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Support Groups

ALS affects the entire family with changes that can be challenging, stressful and at times frightening. Talking about it sometimes helps, as does having useful information on what to expect and on managing symptoms. The support group is an essential tool in helping patients and their caregivers, families and friends live with ALS. If you are interested in starting a support group in your area please contact ALS of Michigan at (800)882-5764.

Phone-in-support group

Takes place each month. Contact ALS of Michigan for exact dates and times.

Ann Arbor

Day /Time:	Second Tuesday of each month 6:30 p.m.- 8:00 p.m.
Location:	Turner Senior Resource Center 2401 Plymouth Road, Ann Arbor

Lansing ALS Support Group

Day /Time:	Third Tuesday of each month 6:30 p.m.- 8:00 p.m.
Location:	Holt United Methodist Church 2321 N. Aurelius Rd. Holt, MI 48842

Southfield ALS Support Group

Day /Time:	First Monday of the Month (separate groups for patients and caregivers) 6:30 p.m.- 8:00 p.m.
Location:	ALS of Michigan, Inc. 24359 Northwestern Hwy. Suite 100 Southfield 48075



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St. Clair/Port Huron

Day /Time:	Second Monday of each month from 6:30 p.m. – 8:00 p.m.
Location:	Fellowship Baptist Church 5200 Park Rd. East China, MI 48054

Sterling Heights

Day /Time:	Second Thursday of each month from 7:00 p.m. – 8:30 p.m.
Location:	Utica United Methodist Church Sterling Heights, MI 48314

Waterford ALS Support Group

Day /Time:	Fourth Monday of each month from 6:30 p.m. – 8:00 p.m.
Location:	Central United Methodist Church 3882 Highland Rd, Waterford, MI 48328

To be added to the support group mailing list, please contact ALS of Michigan. If you need further information, please call the ALS office at (248) 354-6100 or (800) 882-5764



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Chat Rooms

ALS Alternative Medicine Yahoo! Club

<http://clubs.yahoo.com/clubs/alsalternativemedicine>

ALS Forums

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

Living-with-ALS Email Group

<http://health.groups.yahoo.com/group/living-with-als/>

Moms with ALS

<http://www.cafemom.com/group/momswithALS>

Muscular Dystrophy Association Chat Rooms

<http://www.mdausa.org/chat/calendar.html>

Patients Like Me

www.patientslikeme.com

Women with ALS

<http://health.groups.yahoo.com/group/womenwithals/>



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Loaner and Used Equipment

ALS of Michigan, Inc. offers a variety of used medical and assistive technology equipment at no charge to ALS patients on a loaner basis. If you have a need please contact us to see if we have equipment available for loan. If you have something that you no longer need please contact us to make a donation. Your donation will not only provide you with a tax deduction but will help provide needed equipment to someone who may be able to use it. Examples of equipment, which is needed or may be available are as follows:

- | | | |
|--------------------|-----------------------|---------------------|
| Canes | Communication Devices | Wheelchair Ramps |
| Manual Wheelchairs | Power Wheelchairs | Wheelchair Cushions |
| Bedside Tables | Transfer Boards | Walkers |
| Transfer Chairs | Recliner Lift Chairs | Hoyer Lifts |

Local City Services, Center for Independent Living, Churches, Senior Centers, or Local Fire Departments may offer a small equipment loan closet to their citizens. If you need help researching your area please contact an ALS of Michigan, Inc. patient services coordinator to assist you (800) 882-5764.

Disability Connection Jackson, Michigan Offers wheelchairs, walkers, commodes, canes, lifts to name a few. (517) 782-6054

Michigan Rehab Services assists those who continue to be employed and will help in obtaining needed equipment in order for a person to continue working. For more information, contact them at Main number for State of Michigan (800) 605-6722

The Muscular Dystrophy Association operates medical equipment loaner closets in Michigan. This program offers medical equipment, as available, for loan at no charge to registered ALS patients for as long a period as is needed. To find an MDA location near you please call (800) 572-1717.

Veteran’s Affairs will be able to assist in helping ALS Veterans obtain needed medical equipment. To find a VA facility near you, please call (800) 827-1000.

