About This Guide

As you and your family become part of a nursing home community, you will likely have questions – on everything from how to manage day to day routines, to how to continue participating in life-long interests and activities. Moving forward, issues may come up that can sometimes be difficult for residents, families, and nursing home staff to anticipate and address. This brochure is intended to provide information, tips and resources to help answer some of those questions. It was developed by DPH in partnership with the Massachusetts Executive Office of Elder Affairs, the Massachusetts Senior Care Association, Leading Age Massachusetts, nursing home resident advocates, and legislators.

In this brochure, the term “family” includes family members, health care agents and/or legal representatives.
Common Questions

Who should I contact if I have questions or concerns about my care?

If you have concerns about either your own care or the care of a family member, first try talking directly to the nursing home staff. Find a staff member you particularly trust and can communicate with easily, such as a nurse on duty or a social worker.

You can also discuss questions or concerns with the facility’s administrator, director of nurses, medical director, or with your personal physician. A list of contacts for your nursing home is included with this brochure.

Many nursing homes have a policy of meeting with residents and families shortly after a resident is admitted, since it may be easier to think of questions after you have had time to adjust to the nursing home. In addition, residents and families are encouraged to attend regular care planning meetings with the staff every 3-4 months, however, you can ask for a care plan meeting at any time.

If after speaking with staff at the nursing home your questions or concerns are not addressed to your satisfaction, contact the Ombudsman assigned to your nursing home by the Executive Office of Elder Affairs. The Ombudsman, who is usually a volunteer, helps to resolve issues between nursing homes and residents and their families. The name and telephone number of the Ombudsman for your nursing home is included with this brochure.

Finally, you may contact the Massachusetts Department of Public Health, which monitors the quality and safety of nursing home care, with any concerns. You can reach DPH at 1-800-462-5540, 24 hours a day, 7 days a week.
Common Questions

Who can receive information and make decisions about me?

You are in charge of your own care while in the nursing home, unless a doctor or court has determined that you are not able to make or communicate health care decisions. Family members or friends may be involved, but only if you agree that they may receive confidential health information and participate in care planning meetings.

What if I can’t make decisions on my own?

If you are unable to make or communicate health care decisions on your own, someone needs to be available to make decisions on your behalf – while still involving you as much as possible.

As a nursing home resident, it is very important that you complete a simple legal document called a “health care proxy”. In this document you will name someone you know and trust (such as a family member or friend) to make health care decisions for you if you are unable to do so. This decision-maker is called a health care agent. With certain medical conditions, you may be able to make decisions at some times and not at others. As long as you are able to make and communicate health care decisions, you remain in charge of your care. If your physician or nurse practitioner determines that you are not capable of making or communicating health care decisions, your designated health care agent would then act on your behalf.

You are also encouraged to have a legal document called an “advance directive” that lets family members and the nursing home know your preferences for end-of-life care.
You will find information on advance directives in your admissions packet. You are encouraged to discuss these advance directives with your physician, nurse practitioner, or social worker.

**When should my family or I be notified about changes in my care or health status?**

Residents or families must be notified immediately if:
- There is an accident that causes an injury which may require medical intervention;
- There is a significant change in the resident’s physical, mental, or psychosocial status; or
- There is a need to significantly alter treatment, including changes in medications.

If you have completed a health care proxy form, the individual you have selected as your health care agent will be contacted first. In other cases, residents or families usually identify one family member to receive this information.

**What if I need to be transferred to the hospital?**

You may need to be hospitalized if you develop a medical condition that cannot be handled by the nursing home. In these situations, the nursing home will let you and your family know that hospital care is being recommended, discuss potential alternatives to hospitalization, and make arrangements to transport you by ambulance to the hospital if appropriate. In emergency situations, a family member may be notified after you are transported to a hospital.
When you need hospital care, there are “bed hold” policies on how long your nursing home bed can be reserved while you are in the hospital. Information about your nursing home’s “bed hold” policy is included in your nursing home admission agreement. If you have questions about this policy, please ask the social worker at your nursing home.

What if the nursing home wants to transfer me to another unit or facility?

Under certain circumstances, a nursing home may transfer a resident to another room or unit to better meet the resident’s health or safety needs. The nursing home should discuss this with you or a family member in advance, unless the situation poses an immediate health or safety risk.

