Of changes to your Care Plan, or in medical or health status
- Of contact information for outside advocacy groups (see page 15 and 16)
- Through written notices in a language or manner you understand (Spanish, Braille, etc.)

Right to Raise Grievances
- Prompt efforts by your nursing home to fix grievances, and a written decision upon request (see page 14)
- Present grievances without discrimination or retaliation, or fear of it
- File a complaint (see page 16)

Right of Access to
- Visitors of your choosing, at any time, and the right to refuse visitors
- Individuals, services, community members, and activities inside and outside the facility
- Personal and medical records
- Your personal physician, state survey agents, and Long Term Care Ombudsman (see page 15)
- Assistance with sensory impairments
- Social, religious, and community activities

Rights Regarding Financial Affairs
- Manage your own financial affairs
- Have information about available services and charges for each service provided by the nursing home
- Personal funds of more than $100 ($50 for Medicaid recipients) deposited by your nursing home in a separate interest-bearing account
- Financial statements quarterly or upon request
- Not to be charged for services covered by Medicaid or Medicare

Right to Privacy
- Regarding personal, financial, and medical affairs
- Private and unrestricted communication with any person of your choice
- Privacy during treatment and care of personal needs

Rights During Discharge/Transfer
- Right to appeal transfer or discharge and to stay at your nursing home while an appeal is pending (see page 7)
- Right to written notice of discharge or transfer that includes: the reason; the effective date; the location you are moving to; appeal rights and process for filing an appeal; and the name and contact information for the Long-Term Care Ombudsman
- Preparation and orientation to ensure safe and orderly transfer or discharge
- Notice of, and the right itself, to return to the facility after hospitalization or therapeutic leave

For more detailed information on these and other nursing home resident rights visit our website at: https://elderjusticeny.org/resources/long-term-care-resources/
PAYING FOR NURSING HOME CARE

When you have decided to move to a nursing home it can be difficult to plan how you will pay for your stay. A good place to start is to learn about some of your options.

**Medicare:** Medicare is health insurance for the elderly and disabled. If you are enrolled in Medicare, and meet certain requirements, it may help cover a nursing home stay for up to 100 days. Requirements include that you must enter a nursing home within 30 days of a hospital stay that lasted at least 3 days. Also, the care that you need at the nursing home must be for the same condition that you received treatment for in the hospital, and a physician must order the treatment and agree that you need skilled care.

For 2020, the first 20 days of the stay are covered in full by Medicare but a co-payment of $176** is required for each of the final 80 days. These numbers change yearly. If your health improves beyond needing skilled care, your coverage may end before 100 days. However, it is important to know that you are still entitled to coverage if you need skilled therapy to maintain your current health status or prevent decline. Coverage CANNOT be revoked because your health is not improving. It’s common to use Medicare before other payment options and many residents have Medicare Advantage plans that offer more coverage but may cost more (check with your plan for coverage details).

**Private Pay:** Some residents pay for their care with their own money. However, due to the expensive nature of nursing home care, this is rare. Others pay privately for as long as they can before switching to Medicaid (see below). The daily rate for any nursing home will be listed in the admission agreement (contract) that you sign.

**Medicaid:** Medicaid is the most common source of funding for nursing home care with 70% of nursing home residents in New York State using the program. Medicaid is health insurance for those who show financial need for the program. To qualify individuals must meet certain limits to their income and resources (savings, property, investments, etc.). If you have excess income or resources, they can be "spent down" by being used to pay for part of your nursing home stay. After you meet the income and resource limits, you will qualify for Medicaid to pay the rest. In most cases, nursing home residents who receive Medicaid keep a $50 monthly allowance to use on personal needs. Medicaid will also "look back" at your finances for the last 60 months. If it's found that you have sold or transferred resources at less than fair market value, the amount of money that you need to "spend down" will increase by the value of that transfer. This will result in a period of ineligibility meaning that you will have to wait longer to receive Medicaid coverage. See the FAQ on the next page for more information on Medicaid.

Frequently Asked Financial Questions

Q: What is a nursing home NAMI?
A: The NAMI or, Net Available Monthly Income, is the amount of money that a Medicaid recipient must contribute to their cost of nursing home care. For most residents this is all of their income except for a $50 monthly Personal Needs Allowance (PNA).

