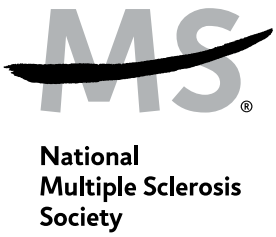
MAXIMIZING INDEPENDENCE

A Guide to Planning for Changing MS Care Needs



MULTIPLE SCLEROSIS (MS) IS A VARIABLE, UNPREDICTABLE DISEASE.

Its symptoms vary from person to person and from time to time in the same person. Many people who live with MS experience a progression of symptoms over the years that gradually results in functional loss and increasing disability. For others, progression occurs from the beginning. In spite of one's disease course, however, managing symptoms and maximizing independence are realistic goals that can assure full and meaningful lives regardless of the disease's impact.

Michael, diagnosed in 2004

Today people who live with chronic disease and disability have more choices and more services available than ever before. Thanks to the Olmstead Supreme Court decision of 1999, it is now a civil right for people with disabilities to live in the least restrictive environment possible. This means that more government funding must now be directed to helping people remain at home and with their families, whenever feasible, so that premature or inappropriate nursing home placement can be avoided. It also means that those who go into nursing homes are increasingly moving there because of the 24-hour clinical services that they need, not by default because they cannot get enough help in their community.

To prepare for making these choices, families must learn about the services that are available to them and how to anticipate and plan for their future needs so that they are ready for whatever lies ahead. MS can change quickly. Crises do not allow time for planning. Becoming savvy about what kinds of services are out there and how to access them is empowering, and assures that families will keep control in their hands while making thoughtful and wise decisions.

This booklet is intended to provide a guide for families as they plan for changing care needs, whether this means seeking home services, exploring supportive housing options, or finding a quality nursing home. Thinking ahead, talking as a family about future needs, and asking important questions of providers will help you remain in control of the future and assured that loved ones living with MS will receive the support and assistance they need to ma age their disease and lead full and enriching lives.

The following organizations have collaborated in the development of this booklet.

THE MULTIPLE SCLEROSIS ASSOCIATION OF AMERICA

THE MULTIPLE SCLEROSIS FOUNDATION

THE NATIONAL MULTIPLE SCLEROSIS SOCIETY

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PLANNING AS A FAMILY

As with MS itself, every family living with MS is different. Some have lived in a community for many years and have strong ties to neighbors and community life; others may have just moved to a neighborhood, or seen their neighborhood change dramatically and no longer have close friends living nearby.

Some are surrounded by large extended families: others have no family members in the immediate vicinity. Financial resources vary. The life cycle of families varies. Needs, options, and choices are different depending on whether you are a family with young children, a family with young adults moving away to start their own lives, or a couple who are beginning retirement. All of this means that the support and resources available to families differ as well. Each family must look at its own situation and make plans that make the most sense for them.

To further complicate the situation each family member is impacted by MS in different ways. Family members are in different places in their lives when it comes to age, experience, responsibilities, life plans, needs, strengths, and emotional makeup. Some have strong opinions; some do not. Each family member copes with MS differently. Some want to learn all they can about the disease and connect with others facing similar challenges; others prefer to handle things alone as a family and not think too much about the disease unless the need arises. Some welcome others coming into their home to help, whether paid or volunteer; others do not feel comfortable with strangers in their home.

Communities where families live also differ considerably. Some are easily accessible and people with disabilities are welcomed and can easily navigate the array of available activities and services. Other communities are older, with antiquated buildings that cannot be easily modified or that are spread out with a significant lack of accessible transportation. Urban communities create different challenges than rural ones: wealthier counties provide richer services than poorer ones.

For all of these reasons there is no right or wrong answer when it comes to families evaluating the current situation and planning for changes that might be needed. What is important is to make sure that all family members participate in the discussion, including the person with MS, and that an effort is made to arrive at consensus regarding what next steps might be needed.