World Medical Relief-Detroit, Michigan Durable Medical Equipment Program. Through the DME program, low-income clients can obtain canes, walkers, hospital beds, over-the-bed tables, commodes, and tub benches. A doctor's prescription is needed to receive durable medical equipment. All items must be picked up from WMR's warehouse. A small handling fee is assessed. **Address:** 11745 Rosa Parks Blvd., Detroit, Michigan 48206-1270 U.S.A. **Phone:** (313) 866-5333 **Fax:** (313) 866-5588**Email:** info@worldmedicalrelief.org

**This is only a small collection of equipment loan closets-for additional information for your area please contact our office at 1-800-882-5764, a patient services person will be able to assist you.*



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Caregiver Information

National Organizations

National Caregiver Organizations

The Center for Family Caregivers

P.O. Box 224 Park Ridge IL 60068, (773) 334-5794

Web site: <http://www.caregiving.com>

Empowering Caregivers

Website: <http://www.care-givers.com/>

Family Caregiver Alliance

180 Montgomery Suite 1100, San Francisco, CA 94104, (800) 445-8106

Web site: www.caregiver.org , Email: Info@caregiver.org

National Alliance for Caregiving

4720 Montgomery Lane, Suite 642, Bethesda, MD 20814, (301) 718-8444,

Web site: <http://www.caregiving.org/>,

National Family Caregivers Association

10400 Conneticut Ave, Suite 500, Kensington, MD 20895-3944, (800) 896-3650

Web site: www.nfcacares.org, Email: thefamilycaregiving.org

Today's Caregiver Magazine & Caregiver.com Web Site

6365 Taft Street, Suite 3006, Hollywood, FL. 33024, (954) 893-0550

Web site: <http://www.caregiver.com/> Email: info@caregiver.com

Programs for Caregivers

Programs for Families-Compassion Partners

Provides free admission to many theme parks in Central Florida for individuals with a life threatening illness. Contact (407) 396-1114 for application information.

Share the Care Groups

Learn how to set up groups made up of family, friends, and the community to take care of someone with a disability based on the book “Share the Care” <http://www.sharethecare.org/>



Family Caregiving – Why Respite?

Being a family caregiver, while a fulfilling role can consume a great deal of physical, mental, and emotional energy. Consequently, respite care is very important because it gives family caregivers an opportunity to create a plan of care for themselves; something a caregiver often overlooks.

Respite care simply means an interval of rest or relief. Respite care gives you, the family caregiver, an opportunity to take a much-needed break from the daily care that you provide for your loved one. A period of respite may be a few hours or a few days at a time, depending on what is decided between you and the care recipient. There are a number of ways you can spend your “time off” during your respite. Here are just a few examples:

- Go to the movies
- Read a book at a nearby park
- Go on a short vacation
- Have someone else care for your loved one while you retreat to another part of the house and watch TV, read a book, or take a nap.
- Attend a caregiving support group
- Sit in the sun
- Take a walk
- Treat yourself to lunch at a restaurant with a friend
- Get a massage/facial/manicure...do something for you

It is important to have a plan for your own self care because doing so can enhance the quality of life for you and the quality of life of your loved one. The more relaxed and fulfilled you feel, the more easily you will be able to provide the necessary care to your loved one. It is also possible that your loved one will appreciate a respite from the normal routine of care as well!

The lack of a conscious plan of self-care can result in **caregiver burnout**. How do you know if you are burning out? Some symptoms of caregiver burnout are:

- Social withdrawal
- Exhaustion
- Inability to concentrate or relax
- Depression
- Inability to sleep
- Anxiety
- Irritability
- Forgetfulness
- Lack of appetite

Caregiver burnout makes the task of caregiving very difficult, if not impossible. It can lead to resentment on the part of the caregiver, and even illness. It is your responsibility as a caregiver to care for yourself as well as the person you are caring for.

Respite care is one tool you can use to help yourself avoid caregiver burnout. To begin taking advantage of the benefits of receiving a reprieve from the routine care you provide to you loved one, follow the three steps below:



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Step 1 – Are you a family caregiver?

The first step to receiving help is to identify whether or not you are a family caregiver. Not everyone considers the care they provide to their loved one as “caregiving”. However, you are indeed a family caregiver if you provide care to an ill family member such as assisting with areas of personal care, emotional support and companionship, finances, and maintaining the household.

Step 2 – Have you discussed your needs with your loved one?

It is important to communicate your needs and desires with your loved one, the person you are providing care for. If you believe that you might like to pursue respite care services, it is essential to discuss this with your loved one. In doing so, you may discover that your loved one is very supportive of the idea. You may also find that having such a conversation opens up doors for even more communication and intimacy.

Step 3 – How do you find out about respite services available to you?

Respite care can take different forms. **In-home respite care** usually involves a trained professional (often from a home health agency) who comes into the house to provide necessary care during a period of time when the caregiver is away. In some communities, there may be a church, volunteer agency or group that provides respite care by a volunteer. (The level of training the care provider should have will depend on the level of care needed by your loved one.)

