

OHCW

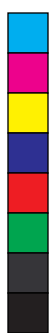
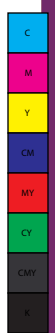
The Ohio Home Care Waiver Program (OHC) meets the needs of people who prefer to get long-term care services and supports in their home or community, rather than in an institutional setting.



Area Agency on Aging 3
Integrity. Independence. Quality of Life.



Area Agency on Aging 3
2423 Allentown Road,
Lima, OH 45805
419-222-7723 • www.aaa3.org



How to contact your Care Manager

Your recovery manager will provide you with a business card with their direct phone number on it. If you do not have that card, the Area Agency on Aging 3 office is open 8:00am- 4:30pm, Monday through Friday. If you call during those hours, your call will be answered by a Community Resource Center expert. Ask for your Care Manager and you will be connected with their extension. Feel free to leave them a detailed message if they are unable to answer your call and they will get back to you as soon as they can within 1 business day.

Please be sure to leave your name and phone number!

The Area Agency on Aging 3 is here to help:

**We are here to answer your questions
and find programs and services to make life easier.**

**Contact AAA3 at 419-222-7723 to learn about
our programs and how we can help you!**




Area Agency on Aging 
Integrity. Independence. Quality of Life.

About Ohio Home Care Waiver

The Ohio Home Care Waiver (OHCW) program is a Medicaid-funded program that enables people the ability to receive care in their home and community instead of residing in a nursing home, rehabilitation facility or hospital. The Ohio Department of Medicaid has contracted with CareSource to manage the Ohio Home Care Waiver program in the state of Ohio.

CareSource is partnering with the Area Agency on Aging 3 to deliver the Ohio Home Care Waiver program in your area. The Area Agency on Aging 3 has many years of experience coordinating care and providing access and referrals to community resources.

CareSource, in partnership with the Area Agency on Aging 3, will provide Care Management for individuals that are determined to be eligible for the Ohio Home Care Waiver program. Along with a team of the enrolled individual's choosing, the assigned Care Manager will work with the enrolled individual to address their home and community-based needs and develop a person-centered care plan to meet the individual's specific needs.

Although Caresource is managing the Ohio Home Care Waiver Program, this does not mean that you have Caresource insurance for your Medicaid benefits.

Wondering what the Area Agency on Aging 3 does?

OUR MISSION:

To provide life-span resources that
INSPIRE, EDUCATE & EMPOWER
older adults, persons with disabilities and family caregivers.

We are your Aging and Disability Resource Center.

We are here to serve you!

Serving the residents of Allen, Auglaize, Butler, Champaign, Clark, Clinton, Darke, Greene, Hancock, Hardin, Logan, Mercer, Miami, Montgomery, Preble, Putnam, Shelby, Van Wert, and Warren Counties.





We are your **senior resource connection**
 In Allen, Auglaize, Butler, Champaign, Clark, Clinton, Darke, Greene,
 Hancock, Hardin, Logan, Mercer, Miami, Montgomery, Preble,
 Putnam, Shelby, Van Wert, and Warren Counties

NOTICE OF PRIVACY PRACTICES EFFECTIVE 4/8/2022

"This notice describes how medical information about you may be used and disclosed and how you can get access to this information. Please review it carefully"

1. The Agency on Aging 3 is required by Federal law to maintain the privacy of any health care information it receives and must provide individuals with notice of its legal duties and privacy practices relating to such information.
2. The medical information received from you will be utilized by Agency on Aging 3 in disclosing to other agencies or providers in order to provide health care services and alternatives to you.
 - a. For example, Agency on Aging 3 will disclose your information to health care providers and home health agencies for the purpose of arranging health care services and/or services for you which are needed based upon your assessment.
3. Your information may be disclosed without your written consent only if you have been informed in advance of the use or disclosure and you have had the opportunity to agree to the disclosure or to prohibit or restrict the disclosure.
4. Any other uses or disclosures of information will be made only with your written authorization, which may be revoked by you.
5. Regarding any information or disclosures about you, you have the right to:
 - a. Request restrictions on the information or disclosure;
 - b. Received confidential communication of protected health care information;
 - c. Inspect and copy health care information about you;
 - d. Amend information about you; and
 - e. Receive an accounting of the different disclosures of your health care information.
6. Agency on Aging 3 is required by Ohio law to only disclose a consumer's information if all the following requirements have been met:
 - a. The consumer has given consent through a written release of information;
 - b. The release of information must be directly for the purpose of administration of a program; and
 - c. The individual or agency receiving the information is subject to the same or similar confidentiality standards as Agency on Aging 3.

A United Way funded agency. A funding agency of the Ohio Department of Aging.

2423 Allentown Road. • Lima, Ohio • 45805 • 419-222-7723 • 1-800-653-7723 • Fax: 419-222-6212 • www.aaa3.org

Updated: August 1, 2021



Department of
Medicaid

Ohio Home Care Waiver Handbook

A resource guide for Ohioans enrolled on the
Ohio Home Care Waiver



Updated: August 1, 2021

**Fill out the information below.
Keep it on hand for easy access.**

Case Managers: Please help with filling in the blanks or attach your card to this page.