John, diagnosed in 2001

FAMILY CONVERSATIONS

Since MS is such a variable disease, needs are constantly changing. Ongoing family conversations are therefore going to be needed. Whenever there is a significant change in disease course or function, or if there is a change in the family that will impact family roles, another conversation needs to happen.

Be honest about your feelings and assumptions and respect the feelings and opinions of others, even though you may not understand or agree with them. The person with MS may have thought the family would always be able to do whatever needed to be done, whether it was administering medications, running errands, cleaning house, or providing hands-on assistance. But situations can change as children move away or a spouse's health declines. In the same way, family members might have assumed that they would always be able to meet all of their loved one's needs. But unanticipated life events, career demands, or failing health can become an issue.

The questions on the following page should be addressed by all members of the family when the current care plan is becoming more difficult and there is recognition that some problem-solving is needed.

CONVERSATION STARTERS

1. How is the family member with MS doing right now? What's working? What isn't?
2. What are his or her medical needs? Personal care needs? Who is doing what? Is any change anticipated?
3. Is the person with MS receiving good clinical care and experiencing some good quality of life?
4. How are other family members doing? Are there new or additional things causing stress? Are they being handled?
5. How much do we know about community resources that might be able to help us?
6. Do we have a clear understanding of the financial resources we have to work with?

WHEN CONVERSATIONS ARE DIFFICULT

When conversation about changing care needs occurs, everyone affected may share a variety of feelings and opinions. Not everyone may agree on what needs to happen next. Simply acknowledging that the discussion is difficult for everyone is a good way to start. Recognize that you are all working together to reach the best possible solution. Sometimes emotions can interfere with communication, so encourage each other to speak calmly about the matters at hand. Setting some ground rules before the conversation begins can help too. Let everyone have a turn to express his or her thoughts. Try not to interrupt. If you don't understand something, ask for clarification when the person finishes speaking.

If, despite your best efforts, a mutually-agreeable decision cannot be reached, consider asking for outside help. A care manager is useful to identify resources and offer suggestions that might not have been considered. Enlisting a social worker, clergyman, or family therapist to assist in the process can improve communication and understanding. Perhaps individual counseling is the best option for those struggling to cope with stress and emotions.

Local professionals can be located by contacting an MS membership organization or reaching out to your state's psychological association at **www.apa.org/practice/refer.html.**

There are certain times when these family conversations are most likely to be triggered. One is when the family realizes they cannot do it alone and that more help is needed at home. Another is when a move to a more supportive housing alternative such as assisted living may be necessary in order to assure safety and maximize the independence of the person with MS. A third is when 24-hour skilled care in a nursing home setting might be necessary. What follows is a guide of questions to ask and resources to research and evaluate for each of these situations.

Michael, diagnosed in 2004

WHEN MORE HELP IS NEEDED AT HOME

The quality of care and quality of life of a person with MS living at home and experiencing more disability and clinical challenges depend on the following:

- Availability of quality hands-on care and assistance that manage clinical symptoms, optimize functioning, and prevent complications.
- A safe environment.
- Accessibility.
- Appropriate mobility equipment and other assistive technology.
- Socialization.
- The opportunity to pursue interests and activities that give value to life.

When these needs can no longer be addressed by family and friends alone, it is time to use other resources to assist in meeting these needs. On page 10 there is a check list that families can use to assess the needs of their loved one and determine where they need to seek further assistance.

If the plan is to look for outside resources, specific questions that families need to think about together include:

FAMILY CONVERSATION PRIOR TO SEEKING HOME SERVICES

1. Who will make phone calls or explore the Internet for resources?
2. What organizations or services can help us?
3. Who will place advertisements, if that is necessary?
4. Who will do the interviewing, whether it is for a personal assistant, a durable medical equipment vendor, or a contractor for home or car modifications?
5. Who will check references and perhaps conduct a background check?
6. Who will train someone coming into the home to provide hands-on assistance?
7. Who will learn about wage and benefit regulations?
8. Who will do a financial review of the person with MS in terms of income, expenses, and assets so that questions regarding financial eligibility for services can be answered?
9. How will services be paid for if insurance and/or other coverage is not available?
10. Is there a family member living far away who might provide financial help for services since he/she cannot be available to provide daily assistance? Who will contact that person?
11. If no financial resources are available, would a home equity loan or reverse mortgage be advisable? Who will check that out?