Another way to partake in respite care services is through a facility or residence that employs trained health care staff on-site. This type of respite would allow your loved one to stay at such a residence on a short-term basis (as determined by you and your loved one) and entitle him or her to receive whatever cares he or she needs. This kind of service may be available through a local long-term care residence, hospital or assisted living facility.

A less formal way of receiving respite care assistance is by utilizing family and friends who are eager to be helpful. The next time a friend or family member asks you how they can help, consider responding by telling them that giving you a break for the day or an evening, or even for a few hours might be the nicest gift they can give you.

For additional information and tips on how to select a respite care provider, contact ALS of Michigan at (800) 882-5764.



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Respite Care Assistance Program

ALS of Michigan recognizes that the responsibility and strain of providing the care needed by PALS (patients with ALS) can result in emotional and physical deterioration or caregivers and the PALS. Providing respite (limited, intermittent relief) to caregivers living with and caring for PALS and to provide care to PALS who require care but do not have caretakers is the goal of this program. Please contact ALS of Michigan, Inc. for information about respite care services and availability.

How Do I Find Home Care Services

Before starting a search, determine the types of services you need. Do you need assistance around the home with meal preparation, light housekeeping, etc. or do you need personal care and skilled nursing care.

ALS of Michigan has a list of home health agencies which identifies the services each agency provides. ALS of Michigan always confirms Worker's Compensation and Employer's Liability coverage by agency prior to service being provided. In addition, The National Association for Home Care & Hospice (NAHC) web site offers a listing of home care providers at www.nahc.org. This locator service will identify agencies within your ZIP code boundaries, and it provides contact information.

Contact your state's departments of health, aging, and social services to obtain a list of licensed agencies. In addition, most state home care and hospice associations maintain directories of existing home care organizations and can identify an appropriate provider. You can locate home care and hospice state associations at www.nahc.org.

Medicare has a web site (Home Health Compare) that provides information about the home health agencies, including areas they serve and their quality of care compared to others in the state. The information is available at: <http://www.medicare.gov/hhcompare>

We have provided a list of agencies that are familiar with our Respite Care Program. In addition, home care providers are listed in the yellow pages under "home care," "hospice," or "nurses." You can also check with your local Area Agency on Aging or United Way for more agencies. Your place of worship also may have information about local home care providers.

How Do I Select the Right Home Care Provider?

Ask these questions:

- How long has this provider been serving the community?
- What kinds of services does the provider offer?
- What procedures does this provider have in place to handle emergencies?
- Does provider have an infection control policy in place?



- Are caregivers available 24 hours a day, 7 days a week?
- How does the provider select and supervise staff.
- Does the provider bill directly to third-party payers?
- Are references available?
- If this is a Medicare provider, how does its quality compare to others on the Medicare Home Health Compare web site?
- Does it protect its employees with written personnel policies?
- Will the same person be providing care? ALS of Michigan recommends at least two caregivers become familiar with case. This insures that someone familiar with case will be sent to home if another caregiver is ill or has an emergency.
- How does agency handle employee no shows?

MI Choice Waiver Program

MI Choice is a home and community-based program. Eligible adults must meet financial requirements and are approved medically appropriate for nursing home care to be a MI Choice participant. This program allows the individual to access services in the community along with receiving support in their own home or other residential setting. Each participant can obtain basic Medicaid-covered services and must receive one or more MI Choice Waiver services. The program includes prescreening, assessments, case management, direct purchase of services, and re-assessment contacts. MI Choice Waiver is a statewide program funded by the Michigan Department of Community Health (MDCH). Eligibility Requirements:

*Frail adults 65 years of age or older

*Persons who are physically disabled age 18 or older

Financial

To be financially eligible for MI Choice, participants must qualify for Medicaid using special income and asset rules. The income limit is 300% of Supplemental Security Income (SSI) allotment set by the federal government each year. Persons currently receiving SSI benefits or Medicaid services meet the program financial criteria.

- Participant's individual income up to \$2,022 per month for 2010. If the client has a spouse, the spouse's income is not computed in the qualifying amount.
- Allowable assets for an individual client are limited to \$2,000. If the client has a spouse living in the community, the federal Protected Spousal Asset guidelines are used.
- ***Amounts are subject to change.**



Medical

Medical status must meet the Michigan Medicaid nursing facility level of care determination criteria.

To apply for this program contact your local Area Agency on Aging (located in local resource section of this manual)

Hospice Information

What is Hospice?