Caresource has contracted with Area Agency on Aging 3 to be your Care Manager

My Case Management Agency

1-844-777-6429

24- Hour Toll-Free Phone Number

My Case Manager's Name and Phone Number

Managed Care Plan (MCP) (if applicable)

MCP Care Manager and Phone Number (if applicable)

**Medicaid Consumer Hotline:
1 (800) 324-8680**

Updated: August 1, 2021

How to use this Handbook

This handbook provides important information about the Ohio Home Care Waiver (OHCW). The information in the handbook should help answer basic questions you have. If you cannot find answers to your questions in this handbook, contact your case manager who is available to assist you. You will receive a new copy of this document each year during your annual assessment.

This handbook is prepared by:
The Ohio Department of Medicaid (ODM)
Bureau of Clinical Operations
Care Coordination Team

For more information, contact the
Medicaid Consumer Hotline:
1 (800) 324-8680

Introduction

The Ohio Home Care Waiver (OHCW) is a home and community-based waiver program administered by the Ohio Department of Medicaid. This waiver provides certain services that allow you to receive supports outside of a hospital or nursing facility.

Ohio Home Care Waiver Services:

- Adult Day Health Services
- Community Integration Service
- Community Transition Service
- Personal Emergency Response System
- Home Care Attendant
- Home Delivered Meals
- Home Maintenance and Chore Service
- Home Modification Service
- Out-of-Home Respite
- Personal Care Aide
- Supplemental Adaptive and Assistive Devices
- Supplemental Transportation Services
- Waiver Nursing

Updated: August 1, 2021

Your Rights

As an individual enrolled on the Ohio Home Care Waiver, you have the right to:

- Be fully informed of all your rights, responsibilities, and what it means to be on a waiver
- Be treated with dignity and respect
- Receive assistance from your case manager (CM)
 - » What is a case manager? A person assigned to you to help with coordinating services that meet your needs.
- Have private meetings with your case manager
- Be protected from abuse, neglect and mistreatment
- Receive information that is timely, accurate and easy to understand
- Choose Medicaid-approved providers who will provide safe, appropriate and high-quality services
- Control how your services are delivered
- Speak in confidence with your case manager and know that your information will be kept confidential
- Participate in the development of your Person-Centered Services Plan
- Request a state hearing to appeal any decisions made by your case management agency (CMA) or the Ohio Department of Medicaid about your waiver eligibility or benefits

Updated: August 1, 2021

- See any files or records related to your health care
- Be informed about how to report concerns with your case manager, services or providers to the Ohio Department of Medicaid

You and your authorized representative (if applicable) direct your waiver services.

- What is an authorized representative? An authorized representative is a person age 18 or older whom you have authorized in writing to make decisions on your behalf about your Ohio Home Care Waiver services.

Your Responsibilities

As an individual enrolled on the Ohio Home Care Waiver, you are responsible for:

- Communicating openly and honestly with your case manager, providers, and other members of your care team
- Providing accurate and complete information, including your medical history
- Actively participating in your service planning and implementation
- Keeping scheduled appointments
- Reporting problems, concerns, changes or incidents to your case manager

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- Informing your case manager if you want or need to change services or providers
- Respecting the rights of your providers
- Working with your care team to resolve problems or concerns
- Refusing to participate in dishonest or illegal activities involving your providers, caregivers or members of your care team.

A complete list of your rights and responsibilities is in the Ohio Administrative Code at codes.ohio.gov/oac/5160-45-03 or request a printed copy from your case manager.

Case Management

All individuals enrolled on the Ohio Medicaid Home Care Waiver receive case management services.

Case management connects you to services and supports that help you get the care you need in an environment where you can be the most independent.

Case management activities include:

- Monitoring your health and welfare
- Periodically assessing your needs, service goals and objectives
- Annually assessing your waiver program eligibility

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- Coordinating meetings with you and your care team
- Authorizing waiver services that meet your needs
- Providing referrals and connecting you to services and providers
- Monitoring the delivery of all services identified in your person-centered service plan
- Transition planning for significant changes, including those changes that occur prior to enrollment on the waiver program, and at significant life milestones such as entering/exiting school or work
- Educating you on how to identify and report incidents, and working with you to develop prevention plans to reduce risks
- Assisting you to develop a meaningful backup plan in the event your provider is unable to or does not show up for work
 - » What is a backup plan? This plan includes one or more people who are able to meet your needs and respond immediately if your regularly scheduled provider is unable to work his or her shift(s).

Updated: August 1, 2021

Changing your case manager or your case management agency:

You may request a change in your case manager or case management agency. If you would like to change your case manager within your current case management agency, please contact your CMA directly. If you would like to change your case management agency (CMA) please submit a brief synopsis of the reason, along with your change request to ODM. These changes are approved on a case-by-case basis. The Department of Medicaid will notify you of whether your request has been approved or declined.