ASSESSMENT OF NEEDS

Rank each of these activities in terms of the person with MS being independent, requiring some assistance, or being unable to do the task without complete assistance.

Function	Independent	Some Assistance	Complete Assistance
Walking			
Use of Mobility Equipment			
Dressing			
Bladder/Bowel Care			
Grooming			
Eating			
Medication Management			
Transfers			
Hygiene			
Housekeeping			
Transportation			
Positioning			
Managing Finances/Bill Paying			
Grocery Shopping			
Ability to Self-direct Care			
Meal Preparation			
Evacuation in Emergency			
Socialization			

Where to Start

As noted previously, the first step a family must take is to clearly identify what they are looking for. What is the major issue it is seeking to address? Is it a housekeeping issue? Is it the need for hands-on direct care? Does it involve the need for home modifications or assistive technology? Is it isolation of the person with MS? Is it safety? Once you know what to look for, the search can begin.

It is important to establish whether the person with MS and/or the family is eligible to receive assistance and/or services from entitlement programs or resources in the community. Sometimes eligibility is due to a person's specific disability and/or chronic condition; sometimes it is because of limited financial resources; at other times it is because of a specific eligibility category such as being a veteran or a caregiver. Although many home services may need to be paid for privately, you first want to make sure the person with MS is not eligible to receive free or discounted services.

It is also important to understand that many agencies providing home care services require home visits to be for a minimum number of hours. For example, even though a person might only need two hours of assistance in the morning, if the agency has a three hour minimum, the family or other payer will need to pay for three hours. Keep this in mind as you budget for services.

PRIMARY PAYERS OF HOME CARE SERVICES

Medicare is a federal health insurance program and pays only for medically necessary skilled home care. It does not pay for on-going daily care such as assistance with activities of daily living (bathing, dressing, grooming, etc.). A physician must sign a plan of care for Medicare-covered home services, they must be provided by a Medicare-certified home health care agency, and the person receiving care must be basically confined to the home. A person with a chronic diagnosis like MS can be eligible for Medicare home services, but only if skilled nursing care is required, not just day-to-day assistance.

Medicaid is a state and federal government program that pays for certain health services, including assistance with activities of daily living, for those who have low incomes and very limited assets. Eligibility varies from state to state, but it is always restrictive in terms of income. Medicaid waivers occasionally broaden that restrictive income requirement so that more people can receive services. It is in Medicaid's interest to do this as Medicaid also pays for a significant amount of nursing home care; it is more cost effective to serve people at home than it is in a more expensive skilled nursing facility.

Private health insurance will sometimes pay for home care services if they are connected to a specific illness or medical event. It does not usually pay for assistance with activities of daily living on an on-going basis.

Long-term care insurance can help with the costs of daily hands-on care. However, this coverage usually comes from a policy that was already in place prior to receiving a diagnosis of MS. Once an MS diagnosis is confirmed, it is virtually impossible to secure a long-term care insurance policy.

The Veteran's Administration contracts with home care agencies in the community through its medical centers to provide home health care services to veterans. Local Veterans Affairs Offices can provide information on eligibility and resources.

Respite Care Services are geared to family caregivers, and are funded to provide families with a break from family caregiving through intermittent in-home services. In order to receive this assistance family members must identify

themselves as 'caregivers'. The website **www.respitelocator.org** provides contact information on local respite services. Remember that these services can come from counties as well as states, so be sure to check both resources.