Sometimes, a nursing home may need to transfer a resident to another facility or discharge them from their current facility. State and federal laws list allowable reasons for transfer or discharge as:

- Your health needs cannot be met in the facility
- You no longer need nursing home care
- You are endangering the health or safety of others
- Payment has not been received after reasonable and appropriate notice
- The nursing home closes

In each case, the nursing home is required to provide written notice to you at least 30 days before the proposed transfer, except when you have been in the nursing home for fewer than 30 days. The written notice must specify:

- The reasons for the transfer
- Transfer effective date
- Where you will be transferred
Common Questions

• How to appeal the transfer to government agencies
• The name, address, and phone number of the local legal services office

If you are filing an appeal, you must file within 30 days of receiving this written notice.

What if I want a new roommate?
Nursing homes do their best to match roommates. However, if you are unhappy with your roommate, you should let the nursing home staff know right away. Unless the nursing home is full, resident move requests can often be accommodated. Conversely, if the nursing home is changing your roommate, Attorney General regulations require you be given 48-hour notice, except in emergency situations.

What if I have questions about medications (including antipsychotic medications), such as: What is the reason for this medication? What are the symptoms that the medication should improve? What are the potential side effects?*

Other than in emergencies, medications are given only with your consent, or the consent of your health care agent or legal representative. You can ask the nurse, physician, or nurse practitioner for information about the medications being given. Medications, when used appropriately, can help promote the resident’s well-being. Medications used inappropriately can compromise a resident’s well-being.

*Source: www.nhqualitycampaign.org/files/AntipsychotFctsheetsFINAL%20508%20Compliant%2003.18.13.pdf
Some experts recommend that non-medication approaches be used before considering the use of antipsychotic medications. It is important to know that a resident always has the right to refuse antipsychotic medications or other treatments.

If you are being asked to approve treatment for yourself or your family member with an antipsychotic medication, you might wish to ask the nurse, physician or nurse practitioner questions such as:

- Did the team attempt to identify the causes of the resident’s behavior before recommending medication to address the behavior?
- Did the team try to use non-medication approaches before trying this medication (e.g., changes in sleep schedules, meals, activities, or how staff interact with the resident)?
- How will this medication be monitored and, if possible, reduced?

What if I’m having difficulty with eating or drinking?

The nursing home assists residents with their ability to eat and drink. This might include nurse aides or a speech or occupational therapist working with a resident, or include provision of special assistive devices or equipment.
Common Questions

Who can I ask about physical therapy?
Physical therapy is provided under a doctor’s order when it can improve your condition. If you are not currently receiving physical therapy services and feel they may be beneficial, talk with your nurse or social worker. If you do not require physical therapy, other care such as a walking program may also be provided to help you maintain your health.

How can I keep track of my personal possessions?
Speak with the nurse or social worker who will be able help you try to locate your possessions. Sometimes it is helpful to ask the staff to speak with laundry workers about items of clothing that cannot be located. You also have the right to a secure, locked area for your valuables.

Who is allowed to see my medical records?
You or your legal representative (or your health care proxy, if applicable) is allowed to see your medical records. Upon a verbal or written request, access is generally granted within 24 hours.
Common Questions

All of these are good topics to discuss when you meet with nursing home staff. In addition, the agencies and organizations listed at the end of this brochure can help you find the appropriate state and federal regulations related to these and other questions you may have.

All state and the federal regulations for nursing homes can be found at: www.mass.gov/dph/dhcq

For further assistance please call The Department of Public Health’s Division of Health Care Quality at (617) 753-8100.
Consumer Checklist

The following are documents and regulations that you should be aware of as a nursing home resident or resident’s family member. If you have not already received these materials, you can ask the nursing home for a copy or contact one of the agencies or organizations listed at the end of this brochure.

❑ Admission Agreement
Nursing homes ask consumers to sign an admission agreement that lays out the rights and responsibilities of the nursing home as well as the rights and responsibilities of the resident and family. Since it is a legal document, consumers are encouraged to have the agreement reviewed by a legal representative before signing it.

❑ Resident Rights Brochure
This brochure, available from the Department of Public Health summarizes the rights of a nursing home resident. Nursing homes are required to protect and promote the rights of all residents. The current version of this brochure may be found at: [www.mass.gov/eohhs/docs/dph/quality/hcq-circular-letters/dhcq-nursing-home-brochure.pdf](http://www.mass.gov/eohhs/docs/dph/quality/hcq-circular-letters/dhcq-nursing-home-brochure.pdf)

❑ Attorney General’s Consumer Protection Regulations
These regulations, which should be given to you at admission, protect consumers by outlining state requirements relating to unfair or deceptive acts or practices, non-discriminatory access to quality care, admission contracts, charges, privacy and other personal rights, personal funds and belongings, medical treatment and information, and discharge and transfers.