Q: What if I have a spouse who lives in the community?
A: There are protections called Spousal Impoverishment Rules, which protect one spouse from going into poverty in order for the other to receive nursing home care through Medicaid. When a married individual applies for nursing home Medicaid, their combined income must be "spent down," or used in the NAMI (see above). However, in 2020, the spouse who is not a Medicaid recipient is allowed to keep combined income of up to $3,216.00. Additionally, the non-Medicaid spouse can hold on to at least $74,820.00 in resources and the Medicaid spouse can hold an additional $15,750.00 worth of resources. These amounts vary yearly and from state to state.

Q: Can my nursing home evict me for non-payment?
A: Before a nursing home can evict a resident for not paying their bill it must try to help the resident find a way to pay. This includes helping residents apply for nursing home Medicaid. If the nursing home has tried to help but the resident still has not paid, it can evict the resident, but must give them 30 days’ notice (see page 7). If you are concerned that you can't pay and your nursing home isn't helping, see page 5 for advice on participating in your care planning and consider calling your local ombudsman for help (see page 15).

Q: Can the Center for Elder Law & Justice (CELJ) help?
A: Yes! If you live in Western New York CELJ may be able to provide you with advice on long-term care planning and other questions related to Medicaid or Medicare at no charge. Call (716) 853-3087 to ask for help.

For more information on paying for your care and Medicaid/Medicare, visit our website at: https://elderjusticeny.org/resources/long-term-care-resources/

**All rates and limits listed are for 2020. These numbers are adjusted on a yearly basis. Check with your plan for rates if you have a Medicare Advantage Plan.**
The baseline care plan is a temporary plan used to guide your care before your home develops your Person-Centered Comprehensive Care Plan (PCCCP). The PCCCP is your best tool to direct your care. It must be developed within 21 days of your admission by a team that includes: you, your doctor or their representative, a registered nurse, a nurse aide, a food and nutrition staff member, any other professional your health needs require, and other individuals that you request be included.

Your PCCCP must be individualized. For example, if you consider yourself a night owl and prefer to sleep in, your nursing home should include the time you prefer to wake up in your care plan. The plan must also include the services you will receive, your goals, and how the services will help you meet your goals. In addition, the plan includes your goals for discharge. For example, if your goal is to improve your health and move out, that should be included in your plan (see page 7 for more information on discharge planning).

CONSIDER THIS

Your Person-Centered Comprehensive Care Plan will be developed with you at a care plan meeting. It can help to think about and write your goals down before the meeting. For example, do your goals include finishing rehab and returning home, living as independently as possible, or managing your pain? Keep track of your goals so that you can explain them to your nursing home.

At any point in the care planning process, you have the right to:

- Be included
- Choose who participates, and in what role
- Request a care plan meeting
- Establish your expected goals and outcomes
- Choose the type, amount, frequency, and duration of care
- See your PCCCP within 24 hours of requesting
- Have a copy of your PCCCP within 2 working days of requesting

Here are some tips for making sure that you are included during care plan meetings:

Before a meeting:

- Ask staff how to contact your social worker or how to request a care plan meeting
- Write down your questions and goals before you go to a care plan meeting
- Share your questions and goals with staff before meeting to help them prepare
- Ask about your condition
- Request a meeting time when your family or other advocates can attend

During a meeting:

- Write down what your doctor and other staff say
- Ask new questions
- If you are confused, ask staff to slow down or explain things again
- Discuss your treatment options and your needs
- Ask who to talk to if you want to request changes later on
- Ask for a copy of your care plan

After a meeting:

- Make sure staff are following your plan and preferences!

If you have tried but still don’t feel involved in your care, your local Long-Term Care Ombudsman Program might be able to help. See page 15 for more details.
DISCHARGE: WHEN DO I HAVE TO LEAVE?

Whether receiving long-term care or rehab at your nursing home, it has to follow certain rules about deciding when you should leave. It must work with you to plan the next step in your care and ensure that you will receive appropriate care that helps you meet your goals. This is called discharge planning. See page 5 for more information on participating in your care planning.

There are only five valid reasons for a nursing home discharge and every resident has the right to appeal any discharge they disagree with (see next page). These reasons are:

1. Your health has improved: If you have completed your rehab or your health has improved, your nursing home can decide that you should return home or go to a lower level of care, such as assisted living.

2. You need more care: If your health has worsened and your nursing home can no longer meet your needs, you can be sent to a higher level of care. This usually means you are being sent to the hospital or emergency room.