COMPANIONS/HOMEMAKER SERVICE

Sometimes the major issue for people living at home is managing the daily activities of meal preparation, keeping up the house, grocery shopping, walking the dog, getting children to school, doing laundry, paying bills, running errands (such as to the bank or dry cleaners), or just having a companion. If that is the kind of assistance you need, you do not need to pay for someone who has credentials for hands-on nursing care.

Where to look for homemaker services?

Probably the least expensive way to find someone is to look to hire privately. Other family caregivers, an MS patient organization, or even your neighbors, can be good sources for tips and advice. Sometimes placing an advertisement in the local paper or putting a 'help wanted' in a local school or college newsletter or a church bulletin can be helpful.

If you do not want to go through the process of hiring and managing a companion or homemaker, you can work with an agency that offers homemaker/companion services. Often coming under the term "Visiting Homemakers," these agencies provide non-medical support services in the home. Hourly costs for these services vary according to location and tasks but generally range from $15–20 an hour. This is a higher rate than you could probably negotiate with a personal hire, but you are paying for the agency to do the hiring, scheduling, monitoring, and paying of the employee. Homemaker services are not covered by public or private insurance.

HOME CARE AIDES, PERSONAL CARE ATTENDANTS, AND HOME HEALTH CARE AIDES

In general, home care aides, personal care attendants and home health aides fulfill similar functions, helping with activities of daily living and perhaps doing some light housekeeping as well.

However, there are also significant differences between them.

Home care aides usually work for various public and private agencies that provide home care services. They are likely to be supervised by a nurse or non-medical manager and given assignments regarding when to visit and what services to perform. They usually work independently with only periodic visits by their supervisors and provide non-medical services to their clients.

Personal care attendants are usually hired by people with MS directly and receive their training and assignment of duties from them. Medicaid increasingly funds these personal hires by people with disabilities as they are viewed as being much more consumer-directed than the traditional clinical model where nurses assess needs and determine services. However, to be eligible for this funding, the person receiving the services must have very limited income and usually be certified as nursing-home eligible.

It is important to create a job description when hiring a personal attendant privately. It should include a list of major duties, hours, requirements, and experience desired.

Home health aides typically work for certified home health or hospice agencies that receive government funding, and therefore must comply with regulations to receive funding. This means that they must work under the direct supervision of a medical professional, usually a nurse. These aides keep records of services performed and of the client's condition and progress. They report changes in the client's condition to the supervisor or case manager. These aides may also work with therapists and other medical staff.

Sometimes home health aides can provide such basic health-related services as checking patients' pulse rate, temperature, and respiration rate. They may also assist with simple prescribed exercises and assist with administering medications, including injections. Occasionally, they change simple dressings, give massages, provide skin care, or assist with orthotics. With special training, experienced home health aides may also assist with medical equipment such as ventilators. Usually a home health care agency coordinates an individual's services based on a doctor's orders.

QUESTIONS TO ASK A HOME SERVICES AGENCY

1. Do you work with insurance companies, Medicare, Medicaid?
2. What services do you provide?
3. How can you meet my needs?
4. What kind of training do you provide your staff?
5. Have your aides worked with people with MS?
6. Do they receive special training?
7. Will I be assigned an aide who will consistently visit?
8. What if the aide can't come on a particular day?
9. Do you require a minimum number of hours per visit? What is the hourly rate?
10. Do you have a sliding scale? Do you charge for travel time?
11. Do you do background checks?
12. How is billing handled?

QUESTIONS TO ASK IF HIRING PRIVATELY

1. Can you tell me about your experience as an aide?
2. These are the duties I need to have done. Are you comfortable meeting these needs?
3. Do you have any experience working with someone with disabilities?
4. What do you know about MS? Are you willing to learn?
5. Are you familiar with mobility equipment, lifts, etc.?
6. How many hours are you looking for?
7. Do you have experience providing transfers?
8. Do you have a driver's license? Are you comfortable around pets?
9. Can you provide references?