Hospice care is a particular type of compassionate care that addresses all the needs of a person who becomes very ill – not just the immediate physical needs, but also the emotional, psychological, social and spiritual needs. In addition, hospice addresses the needs of the family and friends of the ill person to the greatest extent possible so that all concerned can maintain dignity and quality of life. An important part of hospice is that patients and families help decide what care is right for them. All patients have certain rights to care, which includes:

- Treatment related to the life-limiting illness that is included in the hospice plan of care, plus medical equipment and supplies, services, and coordination of care.
- Medications to control the pain and other symptoms of the life-limiting illness.
- Hospice inpatient care (both acute care and respite care) in a hospice facility.
- Home visits by hospice staff, plus skilled in-home nursing for crisis management.
- Consulting physician.
- Volunteer support.
- Bereavement follow-up.

Hospice is a choice, not a requirement. The patient may choose to withdraw from the hospice plan of care at any time to seek other medical treatments that may become available.

Hospice programs exist in every county in Michigan. Hospice workers and volunteers in all these locations are dedicated to providing care to the seriously ill in a manner that honors them and celebrates their lives.

To locate a hospice provider in your area, visit <http://www.mihospice.org>

How Do You Get Hospice Care?

Most patients admitted to a hospice program are referred by their physicians. Others come themselves or are referred by the hospital, a community agency or by a friend or relative. Family members may request counseling from the hospice care program even if the patient does not wish to



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be admitted to the program. If you are interested in learning about or getting hospice care talk to your physician or contact a hospice provider in your area.

How Much Does Hospice Cost?

Hospice care is covered by Medicare and/or Medicaid and private insurance. Patients may be asked to meet co-pay or other uncovered costs. However, no one will ever be turned down for financial reasons.

What Services does Hospice Provide?

Hospice works in conjunction with the patient's physician providing care under a plan of treatment designed by the team in conjunction with the patient and family. Hospice services offered and paid for by both Medicare and Medicaid:

- Physician services (both the hospice medical director and the patient's own physician for services related to the terminal illness).
- Nursing care.
- Medical equipment (designed to providing comfort to the patient).
- Medical supplies.
- Outpatient drugs for symptom management and pain relief.
- Short-term in-patient care, including hospitalization if needed and respite care.
- Home health aide and homemaker services.
- Physical, occupational, and other therapies.
- Medical social services.
- Spiritual counseling.
- Bereavement programs.
- Services by trained volunteers.
- Dietary and other counseling.
- Care of the body after death.

Is Hospice affiliated with any Religious Organization?

Hospice is not an off-shoot of any religion. While some churches and religions have started hospices (sometimes in connection with their hospitals), these hospices serve a broad community and do not require patients to adhere to any particular set of beliefs.

National Organization & Palliative Care Organization (NHPCO)

1700 Diagonal Road, Suite 625
Alexandria, Virginia 22314
703/837-1500 (phone)
703/837-1233 (fax)
800/658-8898
<http://www.nhpc.org>



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More Information

If interested in getting more information about Michigan hospice organizations please contact ALS of Michigan at (800) 882-5764 or The Michigan Hospice and Palliative Care Organization (800) 536-6300 Fax (517) 886-6737 6015 West St. Joseph Highway, Suite 104 Lansing Michigan 48917 www.mihospice.org.

Grief / Bereavement Groups

If you have lost a loved one, you may want to consider participating in one of the many free grief support groups offered. Groups are made up of caring people who know the pain and turmoil of grief. Most are led by a grief counselor. If you are in emotional pain because someone you love has died, please consider attending a meeting. The groups are generally ongoing and you are welcome to join them at any time and at any location. Dates and times can change without our knowledge; please use the contact phone number to confirm date and time before attending a group. Many hospice organizations offer support groups, below is a listing of a few that offer regular grief and loss support groups. You can also check your local church and synagogue for grief support groups.

To locate a hospice in your area go to <http://mihospice.org> or contact 1-800-536-6300

Angela Hospice

14100 Newburgh Rd, Livonia, MI 48154
(734) 464-7810

For more information, including dates and times, please call at (734) 464-7810 or visit Website: www.angelahospice.org

Hospice of Michigan

400 Mack Avenue
Detroit, MI 48201
(313) 578-5000 or (888) 247-5181
Website: www.hom.org

SandCastles-Henry Ford Hospital

A division of Hospices of Henry Ford, provides service for children (ages 3 to 18) who have experienced the death of someone close to them. By allowing children to express their grief in an understanding and accepting environment.
(313) 874-6881.