❑ Family Council Rights
The Family Council is managed by family, friends, or chosen representatives and advocates for all residents in a nursing home. The facility is to consider the views and act upon the Council’s grievances and recommendations concerning proposed policy and operational decisions that affect resident care and quality of life. Federal and state regulations support independent Family
Council’s and a notice that a resident’s family member (or representative) has the right to form a Family Council should be given to you at admission. If an independent Family Council exists, contact information and the meeting day, time, and location should also be given to you at admission. If such a council does not exist, the ombudsman for the nursing home or the Massachusetts Advocates for Nursing Home Reform can help you start an independent Family Council.

Visitation Rights

It is the nursing home’s responsibility to protect and promote your right to have visitors and access to individuals on a 24-hour basis. You also have the right to deny or withdraw your consent at any time. Immediate family, your doctor, and certain officials are not subject to visiting hour limitations or other restrictions not imposed by you, unless necessary to protect the safety of you or other residents. An individual or representative of an agency providing health, social, legal or other services to you has “reasonable access”, which means that the nursing home may establish guidelines regarding the circumstances of the visit, such as location. All other individuals are subject to “reasonable restrictions” imposed by the facility to protect the security of all the facility’s residents. If restrictions are imposed by the facility, the resident and the visitor should be informed of the reasons, and what change is necessary for removal of the restrictions. If you feel the nursing home has violated your access or visitation rights, contact your Ombudsman or DPH.

Health Screenings

Federal and state regulations mandate that long term care facilities provide all residents with the care and services needed to attain or maintain the highest level of physical, mental and psychosocial well-being. The Department of Public Health has compiled clinical guidelines for preventive health screenings for residents of long term care facilities. These guidelines include, but are not limited to: physical examinations, preventive, restorative, and prompt emergency dental services, cancer screenings (including oral), hearing and vision assessments and immunizations. The complete list of long term care
health maintenance guidelines can be found at: www.mass.gov/eohhs/gov/departments/dph/programs/hcq/health-care-quality/healthcare-quality/health-care-facilities/long-term-care-facilities/long-term-care-facilities-circular-letters.html (See Circular Letter #11-01-543 and attachments). If a resident is unable to pay for needed dental services, the facility should assist you to attempt to find alternative funding sources or alternative dental care services.

❑ **Health Care Proxy Form**

All nursing home residents are encouraged to complete a health care proxy form to identify someone (either a family member or friend) who can act on your behalf if you can no longer make or communicate health care decisions. The nursing home can provide you with a copy of the form and instructions for filling it out. It is important for you to provide the nursing home with a copy of your completed form.

❑ **Advance Directive Form**

All residents are encouraged to complete an advance directive to document your end-of-life wishes in the event that you are terminally ill and unable to communicate. For more information and to obtain a copy of the Massachusetts advance directive form, visit the National Hospice and Palliative Care Organization’s Caring Connections website at www.caringinfo.org. It is important for you to provide the nursing home with a copy of any completed advance directive.

❑ **Privacy Requirements**

The federal Health Insurance Portability and Accountability Act (HIPAA) protects the privacy and confidentiality of personal medical information. Generally, nursing homes are prohibited from sharing personal health information, except to provide health care treatment and services, bill and collect payment from health insurers, or for quality improvement or staff training purposes. For more information about HIPAA, visit the U.S. Department of Health and Human Services’ health information privacy website at: www.hhs.gov/ocr/privacy.
The information provided in this brochure is for informational purposes only and is not meant to substitute for legal advice.

Massachusetts Department of Public Health
Division of Health Care Quality
67 Forest Street
Marlborough, MA 01752
617-753-8000 or 1-800-462-5540
www.mass.gov/dph

Massachusetts Senior Care Association
2310 Washington Street
Suite 300
Newton Lower Falls, MA 02462
617-558-0202 or 1-800-CARE-FOR
www.maseniorcare.org

Leading Age Massachusetts
246 Walnut Street
Suite 203
Newton, MA 02460
617-244-2999
www.leadingagema.org

MA Executive Office of Elder Affairs
Long Term Care Ombudsman Program
One Ashburton Place
Boston, MA 02108
617-727-7750 or 1-800-243-4636
www.mass.gov/elders

MA Executive Office of Health and Human Services
Division of Medical Assistance
One Ashburton Place, 11th Floor
Boston, MA 02108
617-573-1770
www.mass.gov/masshealth

Office of the Attorney General
Consumer Protection Division
One Ashburton Place
Boston, MA 02108
617-727-2200
www.mass.gov/ago

Massachusetts Advocates for Nursing Home Reform
PO Box 560224
Medford, MA 02156
1-800-988-4450
www.manhr.org