To request a change, submit your request in one of the following ways:

- Send an e-mail: caremanagement@medicaid.ohio.gov
- Send a fax: 614-466-6945
- Mail your request to:
Ohio Department of Medicaid
Bureau of Clinical Operations
Attn: CMA Change
P.O. Box 43214
Columbus, OH 43215

Reporting Incidents

Be sure to report any incidents:

An incident is any event that is inconsistent with your routine care and is harmful or potentially harmful to you. You or a member of your care team should notify your case manager within 24 hours of an incident.

The Ohio Department of Medicaid, its case management agencies, and its provider oversight agency perform activities to make sure that you are protected from harm.

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Incident investigation and follow up includes:

- Making sure you are healthy and safe, and medical attention is sought as needed
- Taking steps to prevent incidents from reoccurring
- Identifying patterns to determine whether you or your providers could benefit from safety education
- Confirming you have the necessary services to remain healthy and safe
- Making sure providers know how to keep you safe and cause no harm
- Educating you on how to report incidents when they occur

Person-Centered Service Plan (PCSP)

Your person-centered service plan (PCSP) is a written outline of your waiver services, other Medicaid services, and all other services (paid and unpaid) needed to keep you safely in your home.

The plan identifies goals and outcomes related to your health and the treatments and services you receive.

How is your plan developed?

Your case manager works with you and your care team to develop a person-centered service plan.

Care team members include your natural supports, an authorized representative (if applicable), providers, your physician, and any others who you would like to include who are involved in your care.

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Your case manager will also:

- Document communication records and/or team meeting minutes in the planning process
- Authorize and assist with arranging services with your service providers and other caregivers
- Ensure the plan details the amount, frequency, scope, and duration of your services
- Assist with identifying and contacting all providers and agencies that are involved in your care
- Schedule meetings, disseminate important information, complete plan updates, maintain documentation, and facilitate collaboration among team members

The person-centered service plan will be updated as often as necessary to continue to reflect your needs.

Your person-centered service plan will address all the following:

- Your care, including your medical and personal care needs
- Your strengths
- Identified goals and desired outcomes
- The setting where you choose to receive your care
- Upkeep of your home environment, including adaptations as applicable

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- How you will access your community, including transportation
- Physical, mental, and behavioral health needs, including any applicable interventions
- School, work, or other day activities
- Medication procurement and management
- Medical and personal care supplies, including equipment
- Backup and emergency plans
- Case management services

Your Providers

You have the right to choose your Medicaid state plan and waiver service providers. The case management agency is responsible for ensuring you are able to choose your providers and assisting you in making a choice, if necessary.

You may choose agency-based providers and/or non-agency providers (NAP).

Find a Provider:

Go online: myohiohcp.org

Call the Medicaid Consumer Hotline: 1 (800) 324-8680

Ohio Department of Job and Family Services
EXPLANATION OF STATE HEARING PROCEDURES

What is a State Hearing?

If you think there has been a mistake or delay on your case, you may want to ask for a state hearing. You can ask for a hearing about actions by either the state department of job and family services or the local agency. Local agencies include the County Department of Job and Family Services (CDJFS), the County Child Support Enforcement Agency (CSEA), and agencies under contract with them.

A state hearing is a meeting with you, someone from the local agency, and a hearing officer from the Ohio Department of Job and Family Services (ODJFS). The person from the local agency will explain the action it has taken or wants to take on your case. Then, you will have a chance to tell why you think the action is wrong. The hearing officer will listen to you and to the local agency, and may ask questions to help bring out all the facts. The hearing officer will review the facts presented at the hearing and recommend a decision based on whether or not the rules were correctly applied in your case.

How to Ask for a Hearing

To ask for a hearing, call or write your local agency or write to the Ohio Department of Job and Family Services, Bureau of State Hearings, PO Box 182825, Columbus, Ohio 43218-2825. If you receive a notice denying, reducing or stopping your assistance or services, you will receive a state hearing request form. Fill out the request form and mail it to State Hearings. You may also fax your hearing request to State Hearings at (614) 728-9574.

We must receive your hearing request within 90 days of the mailing date of the notice of action. However, if you receive food assistance, you may request a hearing on the amount of your food assistance at any time during your certification period.

If someone else makes a written request for you, it must include a written statement, signed by you, telling us that person is your representative. Only you can make a request by telephone.

How to Request a Telephone Hearing

If you cannot attend the hearing at the scheduled location as a result of not having transportation, child care, medical limitations, etc., you can call 1-866-635-3748 and choose to participate by telephone. If you participate by telephone, the hearing officer assigned to your appeal will call you on the day of your hearing at the scheduled time for your hearing at the telephone number you provide.

Continuing Assistance or Services

If you receive a notice that your assistance or services will be reduced, stopped, or restricted, you must request a state hearing within 15 days of receiving that notice in order to continue receiving your benefits until your hearing decision is issued.

In the food assistance program, your benefits will not continue if you were denied or if the certification period has expired. After the certification period, you must reapply and be found eligible.

If your assistance or services have been changed without written notice, or if the change was made even though you requested a timely hearing, you can call the Bureau of State Hearings, to inquire if you should receive continuing benefits. Call us, toll free at the following number: 1-866-635-3748, and choose option number one from the automated voice menu.

