



An information
resource guide to
end of life care



Preface

Intro/Background – Purpose

This consumer guide provides a variety of resources to help people who have a terminal illness. Some of these resources also provide help to family members, many of whom are primary caregivers who need information and professional support. The focus is on quality of care, improved pain management, maintaining dignity and preserving rights. We trust you will find these resources useful, caring and compassionate.

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Services

Providers

Regulation

- Michigan Department of Community Health
Bureau of Health Systems
<http://www.michigan.gov/mdch>
Lansing Information Line - (517) 373-1820
This component of State government is responsible for the licensing, regulation and investigation of all health care providers and facilities, including physicians, nursing homes, hospitals and hospices.

Hospice

- The Michigan Hospice and Palliative Care Organization
www.mihospice.org
1-800-536-6300
The Michigan Hospice and Palliative Care Organization publishes an extensive guide to available hospice care in Michigan. It is Free.
- The National Hospice Foundation
www.hospiceinfo.org
1-800-338-8619
A consumer brochure is available from the National Hospice Foundation
- The National Hospice and Palliative Care Organization
www.nhpco.org
Alexandria, VA Office – (703) 837-1500
A fantastic database is available online or they are available by phone to find the most appropriate hospice care available in any state.

This is a partial list of various web sites about Hospice Care. Nearly all of these provide additional links.

Hospice Care in General

- <http://www.geocities.com/Wellesley/3924/hospice.html>
- <http://www.cp-tel.net/pamnorth/hospice.htm> - *Pam's Hospice Page*

Alzheimer's disease specific

- <http://www.alzwell.com/>

Reflections Medical Links

- <http://www.geocities.com/HotSprings/Spa/2439/tygrscam.html>

Hospice and Palliative Care Resources

<http://wings.buffalo.edu/faculty/research/bioethics/hospice.html>

<http://www.hospicenet.org/>

Hospitals

- The Michigan Health and Hospital Association
www.mha.org
Lansing Office - (517) 323-3443
The Association represents most of Michigan's hospitals. They can put you in touch with the most appropriate one for your question or care.

Long Term Care / Nursing Homes

- Health Care Association of Michigan
www.hcam.org
Lansing Office – (517) 627-1561
HCAM represents for-profit nursing homes across the State of Michigan. They offer a wealth of information available as to end of life options.
- Michigan Association Homes and Services to the Aging
Lansing Office – (517) 323-3687
MAHSA represents not-for-profit nursing homes in the State of Michigan. They offer assistance in providing care and networking between facilities
- Michigan Department of Community Health – Bureau of Health Systems
<http://www.michigan.gov/mdch>
Lansing Information Line - (517) 373-1820
This group is responsible for the regulation and investigation of nursing homes and hospice providers.

Nurses

- Michigan Nurses Association
<http://www.minurses.org/>
1-800-832-2051
This organization is the largest in Michigan representing nurses, and can offer helpful information on many health-related topics.

Physicians

- Michigan State Medical Society
<http://www.msms.org>
Lansing office - (517) 337-1351
This professional organization represents primarily Michigan medical doctors (MDs) and offers information about health care in all specialties. Through their website and Lansing office, a great amount of useful information is available for end of life care. Some of their more helpful sites are:

MSMS Patient Education and Medical Links

<http://www.msms.org/biodefense/index.html>

MSMS on AIDS

<http://www.msms.org/peml/aids/aids.html>

MSMS on Physician-Assisted Living: Improving End-of-Life Care

<http://www.msms.org/peml/elc/elc.html>

MSMS on Organ Donation

<http://www.msms.org/peml/odon/odon.html>

MSMS link to Easing Cancer Pain: A CD-ROM for Cancer Patients

<http://www.msms.org/peml/cp/cp.html>

- Michigan Osteopathic Association
Lansing office – (517) 347-1555
<http://www.moa-do.com>
This professional organization represents primarily Michigan osteopathic doctors (DOs) in the State, and offers information about health care in all specialties. It also can refer to appropriate resources.

Home Health Agencies

- Michigan Home Health Association
2140 University Drive, Suite 220
Okemos, MI 48864
(517)-349-8089

Organ and Tissue Donation

- Gift of Life-Transplantation Society of Michigan
2203 Platt Road
Ann Arbor, MI 48104-9836
800-482-4881 to obtain more information or enroll with the donor registry
<http://www.tsm-giftoflife.org>

Michigan Public Sector Programs

Michigan Department of Community Health
320 S. Walnut Street, Lansing, MI 48913
General Information
<http://www.michigan.gov/mdch>

End of Life home web page

<http://www.michigan.gov/ltc/0,1607,7-148-7592---,00.htr>

Easing Cancer Pain: A CD-ROM for Cancer Patients

<http://commtechlab.msu.edu/sites/cancerpain/>



Local Health Departments

Funded primarily through the Michigan Department of Community Health (DCH), these entities offer a wide range of health and referral services to all residents. There are 45 departments that serve all 83 counties. The extent of services and information available for end of life planning, range from community resource directories, disease-specific support groups, physician referral, referral for health care services, and contacts for bereavement counseling.

