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.html

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 Michigianians 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  
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.

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<th>Phone Type</th>
<th>Phone Number</th>
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<tr>
<td>Toll-Free Phone</td>
<td>1-888-545-5222</td>
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<tr>
<td>Local Phone</td>
<td>1-847-949-6058</td>
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American Board of Medical Specialties

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

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<tr>
<td>Toll-Free Phone</td>
<td>1-866-275-2267</td>
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American Hospital Association

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

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<tr>
<td>Toll-Free Phone</td>
<td>1-800-424-4301</td>
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<tr>
<td>Local Phone</td>
<td>1-312-422-3000</td>
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College of American Pathologists

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

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<tr>
<td>Toll-Free Phone</td>
<td>1-800-323-4040</td>
</tr>
<tr>
<td>Local Phone</td>
<td>1-847-832-7000</td>
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<td></td>
<td>1-847-832-7000 TTY</td>
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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.

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<tr>
<td>Toll-Free Phone</td>
<td>1-800-973-3773</td>
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<tr>
<td>Local Phone</td>
<td>1-651-644-9877</td>
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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.

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<th>Phone Type</th>
<th>Phone Number</th>
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<tr>
<td>Local Phone</td>
<td>1-517-241-2626</td>
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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

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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

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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

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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

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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


*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

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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

**TTY**: 1-800-535-6152

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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

**TTY**: 1-800-318-8782

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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

**TTY**: 1-800-722-8140

**Español Teléfono**: 1-800-213-1682

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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 – wither 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