If your assistance is continuing and you lose the hearing, you may have to pay back any benefits that you were not eligible to receive.

The continuing assistance provisions described in this section do not apply to the child support program. If you request a hearing about child support services, your hearing request will have no effect on your receipt of services while your hearing is pending.

County Conference

An informal meeting with a person from the local agency may settle the issue without the need for a state hearing.

Often this is the quickest way to solve a problem. At this meeting your case will be reviewed with you. If a mistake has been made, it can be corrected without the need for a state hearing. You can set up a county conference by asking your county worker. If you are not satisfied with the results, you can still have a state hearing.

You do not have to have a county conference to have a state hearing. Asking for a county conference will not delay your state hearing.

When Will the Hearing be Held?

After your request for a hearing is received, the Bureau of State Hearings will send you a scheduling notice giving the date, time and place of the hearing. This notice will be sent to you at least 10 days before the hearing. The notice will also tell you what to do if you cannot come to the hearing as scheduled.

Where are Hearings Held?

Hearings are usually held at the local agency. If you are unable to go there, the hearing may be held some other place that is convenient to you and to the other people involved. If you want the hearing held somewhere other than the local agency, be sure to tell us that in your hearing request.

Postponement of the Hearing

If you cannot come to the hearing as scheduled, or if you need more time to prepare, you can ask the hearings section for a postponement. In the food assistance program, postponement is limited to 30 days from the date of the first scheduled hearing. In all other programs, you must have a good reason to postpone the hearing.

If You Do Not Attend the Hearing

The Bureau of State Hearings will send you a dismissal notice if you do not come to the hearing. If you want to continue with your hearing request, you must contact State Hearings within 10 days and explain why you did not come to the hearing along with any verification. Verifications are documents or papers that prove why you missed your scheduled hearing. Once you have submitted your good cause verification, the hearing authority will decide if the documentation you provide is sufficient. If you do not call within 10 days and show good cause or proof for missing the hearing, it will be dismissed and you will lose the hearing. The local agency can then go ahead with the action it was planning to take.

If you disagree with the dismissal, the dismissal notice will tell you how to ask for an administrative appeal.

Before the Hearing

You may have someone (lawyer, welfare rights person, friend or relative) go to the hearing to present your case for you. If you are not going to be at the hearing, the person attending for you must bring a written statement from you saying he or she is your representative.

If you want legal help at the hearing, you must make arrangements before the hearing. Contact your local legal aid program to see if you qualify for free help.

If you do not know how to reach your local aid office, call 866-529-6446 (866-LAW-OHIO), toll-free, for the local number or search the Legal Aid directory at <http://www.ohiolegalservices.org/programs>. If you want notice of the hearing sent to your lawyer, you must give the Bureau of State Hearings your lawyer's name and address.

You and your representative have the right to look at your case file and the written rules being applied to your case. If your hearing is about work registration or employment and training, you may also look at your employment and training file. You can get a free copy of any case record documents that are related to your hearing request. Any person acting for you must provide a signed statement from you before looking at your case record or receiving copies of case record documents.

The local agency does not have to show you confidential records, such as names of people who have given information against you, records of criminal proceedings, and certain medical records.

Confidential records which you could not look at or question cannot be presented at the hearing or be used by the hearing officer in reaching a decision.

Subpoena

You can ask the hearing authority to subpoena documents or witnesses that would not otherwise be available and are essential to your case. You must request the subpoena at least five calendar days before the date of the hearing and provide the name and the address of the person or document you want to subpoena.

At the Hearing

You may bring witnesses, friends, relatives, or your lawyer to help you present your case. The hearing officer may limit the number of witnesses allowed in the hearing at any one time if there is not enough room. You and your representative will have the right to look at the evidence used at the hearing, present your side of the case without undue interference, ask questions, and bring papers or other evidence to support your case.

The hearing will be recorded by the hearing officer so that the facts are taken down correctly. After the hearing decision is issued, you can get a free copy of the recording by contacting the Bureau of State Hearings.

The hearing officer will listen to both sides but will not make a decision at the hearing. Instead, you will receive a written decision in the mail issued by the hearing authority.

Group Hearings

The Bureau of State Hearings may combine several individual hearing requests into a single group hearing, but only if there is no disagreement about the facts of each case and all involve related issues of state or federal law or county policy. The notice to schedule your hearing will tell you if you are scheduled for a group hearing.

You and your representative will be allowed to present your own case individually and you will have the same rights at a group hearing as you would at an individual hearing.

After the Hearing

You should receive a hearing decision within 60 days of your hearing request if the hearing was only about food assistance, and within 90 days for all other programs.

If you disagree with the hearing decision, your written decision will tell you how to ask for an administrative appeal.

Compliance with the Hearing Decision

If the hearing decision orders an increase in your food assistance, you should get the increase about 10 days from the decision date. If the decision orders a decrease in your food assistance, you should get the new, smaller amount the next time you regularly get food assistance.