- Local Health Departments
Michigan Department of Community Health
Lansing Information Line (517) 373-3740
http://www.michigan.gov/mdch/1,1607,7-132-2942_4910_4920-33583--,00.html
- Michigan Association for Local Public Health
<http://www.malph.org/>
Lansing Office (517) 485-0660

Community Mental Health Service Programs

Funded primarily through the Michigan Department of Community Health, these entities offer a wide range of mental health and substance abuse services to all residents. There are 49 community mental health agencies that serve all 83 counties. The extent of services and information available for end of life planning, range from emergency services, evaluations, telephone and on-site counseling, care management for caregivers and their families, in-home respite care, education programs for families and professionals, adult day care, speaker's bureaus, support and self-help groups, and referral.

- Michigan Department of Community Health
Mental Health and Substance Abuse
http://www.michigan.gov/mdch/0,1607,7-132-2941_4868---,00.html
The website provides many mental health resources, answers questions, and lists links from around the country for even more information. Mental health services are available to all in Michigan.

- Michigan Association of Community Mental Health Boards
Lansing office (517) 374-6848.
<http://www.macmhb.org>
This organization and its website provide information primarily for mental health professionals, but also lists all 49 CMH programs that serve all 83 counties in the State of Michigan and how to reach them. Or, call the office at the number above.

Area Agencies on Aging(AAA)

Funded primarily through the Michigan Office of Services to the Aging, these agencies offer a wide range of information and referral services to residents who are primarily age 60 and older. There are 16 agencies that serve all 83 counties. The extent of services and information available for end of life care planning, range from volunteer and bereavement programs, one-on-one support, disease specific support groups, meals-on-wheels, care management for caregivers and their families, to transportation and other supportive services. The AAAs also offer prescription drug financial assistance, food programs and end-of-life assistance. Services are provided primarily through service provider agencies that contract with the AAAs.

- Michigan Office of Services to the Aging
(517) 373-8230
<http://www.miseniors.net>
The Office of Services to the Aging (OSA) is designated as the State Unit on Aging for Michigan. The OSA has the responsibility of overseeing administration of Older Americans Act and Older Michiganians Act programs in Michigan. It provides oversight for the area agencies on aging (AAAs), sets policies for service delivery and, through its 15-member Commission on Aging, approves funds to the AAAs.
- Area Agency on Aging Region 1-C (West and Southern Wayne County)
<http://www.aaa1c.org/aaa.htm>
This site also includes a list of AAA's across the State of Michigan.

Support and Advocacy Groups

Many of the already-listed sources will have information on support groups, but there are some worth mentioning here.

General

- Michigan Association of Centers for Independent Living
<http://www.michigan.gov/mdcd>
East Lansing Office (517) 339-0539
- Citizens for Better Care
<http://www.cbcmi.org>
1-800-833-9548
Information and advocacy to enhance the self-determination and well-being of long term care consumers in Michigan

By Topic

Aging—Aging with Dignity—the Five Wishes Organization provides information on living wills and much more. Toll Free: (888) 5-WISHES

Alzheimers – call the National Alzheimer’s Association for the chapter nearest you.
1-800-337-3827

Internet-Based Sources

Aging
<http://www.agingwithdignity.org>

Cancer
<http://www.supportpath.com/>

General
<http://www.dying.about.com/health/dying/library/blsup.htm>
This site has information from an unbiased source with information about support groups, hospice, losing a loved one and much more

http://www.dmoz.org/Society/Support_Groups/Personal_Loss/
This site has an extensive list of support groups available on the internet.

<http://www.agingwithdignity.org/5wishes.html>

Many of the above groups such as the hospitals or doctors will have information on support groups.



How To Pay For Services

Public Assistance

Medicare

Medicare is a federal program that covers the majority of American citizens age 65 and over and those who have permanent kidney failure and certain people with disabilities with health care insurance. It is the nation's largest health insurance program, covering approximately 39 million Americans..