3. You are endangering others: In extreme cases, nursing homes will discharge a resident if they are putting the health and safety of other residents in danger.

4. You haven’t paid: Nursing homes are required to help you manage your finances to the extent that you would like. They are also required to help residents apply for Medicaid when it’s needed. If the nursing home has done all that it can to help a resident pay for their stay, and the resident still has not paid, they can tell the resident to leave after providing 30 days’ notice.

5. The nursing home closes: In rare cases nursing homes close but they, or the NYS Department of Health, will still be responsible for helping you plan your next step.

Although your nursing home must follow the reasons above, you can leave whenever you want. You can request, for example, that your nursing home help you plan to go to a new nursing home or any other setting that fits your goals.

In some cases, residents do not feel that they need help planning and do not want to wait to leave. You have the right to leave whenever you want to. If your nursing home thinks you need more care but you still want to leave, you can leave Against Medical Advice (AMA) at any time.

Here are some reasons that your nursing home is NOT allowed to use when asking you to leave:

1. **You need long-term care:** All nursing homes in New York State provide long-term care. Even if you were admitted to receive short-term rehabilitation, you have the right to stay for long-term care.

2. **You haven’t paid but your Medicaid application is pending or Medicare is considering paying your claim.**

3. **Your Medicare coverage has ended:** Medicare will only cover a maximum of 100 days of nursing home care, but if your current insurance coverage is ending, your nursing home is responsible for helping you plan how to pay after it ends. This includes helping apply for Medicaid and any other options that you might qualify for.

4. **Your health has improved when it actually has not and you still need nursing home level of care.**

5. **You refuse medical treatment.**

6. **You filed or want to file a complaint or grievance.**

7. **You are in the hospital:** If you go to the hospital to receive acute medical treatment you have the right to return to the first available bed in your nursing home. You may also pay to hold the bed that you left. Ask a staff member to provide you with your nursing home’s bed-hold policy.

8. **For any reason to an unsafe setting:** Nursing homes cannot discharge residents to a location where they would be unsafe.

9. **For any reason without proper notice or during a pending appeal (see below).**

If your nursing home has decided to ask you to leave it is required to provide you with a Discharge Notice which explains why it thinks you should leave and when. This notice also explains your right to appeal your discharge. If you think your nursing home is asking you to leave for an improper reason, you can contact the NYS Department of Health to request an appeal by calling 1-888-201-4563.

If you are a resident of Western New York, you can contact your local ombudsman at 716-817-9222 to discuss your rights or the Center for Elder Law & Justice at 716-853-3087 for possible representation during a discharge appeal. All other New Yorkers should contact their local ombudsman which can be found online at: https://aging.ny.gov/long-term-care-ombudsman-program
RIGHT TO RETURN TO THE COMMUNITY

If you would like to return home, or to any other living arrangement in the community, you have the right to do so and your nursing home has a legal obligation to help you and to engage in discharge planning (see page 7).

Nursing homes have to do their best to help you achieve your highest quality of life. This includes helping you with discharge planning, or in other words, planning how you will return home. Your social worker should be able to help.

Q: Where do I start?
A: Reach out to your social worker to discuss your unique situation and your options. You may want to request a care plan meeting (see page 5).

Q: What if my nursing home refuses to help or only does the bare minimum?
A: You can call your local ombudsman for help. Ombudsmen are experts on nursing home resident rights and can help you advocate to get the discharge planning that you need (see page 15).

Q: Can anyone else help me?
A: Yes! See below for some programs that you may be eligible for.

Western New York Independent Living Center: (716) 836-0822
- The center has an initiative intended to help residents in nursing homes return to the community.

New York Connects: https://www.nyconnects.ny.gov/
- NY Connects provides options counseling to help you make informed choices about your care. Every county has a NY Connects program. Visit the website above to find your program and explore online resources.

Please also visit our website for more long-term care planning information and resources:
https://elderjusticeny.org/resources/long-term-care-resources/

RESIDENT AND FAMILY COUNCILS

Nursing home residents and their families have the right to join together to:
- Discuss and offer suggestions for resident care, treatment, and quality of life;
- Support each other;
- Plan resident and family activities or participate in educational activities; or
- For any other purpose.

These meetings usually take place via a resident council, family council, or both. They can be a valuable tool to make positive changes in your nursing home. If requested, your nursing home must provide:
- A private space to meet;
- Notice to residents and family of meetings; and
- An assigned staff person.