In all other programs, the agency must take the action ordered by the decision within 15 days of the date the decision is issued, but always within 90 days of your hearing request. Contact the Bureau of State Hearings if you have not promptly received the benefits awarded by the hearing decision.

Another Action Requires Another Hearing

If you receive another prior notice that says the local agency wants to change your assistance or services while you are waiting for a hearing or hearing decision, you must ask for another hearing if you disagree with the new action. A separate hearing will be conducted on the new notice.



U.S. DEPARTMENT
OF HEALTH AND
HUMAN SERVICES



National Institute
on Aging

Advance Care Planning *Tips from the National Institute on Aging*

Advance care planning is not just about old age. At any age, a medical crisis could leave you too ill to make your own healthcare decisions. Even if you are not sick now, planning for health care in the future is an important step toward making sure you get the medical care you would want, if you are unable to speak for yourself and doctors and family members are making the decisions for you.

Many Americans face questions about medical treatment but may not be capable of making those decisions, for example, in an emergency or at the end of life. This tip sheet will explain the types of decisions that may need to be made in such cases and questions you can think about now so you're prepared later. It can help you think about who you would want to make decisions for you if you can't make them yourself. It will also discuss ways you can share your wishes with others. Knowing who you want to make decisions on your behalf and how you would decide might take some of the burden off family and friends.

What Is Advance Care Planning?

Advance care planning involves learning about the types of decisions that might need to be made, considering those decisions ahead of time, and then letting others know—both your family and your healthcare providers—about your preferences. These preferences are often

put into an *advance directive*, a legal document that goes into effect only if you are incapacitated and unable to speak for yourself. This could be the result of disease or severe injury—no matter how old you are. It helps others know what type of medical care you want.

An advance directive also allows you to express your values and desires related to end-of-life care. You might think of it as a living document—one that you can adjust as your situation changes because of new information or a change in your health.

Research shows that advance directives can make a difference, and that people who document their preferences in this way are more likely to get the care they prefer at the end of life than people who do not.

Decisions That Could Come Up

Sometimes decisions must be made about the use of emergency treatments to keep you alive. Doctors can use several artificial or mechanical ways to try to do this. Decisions that might come up at this time relate to:

- CPR (cardiopulmonary resuscitation)
- Ventilator use
- Artificial nutrition (tube feeding) and artificial hydration (IV, or intravenous, fluids)
- Comfort care

ADVANCE CARE PLANNING

CPR. Cardiopulmonary resuscitation might restore your heartbeat if your heart stops or is in a life-threatening abnormal rhythm. It involves repeatedly pushing on the chest with force, while putting air into the lungs. This force has to be quite strong, and sometimes ribs are broken or a lung collapses. Electric shocks, known as defibrillation, and medicines might also be used as part of the process. The heart of a young, otherwise healthy person might resume beating normally after CPR. Often, CPR does not succeed in older adults who have multiple chronic illnesses or who are already frail.

Ventilator use. Ventilators are machines that help you breathe. A tube connected to the ventilator is put through the throat into the trachea (windpipe) so the machine can force air into the lungs. Putting the tube down the throat is called intubation. Because the tube is uncomfortable, medicines are often used to keep you sedated while on a ventilator. If you are expected to remain on a ventilator for a long time, a doctor may perform a tracheotomy or “trach” (rhymes with “make”). During this bedside surgery, the tube is inserted directly into the trachea through a hole in the neck. For long-term help with breathing, a trach is more comfortable, and sedation is not needed. People using such a breathing tube are not able to speak without special help because exhaled air does not go past their vocal cords.

Artificial nutrition and hydration. If you are not able to eat, you may be fed through a feeding tube that is threaded through the nose down to your stomach. If tube feeding is still needed for an extended period, a feeding tube may be surgically inserted directly into your stomach. Hand feeding (sometimes called assisted oral feeding) is an alternative to tube feeding. This approach may have fewer risks, especially for people with dementia.

If you are not able to drink, you may be provided with IV fluids. These are delivered through a thin plastic tube inserted into a vein.

Artificial nutrition and hydration can be helpful if you are recovering from an illness. However, studies have shown that artificial nutrition toward the end of life does not meaningfully prolong life. Artificial nutrition and hydration may also be harmful if the dying body cannot use the nutrition properly.

Comfort care. Comfort care is anything that can be done to soothe you and relieve suffering while staying in line with your wishes. Comfort care includes managing shortness of breath; limiting medical testing; providing spiritual and emotional counseling; and giving medication for pain, anxiety, nausea, or constipation.

Getting Started

Start by thinking about what kind of treatment you do or do not want in a medical emergency. It might help to talk with your doctor about how your current health conditions might influence your health in the future. For example, what decisions would you or your family face if your high blood pressure leads to a stroke? You can ask your doctor to help you understand and think through your choices before you put them in writing. Medicare or private health insurance may cover advance care planning discussions with your doctor.

If you don't have any medical issues now, your family medical history might be a clue to help you think about the future. Talk with your doctor about decisions that might come up if you develop health problems similar to those of other family members.

In considering treatment decisions, your personal values are key. Is your main desire to have the most days of life? Or, would your focus be on quality of life, as you see it?

