



24359 Northwestern Hwy. • Suite 100 • Southfield, Michigan • 48075
phone 800.882.5764 • *email* alsofmi@alsofmi.org • *website* www.alsofmi.org

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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. Led by professionals, support groups provide opportunities for group members to share their personal experiences and to learn more about living with ALS. They learn they are not alone nor without help or hope. Meetings are free and open to all patients and concerned others regardless of where treated. They occasionally offer speakers on relevant topics and are designed to share information as well as strategies for preserving the independence and quality of life of both ALS patients and their caregivers.

What is an ALS Support Group?

- IT IS sharing helpful hints in dealing with doctors, employers, friends, and relatives.
- IT IS sharing practical advice on day-to-day living with ALS.
- IT IS facilitators and participants who have genuine concern for others.
- IT IS a safe place to express oneself.
- IT IS families who just found out "they" have ALS and who want to know more.
- IT IS guest speakers, current research, diets, books, therapies and beliefs.
- IT IS individuals who share experiences about participating in clinical trials.
- IT IS sometimes about the tremendous stress put on relationships and families.
- IT IS a place where you can reach out and help others by sharing your experience.
- IT IS Where people who know what it is to live with ALS help those that don't.
- IT IS about hope and helping.

IT IS NOT Group Therapy. There is no psychological jargon or probing into one's personal life. You don't have to talk if you don't want to.

IT IS NOT going to enable you or your loved ones to breeze through the devastating experience of living with ALS. It will provide help and support.



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Support Group Meetings

No formal registration is required - you do not need to call ahead

Ann Arbor ALS Support Group

Day /Time:	Second Monday of each month from 6:30 p.m. – 8:00 p.m.
Location:	Turner Senior Resource Center 2401 Plymouth Rd Ann Arbor 48105
Phone:	Contact ALS of Michigan at (800) 882-5764

Jackson ALS Support Group

Day /Time:	Second Wednesday of each month from 6:30 pm to 8:00 pm
Location:	Jackson City Med Care Facility 524 Lansing Ave., Jackson, MI 49201
Phone:	Contact ALS of Michigan at (800) 882-5764

Lansing ALS Support Group

Day /Time:	3 rd Tuesday of each month 6:30 p.m.- 8:00 p.m.
Location:	Holt United Methodist Church 2321 N. Aurelius Rd. Holt, MI 48842
Phone:	Contact ALS of Michigan at (800) 882-5764

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
Phone:	Contact ALS of Michigan at (800) 882-5764



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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
Phone:	Contact ALS of Michigan at (800) 882-5764

Sterling Heights

Day /Time:	Third Tuesday of each month from 7:00 p.m. – 8:30 p.m.
Location:	Utica United Methodist Church Sterling Heights, MI 48314
Phone:	Contact ALS of Michigan at (800) 882-5764

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
Phone:	Contact ALS of Michigan at (800) 882-5764

Group meetings involving speakers will be announced as soon as possible in advance of the meeting. 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 and ask for Simone Bradford, LMSW, Director, Program Services.

If you are interested in starting a support group in your area please contact ALS of Michigan at (800)882-5764.



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Online Support

Living-with-ALS Email Group

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

Patients Like Me

www.patientslikeme.com

Chat Rooms

ALS Alternative Medicine Yahoo! Club

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

Moms with ALS

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

Muscular Dystrophy Association Chat Rooms

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

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 (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 may be able to assist in helping 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



Recommended Books and Videos

The following books and videos were selected based on suggestions from ALS patients, families, and caregivers. By listing them here, we are not intending to endorse any particular publication. Please know it is impossible to list all the ALS books that are available. If you have any suggestions or would like donate to our lending library, please feel free to call our office.

Biographical

Charlie's Victory by Charlie & Lucy Wedemeyer. Charlie is an ALS patient who was diagnosed in 1978. This book is the whole story in Charlie and Lucy's words. It is a triumphant story of courage and love as seen in PBS's Emmy-winning documentary "One More Season" and television's "Quiet Victory". Available for loan from ALS of Michigan or Available for purchase from the Charlie Wedemeyer Family Outreach (408) 399-4334.

How Will They Know If I'm Dead?: Transcending Disability and Terminal Illness by Robert C. Horn III. Most books on terminal illness focus on death and dying. This book is about neither. This book is about a real person and a true hero, Bob Horn. Diagnosed with ALS, Bob had to deal with the reality that his situation was terminal. How Bob and his family cope, or "battle" as Bob calls it, with disability and terminal illness is an amazing story. Available for loan from ALS of Michigan, Inc.