<http://www.medicare.gov/>

Most Americans are automatically enrolled with Medicare for the month they turn 65 years old. For many others, applications are handled by the federal Social Security Administration (SSA). 1-800-772-1213.

Michigan has many local Social Security Offices.

Medicare has Two Parts (more details in Appendix)

- Part A is called Hospital Insurance, and most people do not have to pay for Part A.
- Part B is called Medical Insurance, and most people pay monthly premiums for coverage under Part B.

Medicaid

Provides necessary health care services to low income and Social Security Income individuals and other low-income persons who are under age 21, pregnant, disabled, blind, or age 65 or older. An average of 1 million people in Michigan are eligible for Medicaid benefits. Medicaid eligibility is determined by the Family Independence Agency department, that has local offices covering all 83 counties in Michigan.

In Michigan, the Medicaid program is administered by the Department of Community Health (DCH), and is funded by both federal and state monies.

General Medicare Information

State Department of Insurance Office of Financial and Insurance Services

Can answer my questions about: Medigap policies available in my area, and insurance questions.

Toll-Free Phone **1-877-999-6442**

Local Phone **1-517-373-0240 (Lansing)**

Other Health Insurance Programs

Department of Defense

Can answer my questions about : Whether I qualify for military retiree health care benefits.

Toll-Free Phone **1-800-538-9552**

Department of Veterans Affairs

Can answer my questions about : VA medical benefits.

Toll-Free Phone **1-800-827-1000**

1-800-829-4833 TTY

Office of Personnel Management

Can answer my questions about : Claims and other issues for retired federal employees and their dependents/survivors.

Toll-Free Phone **1-888-767-6738**

1-800-878-5707 TTY

Local Phone **1-202-606-0500**

Quality of Care/Complaints

Accreditation Association for Ambulatory Health Care

Can answer my questions about : Finding out if urgent care centers and ambulatory surgical centers are accredited or not.

Local Phone **1-847-853-6060**

American Association for Accreditation of Ambulatory Surgical Facilities

Can answer my questions about : Finding out if an ambulatory surgical center is accredited or not.

Toll-Free Phone **1-888-545-5222**

Local Phone **1-847-949-6058**

American Board of Medical Specialties

Can answer my questions about : Finding out if a doctor is board certified.

Toll-Free Phone **1-866-275-2267**

American Hospital Association

Can answer my questions about : Finding a voluntary list of patients' rights in a hospital.

Toll-Free Phone **1-800-424-4301**

Local Phone **1-312-422-3000**

College of American Pathologists

Can answer my questions about : Finding out if the lab where your blood tests are sent is accredited or not.

Toll-Free Phone **1-800-323-4040**

Local Phone **1-847-832-7000**

1-847-832-7000 TTY

ESRD – End-Stage Renal Disease Networks End Stage Renal Disease Network #11

Can answer my questions about : Where to submit a complaint about the quality of care I received from my kidney dialysis facility.

Toll-Free Phone **1-800-973-3773**

Local Phone **1-651-644-9877**

ESRD State Survey Agency Michigan Department of Consumer & Industry Services, Bureau of Health Systems

Can answer my questions about : Complaints about the quality of care in dialysis facilities.

Local Phone **1-517-241-2626**

Joint Commission on Accreditation of Healthcare Organizations (JCAHO)

Can answer my questions about : Finding out if your health care organization is accredited or not.

Local Phone **1-630-792-5800**

Nursing Home State Survey Agency Department Of Consumer and Industry Services

Can answer my questions about : Where to submit a complaint about the quality of life or quality of care inside a nursing home.

Toll-Free Phone **1-800-882-6006 (In-State Calls Only)**

Local Phone **1-517-334-8408**

Office for Civil Rights

Can answer my questions about : Submitting a complaint about discrimination.

Toll-Free Phone **1-800-368-1019**

1-800-537-7697 TTY

Local Phone **1-312-886-2359**

1-312-353-5693 TTY

Michigan’s Long Term Care Ombudsman Citizens For Better Care

Can answer my questions about: Obtaining information on nursing homes or resolving problems between nursing homes and residents or their families.

Toll-Free Phone **1-866-485-9393 (In-State Calls Only)**

1-800-649-3777 TTY

Local Phone **1-517-347-7398**

PRO – Peer Review Organization Michigan Peer Review Organization, Inc.

Can answer my questions about : Complaints about quality of care, and filing an appeal or complaint.

Toll-Free Phone **1-800-365-5899**

Local Phone **1-734-459-0900**

General Health Information

Agency of Healthcare Research and Quality (AHRQ)

Can answer my questions about : Ordering brochures on "Choosing a Hospital, Choosing Treatments and Choosing a Hospital."