What Is Palliative Care? What Is Hospice Care?

Palliative care treats the symptoms of a serious illness, such as pain and discomfort. It is offered alongside medical treatment for the illness itself (for example, chemotherapy for cancer or dialysis for kidney failure). In addition to helping with symptoms, palliative care can help patients understand their choices for medical treatment. The organized services available through palliative care may be helpful to any older person having a lot of general discomfort and disability with serious illness.

Hospice care is comfort care and support that is provided after attempts to cure or treat an illness have stopped. It may be offered in the home, a hospice facility, a skilled nursing facility, or a hospital. A team of healthcare providers works together to provide the care and support. The goal is to ensure the best quality of life in a patient's final days, weeks, or months. After death, the hospice team continues to offer support to the family.

Hospice and palliative care are not the same thing, but both have the same goal: to keep you comfortable. If you are receiving hospice care, you can choose to move back to curative care if you decide to pursue treatments to cure your illness.

For more information, see the NIA booklet *End of Life: Helping with Comfort and Care*.

What if an illness leaves you paralyzed or in a permanent coma and you need to be on a ventilator? Would you want that?

What makes life meaningful to you? If your heart stops or you have trouble breathing, would you want to undergo life-saving measures if it meant that, in the future, you could be well enough to spend time with your family? Would you be content if the emergency left you simply able to spend your days listening to books on tape or gazing out the window?

But, there are many other scenarios. Here are a few. What would you decide?

- If a stroke leaves you unable to move and then your heart stops, would you want CPR? What if you were also mentally impaired by a stroke—does your decision change?
- What if you are in pain at the end of life? Do you want medication to treat the pain, even if it will make you more drowsy and lethargic?

- What if you are permanently unconscious and then develop pneumonia? Would you want antibiotics and to be placed on a ventilator?

For some people, staying alive as long as medically possible, or long enough to see an important event like a grandchild's wedding, is the most important thing. An advance directive can help to make that possible. Others have a clear idea about when they would no longer want to prolong their life. An advance directive can help with that, too.

Your decisions about how to handle any of these situations could be different at age 40 than at age 85. Or, they could be different if you have an incurable condition as opposed to being generally healthy. An advance directive allows you to provide instructions for these types of situations and then to change the instructions as you get older or if your viewpoint changes.

Making Your Wishes Known

There are two main elements in an advance directive—a living will and a durable power of attorney for health care. There are also other documents that can supplement your advance directive. You can choose which documents to create, depending on how you want decisions to be made.

Living will. A living will is a written document that helps you tell doctors how you want to be treated if you are dying or permanently unconscious and cannot make your own decisions about emergency treatment. In a living will, you can say which of the procedures described above you would want, which ones you wouldn't want, and under which conditions each of your choices applies.

Durable power of attorney for health care.

A durable power of attorney for health care is a legal document naming a healthcare proxy, someone to make medical decisions for you at times when you are unable to do so. Your proxy, also known as a representative, surrogate, or agent, should be familiar with your values and wishes. This means that he or she will be able to decide as you would when treatment decisions need to be made. A proxy can be chosen in addition to or instead of a living will. Having a healthcare proxy helps you plan for situations that cannot be foreseen, like a serious auto accident.

Some people are reluctant to put specific health decisions in writing. For them, naming a healthcare proxy might be a good approach, especially if there is someone they feel comfortable talking with about their values and preferences. A named proxy can evaluate each situation or treatment option independently.

Other advance care planning documents.

You might also want to prepare documents to express your wishes about a single medical

issue or something not already covered in your advance directive. A living will usually covers only the specific life-sustaining treatments discussed earlier. You might want to give your healthcare proxy specific instructions about other issues, such as blood transfusion or kidney dialysis. This is especially important if your doctor suggests that, given your health condition, such treatments might be needed in the future.

Medical issues that might arise at the end of life include DNR orders, organ and tissue donation, and POLST or MOLST forms.

A *DNR (do not resuscitate) order* tells medical staff in a hospital or nursing facility that you do not want them to try to return your heart to a normal rhythm if it stops or is beating unsustainably using CPR or other life-support measures. Sometimes this document is referred to as a DNAR (do not attempt resuscitation) or an AND (allow natural death) order. Even though a living will might say CPR is not wanted, it is helpful to have a DNR order as part of your medical file if you go to a hospital. Posting a DNR next to your bed might avoid confusion in an emergency situation. Without a DNR order, medical staff will make every effort to restore your breathing and the normal rhythm of your heart.

A similar document, called a *DNI (do not intubate) order*, tells medical staff in a hospital or nursing facility that you do not want to be put on a breathing machine.

A *non-hospital DNR* order will alert emergency medical personnel to your wishes regarding measures to restore your heartbeat or breathing if you are not in the hospital.

Organ and tissue donation allows organs or body parts from a generally healthy person who has died to be transplanted into people who need them. Commonly, the heart, lungs,

pancreas, kidneys, corneas, liver, and skin are donated. There is no age limit for organ and tissue donation. You can carry a donation card in your wallet. Some states allow you to add this decision to your driver's license. Some people also include organ donation in their advance care planning documents.