In Sunshine and In Shadow: Personal Portraits of ALS by Judy Oliver (Editor). During her husband's battle with ALS, Judy Oliver discovered that the experience of others living with ALS provided inspiration, courage, coping strategies and hope. Her book - capturing the experience of others from around the world - will inspire you, too. Available for loan from ALS of Michigan, Inc.

Journeys With ALS: Personal Tales of Courage and Coping with Lou Gehrig's Disease by David Feigenbaum. This book was compiled by an ALS victim who has gathered 33 personal stories from fellow ALS patients and/or their caregivers. There is a lesson here for all of us about coping with a terminal illness and the silver lining to be found in even the worst of situations. Available for loan from ALS of Michigan, Inc.

Laugh, I Thought I'd Die: My Life with ALS by Dennis Kaye. ALS patient Dennis Kaye in his own words uses humor and laughter to describe his ALS journey. Available for purchase from ALS Society of Canada or loan from ALS of Michigan, Inc.

Tuesdays with Morrie: An Old Man, a Young Man, and Life's Greatest Lesson by Mitch Albom. This is a true story about the love between a spiritual mentor and his pupil. We meet Morrie Schwartz and are privy to intimate moments of his final days as he lies dying from ALS. Even on his deathbed, this twinkling-eyed mensch manages to teach us all about living robustly and fully.



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Rowing Without Oars: A Memoir of Living and Dying by Ulla-Carin Lindquist. Swedish newscasters battle with ALS. Diagnosed when she was 50 years old she describes her feelings and how she coped with the diagnosis and lived with the disease. Available for loan from ALS of Michigan, Inc.

Breathing/Ventilation

Ventilation: The Decision Making Process by the Les Turner ALS Foundation. A 20-minute video designed for ALS patients, family members and health professionals. It includes interviews with three ventilator dependent ALS patients, family members and the medical staff Northwestern University Medical School. Video - List Price: \$20.00.
Available for purchase from The Les Turner Foundation. (847) 679-3311.

Caregiving

Caregiving: The Spiritual Journey of Love, Loss, and Renewal by Beth Witrogen McLeod. A rare blend of powerful storytelling and practical information, this book presents advice from leaders in the fields of aging, medicine, finance, and spirituality and explores medical and financial problems as well as such issues as depression, stress, housing, home care, and end-of-life concerns. McLeod also draws on the wisdom of Buddhism, Judaism, Christianity, Islam, and shamanism, and on the writings of current and past spiritual figures. Available for loan from ALS of Michigan, Inc.

On Eagle's Wings by Connie C. Bobo. A practical guide for the care of terminally ill loved ones, this book provides step-by-step guidelines. Excerpts from the personal journals of Perry, an ALS victim, and his wife and caregiver give a candid portrayal of the fear, anger, pain, frustration and guilt that accompany the battle against a terminal illness. From their personal experiences, the reader can learn practical and economical tips on caregiving. Available for loan from ALS of Michigan, Inc.

Share the Care: How to Organize a Group to Care for Someone Who Is Seriously Ill by Cappy Capossela. This is a step-by-step guide to the group approach of forming a caregiving network. Offers valuable guidelines, compassionate suggestions, and a workbook that offers support to help free the patient from worry and the caregiver from burnout. Available for loan from ALS of Michigan (800) 882-5764 Also available in Video \$100.00

When a Loved One has ALS: A Caregiver's Guide by the Muscular Dystrophy Association. A comprehensive guide to caring for a person with ALS at home. Covers physical care, psychological and emotional concerns and getting financial assistance. Available for online reading or for purchase from MDA (800-572-1717).



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Children/Teens

Grandpa, What is ALS? by **Bonny Gold-Babins**. This is the story of the love shared by a grandfather, who develops ALS, and his grandchild who learns to accept and understand the disease. This book is for the whole family regardless of age. Available online for reading at <http://www.alsab.ca/kids/index.html>. Available for purchase from the ALS Society of Alberta (888) 309-1111.