The assigned staff person must be approved by the resident or family council. They are responsible for providing assistance and responding to written requests that result from council meetings as well as communicating between the council and the nursing home administration.

It’s also important to note that every resident has a right to attend these meetings and the assigned staff person, other staff, and any other guest can attend only with the permission of the council.

These councils can be very effective because your nursing home is required to:
- Consider and act promptly on grievances and recommendations of resident or family councils; and
- Demonstrate and justify their response to those grievances and recommendations.

You can ask your Director of Activities, Social Worker, or any other staff if your nursing home has a resident or family council. If they do not, you can also ask for help in starting one!
**INFORMED CONSENT**

Informed consent is a phrase used to describe every patient's right to have information and to ask questions before receiving healthcare treatment. Prior to receiving treatment, including medications, you have the right to have your condition explained, and to understand your treatment options, including the risks and benefits of those options.

You also have the right to choose the physician who provides you with information about your condition and treatment options (see page 13). You have the right to refuse any treatment that you are offered and can change your mind at any point about treatments you are receiving. Your healthcare and long-term care should be a shared decision-making process between you and your health care providers. If you feel like you have not been involved in making your healthcare decisions, see page 5 for information on participating in your care and page 15 to learn how an ombudsman might be able to help.

If you make health care decisions for somebody else (if you are a healthcare proxy, power of attorney, legal guardian, etc.) the right to informed consent extends to you with input from the person for whom you make decisions when they are able to provide it.

**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. **While in a nursing home, 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 resident.** Some information that you should keep about every medication you take includes:

- **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**
- **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**

**Use “Medication Reconciliation”**

Medication reconciliation is when a patient or nursing home resident 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 can help 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 have to go to the hospital or other facilities that are outside your nursing home.

**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.
Nursing homes provide the highest level of care in New York State outside of hospitals and, as such, must follow certain regulations about that care. This includes your right to choose your doctor and other standards about the care that your doctor gives you. It’s important to know these rights to make sure that your facility is honoring them. As a nursing home resident, you have the right to...

**Have a Doctor**

Every nursing home resident has the right to have their care supervised by a doctor. This includes having a doctor participate in your assessment, care planning, monitoring of your medical status, and in providing consultation and treatment when contacted by your nursing home.

**Regular Visits**

You have the right to an in-person visit by a doctor once every 30 days for your first 3 months and once every 60 days after that. After the first 3 visits your doctor can take turns making your visits with other staff but must visit at least every other 60-day visit.

**Choose your Doctor**

You have the right to choose your doctor as long as your chosen doctor is qualified and willing to supervise your care. If your doctor is not qualified or doesn't want to supervise your care, your nursing home must work with you to consider your other options.

**Know Your Doctor**

Your nursing home must keep and provide your doctor’s name, specialty, and contact information. They must also do this for other primary care providers.

**Specialized Rehab**

If your care plan calls for specialized rehab, your nursing home must either provide it or hire someone to provide it. This includes but is not limited to physical therapy, speech-language pathology, occupational therapy, and respiratory therapy.

**Have a Dentist**

A dentist must be available to each resident. Depending on how you pay for your care, a nursing home can charge you extra for dental care. However, if you are unable to pay for dental services, your nursing home must attempt to find another way to provide your dental care such as a dental school or dental hygiene delivered to you in your nursing home.

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**RIGHT TO CHOOSE YOUR DOCTOR**

Every nursing home is required to have a grievance process that their residents can use. A grievance is a formal complaint. You can include your name with your grievance or file it anonymously and your nursing home is required to keep your grievance confidential. A grievance can be about any issue you have, including, concerns about your care and treatment. Every nursing home resident has the right to file a grievance without fear or punishment. Your nursing home is required to:

- Have a grievance official who investigates and responds to grievances.
- Provide residents with contact information for the official.
- Make information on how to file a grievance available to residents.
- Accept written OR spoken grievances.
- Quickly resolve all grievances and provide any resident who files a grievance with a response in writing that includes: the date and a summary of the grievance, how it was investigated, whether the grievance was confirmed, and any action taken or to be taken as a result.
- Have a reasonable time frame for when residents can expect a response to their grievance.
- Create an environment where residents feel safe to file grievances.
- Take every resident concern seriously.