Toll-Free Phone **1-800-358-9295**

American Association of Kidney Patients

Can answer my questions about : Educational materials for people with kidney disease.

Toll-Free Phone **1-800-749-2257**

Local Number **1-813-636-8100**

American Cancer Society

Can answer my questions about : Finding information on cancer.

Toll-Free Phone **1-800-227-2345**

American Kidney Fund

Can answer my questions about : Financial assistance and educational materials for people with kidney disease.

Toll-Free Phone **1-800-638-8299**

Local Phone **1-301-881-3052**

Internal Revenue Service

Can answer my questions about : Obtaining materials/forms for income tax filing and how Medicare Savings Accounts can affect my income taxes.

Toll-Free Phone **1-800-829-1040**

1-800-829-4059 TTY

National Cancer Institute's Cancer Information Service

Can answer my questions about : Information on cancer treatments, clinical trials, alternative medicine, coping with side effects, and other cancer related information.

Toll-Free Phone **1-800-422-6237**

1-800-332-8615 TTY

National Institute on Aging Information Center

Can answer my questions about : Discussing health concerns, medicines, and other issues important to older people.

Toll-Free Phone **1-800-222-2225**

1-800-222-4225 TTY

National Kidney and Urologic Diseases Information

Can answer my questions about : Educational materials for people with kidney disease.

Toll-Free Phone **1-800-891-5390 Clearinghouse**

Local Phone **1-301-654-4415**

National Kidney Foundation, Inc.

Can answer my questions about : Support groups and educational materials for people with kidney disease.

Toll-Free Phone **1-800-622-9010**

Local Number **1-212-889-2210**

Billing Medicare/Fraud and Abuse

DHHS OIG – US Department of Health and Human Services Office of the Inspector General

Can answer my questions about : Reporting fraud and abuse.

Toll-Free Phone **1-800-447-8477**

1-800-377-4950 TTY

DMERC – Durable Medical Equipment Regional Carrier “Adminastar” Federal

Can answer my questions about : Bills for durable medical equipment and supplies used in the home, and can provide a list of approved suppliers of such equipment.

Toll-Free Phone **1-800-270-2313**

Local Phone **1-317-841-4677 TTY**

Medicare Fiscal Intermediary United Government Services

Can answer my questions about : Part A bills and services, hospital care, skilled nursing care, and fraud and abuse.

Toll-Free Phone 1-866-804-0686

Medicare Carrier Wisconsin Physicians Service

Can answer my questions about : Part B bills, services, and fraud and abuse.

Toll-Free Phone 1-800-482-4045

1-800-535-6152 TTY

Medicare Coordination of Benefits Contractor

Can answer my questions about : Medicare Secondary Payer, and who pays first if you have more health insurance than Medicare.

Toll-Free Phone 1-800-999-1118

1-800-318-8782 TTY

RHHI – Regional Home Health Intermediary United Government Services

Can answer my questions about : Home health, hospice care, and fraud and abuse.

Toll-Free Phone 1-800-531-9695

1-800-722-8140 TTY

Español Teléfono 1-800-213-1682

RRB Carrier – Railroad Retirement Board Carrier Palmetto Government Benefits Administrators (for RRB beneficiaries only)

Can answer my questions about : Part B bills and services.

Toll-Free Phone 1-800-833-4455

Health Care Facilities and Services in Michigan

American Self-Help Clearinghouse

Can answer my questions about: Finding specific health support groups in your area..

Toll-Free Phone 1-800-367-6274 (In-State Calls Only)

Local Phone 1-973-326-6789

Eldercare Location

Can answer my questions about:

Finding necessary and convenient services for the elderly in my community.

Toll-Free Phone 1-800-677-1116

Primary Care Association Michigan Primary Care Association

Can answer my questions about : Finding a Federally Qualified Health Center (FQHC) closest to me to help me lower my health care costs. FQHCs include community health centers, tribal health clinics, migrant health services, and health centers for the homeless.

Toll-Free Phone 1-800-752-7268

Local Phone 1-517-381-8000

State Hospice Organization Michigan Hospice and Palliative Care Organization

Can answer my questions about : Finding a local hospice program, cost, and use of hospice.

Toll-Free Phone 1-800-536-6300

Local Phone 1-517-886-6667

Health Care Decision–Making

- *“Planning for your Peace of Mind”*

Available from your State Representative or Senator

“Planning for your Peace of Mind” is a booklet, printed by the Legislative Service Bureau that can be very useful in organizing information. It includes facts and some limited advice about:

- Your Personal Records
- Medical and Prescription Records
- Michigan’s Statutory Will
- Advance Directive for Health Care
- Organ Donation

Find your State Senator

Contact the Secretary of the Senate Office

(517) 373-2400

www.senate.state.mi.us

The website allows you to search for your Representative by City, District Number or Name.