Helping Children Cope With Death by **The Dougy Center**. Provides a comprehensive, easy-to-read overview of issues facing grieving children, and ways to help them. Based on The Dougy Center's work with children, teens and families, this guidebook contains information on a child's understanding of death, relevant developmental issues, how to explain death to children, how to know when to get professional help, and much more. Available for purchase from The Dougy Center. (503-775-5683)

Helping Teens Cope With Death by **The Dougy Center**. Learn how a death of a loved one can impact a teen and how to help. This practical guide explains common grief reactions of teenagers, challenges grieving teens face, advice from parents to parents, when to seek professional help, and much more. Taken directly from what teens have taught us about supporting them. Available for purchase from The Dougy Center. (503-775-5683)

How Children Grieve by **The Dougy Center**. An inspiring one half-hour video presentation outlining four basic principles for supporting grieving children, three tasks grieving children grapple with, and three common reactions of grieving children. VHS Video – 30 min Available for purchase from The Dougy Center. (503-775-5683)

In My Dreams...I Do! by **Linda Saran**. This children's book was inspired by the author's mother who continued to nurture an intimate relationship with her grandchildren despite her battle with ALS. The book is about two sisters who escape the world of their grandmother's physical limitations to her dream realm where anything is possible. Available for purchase from the Les Turner Foundation. (847-679-3311)

Someone You Know Has ALS by **Lois Clark**. A simple way to help children understand and cope with ALS. Available for purchase from the ALS Society of Alberta (888-309-1111).

What About the Kids? Understanding Their Needs in Funeral Planning and Services by **The Dougy Center**. This guidebook was developed to help adults support children before, during and after a funeral or memorial service. It covers what children and teens want and need from funerals. It suggests options for involving them and discusses how to explain terms such as burial and cremation to children. Available for purchase from The Dougy Center. (503-775-5683)



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Communication/Swallowing/Eating

State of the Art Communication for PALS-DVD. This DVD demonstrates a few of the communication aids and technologies available to ALS patients. Available for loan from ALS of Michigan, Inc..

The Dysphagia Cookbook by Elayne Achilles, Ed.D This cookbook is geared to a specific population of those who have difficulty eating and swallowing. Available for loan or through amazon.com

Easy-to-Swallow Easy-to Chew Cookbook by Donna L. Weihofen, R.D., M.S. and Joanne Robbins, PD.D., CCC-SLP, and Paula A. Sullivan, M.S., CCC-SLP. 150 recipes for people who have difficulty swallowing. Available for Purchase through Amazon.com or for loan from ALS of Michigan, Inc.

Maintaining Nutrition by the Muscular Dystrophy Association. Designed primarily for use by health professionals who care for those with ALS, this book covers swallowing, diet, alternative feeding methods and tube feeding. Available for purchase from MDA. (800-572-1717).

Meals by the Muscular Dystrophy Association. ALS can affect the muscles of the tongue and throat which chewing and swallowing food very difficult. Meals is a cookbook that offers nourishing recipes for the preparation of easy-to-swallow foods. Available for purchase from MDA. (800-572-1717).
Available for loan from ALS of Michigan (800) 882-5764.

Non-Chew Cookbook by J. Randy Wilson. The Non-Chew Cookbook was written for people suffering from chewing, swallowing and dry mouth disorders. It has received many endorsements from a wide variety of medical professionals. Available for loan from ALS of Michigan, Inc.

Coping/Inspirational/Religious

Hard Choices for Loving People by Hank Dunn. This book looks at issues related to CPR, Artificial Feeding, Comfort Care and the Patient with a life threatening illness. Written by a chaplain. Available for loan. From ALS of Michigan, Inc.

Meeting the Challenge: Living with Chronic Illness by Audrey Kron, M.A., CGP
Both for patient living with the disease and their family. Looks at some of the challenges couples and families face when dealing with a chronic illness. Available for loan through ALS of Michigan, Inc.



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When Your Doctor Has Bad News: Simple Steps to Strength, Healing & Hope by Al B. Weir, M.D. 2002-2003 President of the Christian Medical association provides readers with practical tips and questions to ask doctors and how to make choices that will achieve healing and being able to live with a disease. Available for loan from ALS of Michigan, Inc.

Death, Dying and Grief

How to Survive the Loss of a Love by Melba Colgrove, PH.D., Harold H. Bloomfield, MD, and Peter McWilliams. Understanding Loss, Surviving, Healing, Growing. Available from ALS of Michigan.