SAFETY AND ACCESSIBILITY

If you have questions about safety and accessibility in your home, an occupational therapist can be an excellent resource to identify ways to improve those areas. When thinking about safety, consider the times when the person with MS is feeling at his/her worst. Can he/she operate the phone? Have emergency exit routes been established? Do the police and fire departments know there is someone in the house living with disabilities?

If home modifications are needed, again consider working with an occupational therapist. Do research on potential funding sources that might be available through Home Improvement Loan Programs, the Veterans Administration, Medicaid Home and Community based Waivers, FHA Loans, Statewide Assistive Technology Funds, the US Department of Agriculture, and IRS tax credits. Local and/or national non-profit organizations, and some churches or religious organizations, may also be of assistance.

ASSISTIVE TECHNOLOGY IN THE HOME

If someone is to have optimal independence at home, he/she must have the necessary assistive technology, particularly when it comes to wheeled mobility such as a power wheelchair. Other products that can assist significantly include lifts, tracking systems that can help move people with disabilities through the house and from floor to floor with minimal assistance, and environmental control units that allow persons with disabilities to do many tasks independently such as control lights, turn the TV on and off, adjust the bed, put shades up and down, etc. An MS membership organization can help you with referrals to help you obtain the technology you need.

ADDRESSING ISOLATION

Opportunities that are available to connect with others include self-help groups, telephone groups, on-line chat rooms and other social networking, and wellness programs. Information about all of these opportunities can be provided by an MS organization. Paratransit (accessible transportation) service is very important if someone must use wheeled mobility. Because of the American with Disabilities Act (ADA) every state must have paratransit service.

Adult Day Programs offer a place to go during the day where people with MS can socialize and be involved in various activities, and at the same time provide families with respite from their ongoing caregiving duties. Programs vary in terms of the days and hours they are open, who attends the program, transportation services, and whether they provide only social activities or medical services as well. Although there are a growing number of day programs serving the non-elderly, younger population, many continue to serve only older individuals, so research will be needed to see if there are any age-appropriate programs in your community. Medicaid pays for some people to attend adult day programs if they meet income eligibility requirements. If paying privately, the cost varies, but averages $40–60/day.

RESOURCES FOR HOME SERVICES

HOME CARE INFORMATION RESOURCES

National Association of Home Care

www.nahc.org

1-202-547-7424

Provides referrals to state associations that can refer callers to local agencies. Offers a free brochure entitled "How to Choose a Home Care Agency: A Consumer's Guide".

Home Health Compare

www.medicare.gov/HomeHealthCompare/search.aspx

A website provided by Medicare where you can see an agency profile of home health care agencies in a particular geographic area and how they compare to each other.

Area Agencies on Aging

www.n4a.org

1-800-677-1116

Supplies information and referral for many long-term care services, including local respite care programs.

Centers for Medicare and Medicaid Services

1-800-MEDICARE

www.cms.gov

Website that provides comprehensive information on the Medicare and Medicaid programs.

Centers for Independent Living

www.ncil.org

This organization advances independent living and the rights of people with disabilities through consumer-driven advocacy. This website can direct you to your local Center for Independent Living and Statewide Independent Living Council.

HOME CARE PUBLICATIONS

Managing Personal Assistants: A Consumer Guide

www.pva.org

1-888-860-7244

Hiring Help at Home

www.nationalMSsociety.org

1-800-344-4867

Publication 907, Tax Highlights for Persons with Disabilities

www.irs.gov

The Personal Care Attendant Guide:
The Art of Finding, Keeping, or Being One

Katie Rodrigues Banister (2007) Demos Medical Publishing, New York

SAFETY AND ACCESSIBILITY

Center for Universal Design

www.design.ncsu.edu

1-800-647-6777

Information, referrals, technical design assistance, publications.

Metropolitan Center for Independent Living, Inc.

www.wheelchairramp.org

1-651-603-2029

On line manual entitled "How to Build Wheelchair Ramps for Homes".