**TRY THIS**

If you would like to file a grievance, or to have a copy of your nursing home’s grievance policy, ask your social worker, activities director, nurse, or any other staff, for contact information for your grievance official. If you can’t find them, or your home doesn’t have one, an ombudsman may be able to help (see page 15).

Here are some examples of issues that you could file a grievance about:

- Receiving poor care
- Not receiving care
- Financial mismanagement
- Lost clothing or other items
- Lack of activities
- Violations of your rights

If you would like to file a complaint with an organization outside of your nursing home, see page 16 for more options.
If you are having trouble getting the quality of care you have a right to, you may want to call the Long-Term Care Ombudsman Program (LTCOP). Nursing homes sometimes fail to respect your rights and when they do, an ombudsman, also known as a resident advocate, may be able to help.

The LTCOP is federally required and all states must have an Ombudsman Program. Ombudsmen are staff and volunteers who are trained to resolve problems for residents of nursing homes (as well as adult care and assisted living facilities). Ombudsmen help residents understand and exercise their right to good care in an environment that promotes and protects their dignity and quality of life. Ombudsmen can also help file complaints (see page 16). Unless you give permission to share your concerns, ombudsmen keep those concerns confidential.

In New York State the LTCOP is divided into regions. Western New York is covered by Region 15 which includes Erie, Niagara, Cattaraugus, and Chautauqua counties. If you are a nursing home resident in any of the counties listed above you can contact your ombudsman with care concerns by calling (716) 817-9222 or 1-844-527-5509.

If you are a resident of New York State but not one of the counties listed above you can call the state ombudsman office at 1-855-582-6769 or find your local ombudsman by visiting: https://aging.ny.gov/long-term-care-ombudsman-program

Here are some issues an ombudsman can help you resolve:

- Lost or stolen personal belongings
- Trouble getting transportation to appointments
- Difficulty getting medications
- Not being able to reach your social worker or other staff
- Help with "discharge planning" (see page 7)
- Ensuring that your Medicaid application is prompt
- Advocating for more participation in your care and care planning (see page 5)
- Other issues of care or quality of life
- Staff not following your care plan

In New York State the LTCOP is divided into regions. Western New York is covered by Region 15 which includes Erie, Niagara, Cattaraugus, and Chautauqua counties. If you are a nursing home resident in any of the counties listed above you can contact your ombudsman with care concerns by calling (716) 817-9222 or 1-844-527-5509.

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**WHERE TO FILE A COMPLAINT**

If you find yourself in a situation where you can't seem to get the care you have a right to, it's important to know where you can file a complaint outside the nursing home. Nursing homes are required to have a formal process through which you can file a grievance (see page 14) but sometimes a grievance is not enough. Filing a complaint for unresolved issues is important because it may help solve your issues and prevent those issues from happening to someone else. Here are some agencies where you can file a complaint:

**The New York State Department of Health (DOH):**
The DOH is responsible for inspecting all nursing homes in New York State and for enforcing all federal and state quality of care and resident rights regulations/rules. Every nursing home complaint is reviewed and investigated by the DOH who then can issue citations or fines.

To file a complaint with the NYS DOH you can call their nursing home complaint line at: 1-888-201-4563. You can also submit a form electronically or find a form to use when submitting via fax or e-mail at this website: https://apps.health.ny.gov/surveyd8/nursing-home-complaint-form

**The New York State Attorney General:**
The NYS Attorney General has a Medicaid Fraud Control Unit (MFCU). It specializes in investigating and prosecuting abuse and neglect of residents in all residential care facilities including nursing homes.

To file a report, call the MFCU hotline at 800-771-7755 or fill out their online form at: https://ag.ny.gov/comments-mfcu

**The U.S. Department of Health and Human Services (DHHS):**
The DHHS receives complaints from individuals whose civil rights have been violated. That is, individuals (including nursing home residents) who have been discriminated against on the basis of race, color, national origin, disability, age, or sex.

To file a report online use the DHHS complaint portal located at: https://ocrportal.hhs.gov/ocr/cp/complaint_frontpage.jsf

To file a complaint in writing, follow instructions available here: https://www.hhs.gov/civil-rights/filing-a-complaint/complaint-process/index.html

If you are a Western New York resident and unsure if you should file a complaint, you can discuss your concerns by calling the Center for Elder Law & Justice at (716) 853-3087 or contact your local ombudsman (see page 15).