On Death and Dying by Elisabeth Kubler-Ross. In this remarkable book, Dr. Kübler-Ross first explored the now-famous five stages of death: denial and isolation, anger, bargaining, depression, and acceptance. Through interviews and conversations, she gives the reader a better understanding of how imminent death affects the patient, the professionals who serve that patient, and the patient's family, bringing hope to all who are involved. Available for loan from ALS of Michigan.

Waking Up: Climbing Through the Darkness by Terry L. Wise. Wife of an ALS patient discusses her journey through the diagnosis, the disease process, and the loss of her husband. Discusses the impact the disease has on caregivers. Available for purchase through www.terrywise.com or Available for loan from ALS of Michigan, Inc.

General ALS Information

ALS Informer A publication of ALS of Michigan, Inc.
Contains newsletter highlights, events, research, and patient services.

Basic Information Series by the ALS Society of Canada. This series of booklets, created in 1990, provides an introduction to various topics faced by people with ALS. Titles include: An Overview for People with ALS; Eating, Drinking, and Swallowing Strategies; Communication Strategies; Mobility Strategies; Breathing Strategies; Coping with Grief and “How Can I Help?” - A Guide for Family and Friends. Available for purchase from the ALS Society of Alberta (888-309-1111).

Manual for People Living With ALS by the ALS Society of Canada. This manual provides information and helpful hints that will assist people with ALS to manage their new challenges. Chapters include What is ALS?, Coping with ALS, Your Healthcare Team, Adapting to Breathing Difficulties, and others. Available online at <http://www.als.ca/manual-acknowledgement.shtml>. Available for purchase from the ALS Society of Alberta (888-309-1111).



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Legal/Financial

Long Goodbye: The Deaths of Nancy Cruzan by William H. Colby. William Colby is the attorney who represented the family of Nancy Cruzan who was in an auto accident and remained in a coma for five years when her family decides to remove her feeding tube. This book discusses the right to die and the legal issues Nancy's Cruzan family faced. Available for loan from ALS of Michigan, Inc.

Lou Gehrig

Iron Horse: Lou Gehrig in His Time by Ray Robinson. A captivating biography of the legendary ball player, known for both his prowess on the field and his courage in life. Robinson re-creates the life of this legendary baseball player and also provides a insightful look at baseball through the depression years. Includes over 50 photographs.

Lou Gehrig: The Luckiest Man by David A. Adler. (Reading level: Ages 4-8) This biography tells Gehrig's story with unassuming simplicity and purposely remains vague about the details of Gehrig's illness. The story is no less affecting without them, and probably contains enough sadness for any child.

The Luckiest Man: The Life and Death of Lou Gehrig by Jonathan Eig. The personal life of Lou Gehrig, his career, and his diagnosis of ALS. Available at Amazon.com or Available for loan from ALS of Michigan, Inc.

Mobility/Travel

Barrier Free Travel: A Nuts and Bolts Guide for Wheelers and Slow Walkers by Candy Harrington. This book is filled with information about accessible travel via plane, train, bus, and ship. Available through Demos Publishing at 1-800-532-8663 List Price: 19.95

Emerging Horizons –A consumer-oriented magazine about accessible travel for people with mobility disabilities www.emerginghorizons.com

Frommer's A Guide for the Disabled Traveler by Frances Barish for Frommer's Travel.

Mobility International USA A guidebook to international exchange, community service, and travel for persons with disabilities, the 225-page book Survival Strategies for Going Abroad: A Guide for People with Disabilities.



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Wheelchairs on the Go: Accessible Fun in Florida is a 424-page guidebook detailed descriptions of accessible accommodations, recreation, theme parks, attractions, historic sites, and hunting or fishing. **888/245-7300; www.wheelchairsonthego.com**

Treatment

Amyotrophic Lateral Sclerosis by Robert G. Miller, MD, Deborah Gelinis, MD, and Patricia O’Conner, RN. This book provides an introduction to ALS, treatment of ALS, managing the symptoms, and the resources available. Available for loan from ALS of Michigan, Inc.

Amyotrophic Lateral Sclerosis: A Comprehensive Guide to Management by Hiroshi Mitsumoto, M.D. and Forbes H. Norris, Jr., M.D. A comprehensive guide that covers every aspect of the management of ALS. Available for loan from ALS of Michigan, Inc.

Amyotrophic Lateral Sclerosis: A Guide for Patients and Families, 2nd Edition by Hiroshi Mitsumoto (Editor). Discusses diagnosis; patient care; therapeutic trials; unorthodox treatments; speech problems; physical therapy; nutrition; environmental adaptations; ventilatory care; long-term care; financial resources; the role of support groups; hospice care, life support systems and the legal, ethical, psychosocial and spiritual aspects of dealing with the disease. Available for loan from ALS of Michigan, Inc.