At the time of death, family members may be asked about organ donation. If those close to you, especially your proxy, know how you feel about organ donation, they will be ready to respond. There is no cost to the donor's family for this gift of life. If the person has requested a DNR order but wants to donate organs, he or she might have to indicate that the desire to donate supersedes the DNR. That is because it might be necessary to use machines to keep the heart beating until the medical staff is ready to remove the donated organs. See *For More Information* for resources about organ and tissue donation.

POLST and MOLST forms provide guidance about your medical care preferences in the form of a doctor's orders. Typically, you create a POLST (Physician Orders for Life-Sustaining Treatment) or MOLST (Medical Orders for Life-Sustaining Treatment) when you are near the end of life or critically ill and know the specific decisions that might need to be made on your behalf. These forms serve as a medical order in addition to your advance directive. They make it possible for you to provide guidance that healthcare professionals can act on immediately in an emergency.

A number of states use POLST and MOLST forms, which are filled out by your doctor or sometimes by a nurse practitioner or physician's assistant. The doctor fills out a POLST or MOLST after discussing your wishes with you and your family. Once signed by your doctor, this form has the same authority as any other medical order. Check with your state department of health to find out if these forms are available where you live.

What About Pacemakers and ICDs?

Some people have pacemakers to help their hearts beat regularly. If you have one and are near death, it may not necessarily keep you alive. But, you might have an ICD (implantable cardioverter-defibrillator) placed under your skin to shock your heart back into regular beatings if the rhythm becomes irregular. If you decline other life-sustaining measures, the ICD may be turned off. You need to state in your advance directive what you want done if the doctor suggests it is time to turn it off.

Selecting Your Healthcare Proxy

If you decide to choose a proxy, think about people you know who share your views and values about life and medical decisions. Your proxy might be a family member, a friend, your lawyer, or someone in your social or spiritual community. It's a good idea to also name an alternate proxy. It is especially important to have a detailed living will if you choose not to name a proxy.

You can decide how much authority your proxy has over your medical care—whether he or she is entitled to make a wide range of decisions or only a few specific ones. Try not to include guidelines that make it impossible for the proxy to fulfill his or her duties. For example, it's probably not unusual for someone to say in conversation, "I don't want to go to a nursing home," but think carefully about whether you want a restriction like that in your advance directive. Sometimes, for financial or medical reasons, that may be the best choice for you.

Of course, check with those you choose as your healthcare proxy and alternate before you name them officially. Make sure they are comfortable with this responsibility.

Making It Official

Once you have talked with your doctor and have an idea of the types of decisions that could come up in the future and whom you would like as a proxy, if you want one at all, the next step is to fill out the legal forms detailing your wishes. A lawyer can help but is not required. If you decide to use a lawyer, don't depend on him or her to help you understand different medical treatments. Start the planning process by talking with your doctor.

Many states have their own advance directive forms. Your local Area Agency on Aging can help you locate the right forms. You can find your area agency phone number by calling the Eldercare Locator toll-free at 1-800-677-1116 or going online at www.eldercare.gov.

Some states require your advance directive to be witnessed; a few require your signature to be notarized. A notary is a person licensed by the state to witness signatures. You might find a notary at your bank, post office, or local library, or call your insurance agent. Some notaries charge a fee.

Some states have registries that can store your advance directive for quick access by health-care providers, your proxy, and anyone else

to whom you have given permission. Private firms also will store your advance directive. There may be a fee for storing your form in a registry. If you store your advance directive in a registry and later make changes, you must replace the original with the updated version in the registry.

Some people spend a lot of time in more than one state—for example, visiting children and grandchildren. If that's your situation, consider preparing an advance directive using forms for each state—and keeping a copy in each place, too.

After You Set Up Your Advance Directive

Give copies of your advance directive to your healthcare proxy and alternate proxy. Give your doctor a copy for your medical records. Tell close family members and friends where you keep a copy. If you have to go to the hospital, give staff there a copy to include in your records. Because you might change your advance directive in the future, it's a good idea to keep track of who receives a copy.

Talking About Your Wishes

It can be helpful to have conversations with the people close to you about how you want to be cared for in a medical emergency or at the end of life. These talks can help you think through the wishes you want to put in your advance directive.

It's especially helpful to talk about your thoughts, beliefs, and values with your healthcare proxy. This will help prepare him or her to make medical decisions that best reflect your values.

After you have completed your advance directive, talk about your decisions with your healthcare proxy, loved ones, and your doctor to explain what you have decided. This way, they are not surprised by your wishes if there is an emergency.

Another way to convey your wishes is to make a video of yourself talking about them. This lets you express your wishes in your own words. Videos do not replace an advance directive, but they can be helpful for your healthcare proxy and your loved ones.

Review your advance care planning decisions from time to time—for example, every 10 years, if not more often. You might want to revise your preferences for care if your situation or your health changes. Or, you might want to make adjustments if you receive a serious diagnosis; if you get married, separated, or divorced; if your spouse dies; or if something happens to your proxy or alternate. If your preferences change, you will want to make sure your doctor, proxy, and family know about them.