Find your State Representative

Contact the Clerk of the House of Representatives

(517) 373-0135

www.house.state.mi.us

The website allows you to search for your Representative by county or zip code.

- *The State Bar of Michigan*

<http://www.michbar.org>

Call Toll-Free - (800) 968-0738

The above toll free number will connect you to the Lawyer Referral Service. They can refer patients to attorneys in their area.

- *TheLAW.com*

<http://www.thelaw.com/>

Information on wills, trusts, and other useful end of life information

- *Health Law information*

<http://hippo.findlaw.com/>

Advance directives, diseases, fraud, insurance, many other topics

General Web Sites

Federal Government Sites

- Administration on Aging – U.S. Department of Health and Human Services
<http://www.aoa.dhhs.gov/aoa/>
Various links to government sites

Other Assorted Sites dealing with End of Life Care

- Growth House, Inc.
<http://www.growthhouse.org/>
Great site for information regarding end of life care and support
- Aging With Dignity
www.agingwithdignity.org
Look under 5 wishes
- AARP - Health Care
<http://www.aarp.com/healthguide/>
AARP, the nation's most accepted senior organization, offers insurance, healthcare and other senior related information.
- The Robert Wood Johnson Foundation
<http://www.rwjf.org>
- Last Acts Campaign to Improve End of Life Care
<http://www.lastacts.org/>
- Americans for Better Care of the Dying
<http://www.abcd-caring.org/>
Information available for those who care about end of life care and pain management – either for caregivers, or those at the end of life.
- Promoting Excellence in End of Life Care
<http://www.endoflifecare.org/>
A project of the Robert Wood Johnson Foundation

- National Program on Self Determination
<http://www.self-determination.org/>
A project of the Robert Wood Johnson Foundation meant to further self-determination of people with disabilities.
- Dying Well – Defining Wellness through the End of Life
<http://www.dyingwell.com/>
Information and personal stories all relating to end of life
- ElderHope, LLC
<http://www.elderhope.com/>
Assorted links regarding all facets of end of life care issues
- American Academy of Hospice and Palliative Care Medicine
<http://aahpm.org/>
Educational materials available for physicians
- Dr. Stall – Patients, Caregivers, and Health Care Professionals
<http://www.acsu.buffalo.edu/~drstall/>
Various links



Pain Related Websites

- Worldwide Congress on Pain
<http://www.pain.com/>
Many links to pain management related sites
- American Pain Society
<http://www.ampainsoc.org/>
Links related to pain management for sufferers and health professionals
- Department of Pain Medicine and Palliative Care – Beth Israel Med Center
<http://www.stoppain.org/>
More links for pain management for all involved in the process of treatment
- Pediatric Pain – Science Helping People
<http://is.dal.ca/~pedpain/pedpain.html>
Canadian website on pediatric pain management. This is rather general, but with links for health care professionals and self-help for families.

- The Mayday Pain Project
<http://www.painandhealth.org/>
 While a separate organization than the fund, below, this is an Upper Peninsula, MI group working towards the reduction of pain in pediatrics, cancer and chronic pain.



Loss Resources

- AARP – Coping with Grief and Loss
<http://www.aarp.org/griefandloss/>
 Grief and Loss resources for seniors
- GROWW – Grief Recovery Online for Widows and Widowers
<http://www.groww.org/>
 This is a rather extensive web site dedicated to offering widows and widowers a place to share grief and find information

Complaint and Appeal Resources

- Office of the Michigan Attorney General
 Health Care Fraud Division
 PO Box 30208
 Lansing, MI 48909
 1-800-242-2873
<http://www.michigan.gov/ag>
- Michigan Department of Consumer and Industry Services
 Office of Financial and Insurance Services
 P.O. Box 30220
 Lansing, MI 48909-7720
 Phone: (517) 373-0220
 Toll Free: 1-877-999-6442
 FAX: (517) 335-4978
- Michigan Long Term Care Ombudsman
 Can answer questions and assist in resolving problems related to nursing homes
<http://www.elderslaw.org>
 Toll-Free 1-866-485-9393

*Michigan Department
of Community Health*



MDCH is an Equal Opportunity Employer, Services and Programs Provider.
xxxx printed at xx cents each with a total cost of \$xxxx.