Amyotrophic Lateral Sclerosis: Diagnosis and Management for the Clinician by Jerry M. Belsh, MD and Philip L. Schiffman, MD. Written for clinicians and covers issues related to diagnosis, treatment, pulmonary function, and ethical and legal issues related to ALS. Available for loan from ALS of Michigan, Inc.

Palliative Care in Amyotrophic Lateral Sclerosis (Motor Neuron Disease) by David Oliver (Editor). Provides a reference for the care of patients with ALS. The palliative care approach to the care of ALS is outlined and the role of the multidisciplinary team is emphasized. All contributors are clinicians and provide guidelines throughout the disease process. Available for loan from ALS of Michigan, Inc.



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Relationship/Intimacy Issues

Enabling Romance A Guide to Love, Sex, and Relationships for People with Disabilities by **Ken Kroll and Erica Levy Klein**. Written by a husband and wife team in which one has a disability. Discusses intimate relationships for those who are disabled or and their partners. Available through New Mobility at www.newmobility.com/bookstore or (888)850-0344. Available for loan from ALS of Michigan

Sexual Function In people with Disability and Chronic Illness-A Health Professional's Guide by **Mara L. Sipski and Craig J. Alexander**. Used by health professionals to discuss issues related to sexuality and dysfunction. Available for loan to health professionals.



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What is a Caregiver?

A caregiver is anyone who is providing support and or assistance to someone who is ill or disabled. ALS caregivers consist of: family members, friends, neighbors, co-workers, home health aids, and hospice workers. Providing care to an ALS patient can be very overwhelming to those involved and that is why it is very important that caregivers have the education and support from the community. ALS of Michigan provides several resources that will support and educate the caregiver. These are through support groups, conferences, counseling, and obtaining outside resources from the community. Please know that the staff of ALS of Michigan, Inc. is here to assist you when you are feeling overwhelmed or just need to talk about your individual situation. We have trained professionals who are able to work with you and your family.

Local Caregiver Support Groups

If you are caring for a loved one, you may want to consider participating in one of the free caregiver support groups available locally. Groups are made up of caring people who know about the frustration and turmoil of caring for someone with a serious illness. 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 contact ALS of Michigan, (800) 882-5764, to confirm date and time before attending a group.

ALS of Michigan, Inc. Caregiver Support Group

First Monday of each month 6:30-8:00 p.m.

24359 Northwestern Hwy. Suite #100

Southfield MI 48075 (800)882-5764

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/>



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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.

Program Description:

- A free program available to any PALS who live within the service area of ALS of Michigan.
- The program is designed to provide respite (limited, intermittent relief) for caregivers and PALS by providing money to nursing agencies for respite services provided to PALS.
- Caregivers or PALS will identify the agency they wish to work with.
- The Patient Services Coordinator or a designated staff person will contact the agency, explain our program, and ensure that our requirements are met.
- Up to \$15 an hour will be paid directly to the agency for respite care services. **The PALS of family are responsible for paying the agency directly for care costs above that amount.**
- Up to 20 hours of care a month will be provided to the family or PALS **when staffing is available. Hours do not carry over from month to month so you are encouraged to use the available 20 hours every month.**
- **Respite care assistance cannot be paid to any type of assisted living facility.**
- The PALS of family will make scheduling arrangements with the agency.

PALS interested in the program need to complete an application form and physician statement and return them to ALS of Michigan.

Program applicants will be eligible for service based on available funding.

Agencies will be required to do criminal background checks on their employees, provide ALS of Michigan with a certificate of workers compensation and a certificate of employer's liability as well as attend one of our agency respite conferences given to educate agencies about the disease and needs of the patient and families.

The agency will bill ALS of Michigan for their services. The services will be verified with the PALS or family and then the agency will be paid.

***ALS of Michigan is currently in the process of expanding their service area
Please call the office to see if respite care is available in your area.**



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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/home.asp>.

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?



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- 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 2009. 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. Currently, the Protected Spousal Asset is one half of the couple's countable assets - no less than \$21,912 and not to exceed \$109,560 in 2009.
- ***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 resources of this manual)



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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/find.vml>

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 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.



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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>

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.



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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.