Be Prepared

What happens if you have no advance directive or have made no plans and you become unable to speak for yourself? In such cases, the state where you live will assign someone to make medical decisions on your behalf. This will probably be your spouse, your parents if they are available, or your children if they are adults. If you have no family members, the state will choose someone to represent your best interests.

Always remember: an advance directive is only used if you are in danger of dying and need certain emergency or special measures to keep you alive, but you are not able to make those decisions on your own. An advance directive allows you to make your wishes about medical treatment known.

It is difficult to predict the future with certainty. You may never face a medical situation where you are unable to speak for yourself and make your wishes known. But having an advance directive may give you and those close to you some peace of mind.

Advance Directive Wallet Card

You might want to make a card to carry in your wallet indicating that you have an advance directive and where it is kept. Here is an example of a wallet card offered by the American Hospital Association. You might want to make a copy or cut this one out to fill out and carry with you. It can also be found online at www.aha.org/2017-12-11-put-it-writing.

Advance Directive NOTIFICATION

Print name _____ Signature _____

I have a health care power of attorney I have an advance directive

I have talked with my family and my doctor about the care I want. If I am unable to speak for myself, please contact:

Name _____ Number _____ (Additional names on back)

Name _____ Number _____

Name _____ Number _____

Name _____ Number _____

Your life. Your terms.

For more information visit:
www.aha.org/putitinwriting

ADVANCE CARE PLANNING

For More Information**Aging with Dignity**

1-850-681-2010

fivewishes@agingwithdignity.org

www.agingwithdignity.org**American Bar Association**

1-800-285-2221 (toll-free)

aging@americanbar.org

www.americanbar.org**CaringInfo****National Hospice and Palliative Care Organization**

1-800-658-8898 (toll-free)

caringinfo@nhpco.org

www.caringinfo.org**Center for Practical Bioethics**

1-800-344-3829 (toll-free)

center@centerforbioethics.org

www.practicalbioethics.org**Donate Life America**

1-804-377-3580

donatelifeamerica@donatelife.net

www.donatelife.net**The Living Bank**

1-800-528-2971 (toll-free)

info@livingbank.org

www.livingbank.org**National Academy of Elder Law Attorneys**

1-703-942-5711

naela@naela.org

www.naela.org**National POLST Paradigm**

1-202-780-8352

info@polst.org

www.polst.org**OrganDonor.gov****Health Resources & Services Administration**www.organdonor.gov**Put It In Writing****American Hospital Association**

1-800-424-4301 (toll-free)

www.aha.org/contactAHAwww.putitinwriting.org**For more information about health and aging, contact:**

National Institute on Aging Information Center

1-800-222-2225 (toll-free) • 1-800-222-4225 (TTY/toll-free)

niaic@nia.nih.gov • www.nia.nih.govVisit www.nia.nih.gov/health to find more health and aging information from NIA and subscribe to email alerts.Visit <https://order.nia.nih.gov> to order free print publications.

JANUARY 2018

NIH PUBLICATION NO. 18-AG-8039

TOLL FREE PHONE NUMBERS



Alzheimer's Helpline	1-800-272-3900
Eldercare Locator	1-800-677-1116
Provides information about service providers across the country	
Legal Aid of Western Ohio	419-724-0460 1-888-534-1432
Legal Hotline for Older Ohioans – Pro Seniors, Inc.	1-800-488-6070
Livanta	1-888-524-9900
Medicare Review organization helps with questions about quality of care, appeal of discharges, and complaints for those insured by Medicare	
Medicaid Consumer Hotline	1-800-324-8680
Medicare Hotline	1-800-633-4227
Medicare Part D.....	1-800-772-1213 1-800-MEDICARE
Nursing Home and Long Term Care Complaints	Local 1-844-853-3188 State 1-800-282-1206
(State and Regional Ombudsman Programs) Investigate and help resolve problems or those using long term care services, either in their own home or in a facility	
Ohio Attorney General	1-800-282-0515
Telemarketing fraud hotline, enforces laws in Ohio that protect consumers, senior resources	
Ohio Consumer's Counsel	1-877-742-5622
Handles complaints/concerns about utilities including electric, water, telephones and natural gas	
Ohio Department of Health	1-800-669-3534
Ohio Department of Insurance	1-800-686-1578
Info on all types of insurance; regulates insurance companies; operates Ohio Senior Health Insurance Information Program (OSHIIP)	
Some information available from the ODI:	
Ohio Shopper's Guide to Long Term Care Insurance	
Ohio Shopper's Guide to Medicare Supplement Insurance and HMO's	
Ohio Consumer's Guide to Health Insurance	
Social Security Administration	1-800-772-1213
Also can apply for Medicare Part D here	
Veteran's Administration (Federal and Ohio)	1-800-827-1000
Victim's Crime Compensation Program	1-800-582-2877
Offers compensation to victim's of crime to help pay legal fees, recoup costs	

Rev. 10/28/2020

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419.222.7723 • www.aaa3.org



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