Assistive Technology in the Home

- Abledata

  www.abledata.com

  800-227-0216

  A database of thousands of accessibility products that can be researched by type or topic.

- Beyond Barriers

  www.beyondbarriers.com

  Catalogue of innovative accessibility products to enhance independence.

ADDRESSING ISOLATION

National Adult Day Services Association

www.nadsa.org

NADSA is the membership organization of adult day providers around the country. The website can help consumers locate day programs in their area.

All three MS organizations offer or provide referral to a variety of social and networking programs, wellness programs, and peer connection and support opportunities.

THE MULTIPLE SCLEROSIS ASSOCIATION OF AMERICA

www.msassociation.org

THE MULTIPLE SCLEROSIS FOUNDATION

www.msfocus.org

THE NATIONAL MULTIPLE SCLEROSIS SOCIETY

www.nationalMSsociety.org

Alexis, diagnosed in 2009

WHEN ASSISTED LIVING OR OTHER SUPPORTIVE HOUSING IS NEEDED

If you believe that home care is no longer practical for the person with MS, or safety in the home is becoming a significant concern, there are many other options and choices. The answer might be to seek one of a growing number of living options that focus on independent living but also include services such as meal service, housekeeping, medication management, etc.

Many triggers can lead to a decision that a move from home may be necessary:

- Fatigue in trying to deal with meal preparation, home maintenance, personal care, etc.
- Feelings of loneliness and isolation
- Difficulty in taking medications at the correct time and dose
- Balance issues
- Poor vision and ability to navigate the home
- Short-term memory loss and forgetfulness that could have safety implications
- Interest in being around people and having more social interaction

There are three major supportive housing alternatives.

ASSISTED LIVING

While assisted living definitions vary from state to state, generally it refers to a residential setting that provides or coordinates flexible personal care services, 24-hour supervision and assistance, home-making and laundry services, social activities, and health-related services. The purpose of assisted living is to foster independence in an environment that combines privacy with socialization. Anyone considering assisted living should be able to personally direct the care that he/she needs. The majority of assisted living residents pay for this housing option privately, although almost all states now have some Medicaid funding directed to assisted living for those who are eligible. Eligibility for assisted living can be restrictive, sometimes only being available to those over 55, sometimes only to those who can independently transfer, etc. Since every state is different, it is important to connect with the licensing agency of assisted living in your state to get more detailed information.

Assisted living has the reputation of being an expensive alternative, sometimes costing $3,000 a month or more, and requiring add-on costs if more personal care is needed than routinely provided. However, it is important to make sure that you do a full financial analysis when comparing the cost of home vs. assisted living. All the costs of living at home such as mortgage, taxes, home maintenance, insurance, meals, housekeeping assistance, utilities, etc. are included in the basic rate of the assisted living facility and need to be factored in when comparing home costs to an all-inclusive housing option.

ADULT FOSTER HOMES

Adult Foster Homes provide supports and services in a smaller group setting for adults who are unable to remain living independently and need assistance with activities of daily living. These homes provide personal assistance services, meals, supervision, and medication management, as well as securing health care and transportation for their residents. Usually they are located within the community and provide a more intimate home-like environment than larger assisted living facilities.

Both assisted living and adult foster homes are licensed by the state, so that is where you will need to get more information about these options. Both of these settings do tend to be oriented to the elderly. However, younger people with disabilities are increasingly using these services as well.

SUPPORTIVE HOUSING

In recent years there has been a move to combine independent apartments with some built-in services, such as group social activities, the services of a social worker, or provision of one meal a day. Supportive Housing is designed for people who only need minimal to moderate care to live independently – such as homemaking or personal care and support.

Supportive housing buildings are owned and operated by municipal governments or non-profit groups, including faith groups, seniors' organizations, service clubs, and cultural groups. Accommodations, on-site services, costs, and the availability of government subsidies vary with each facility.

Accommodations usually consist of rental units within an apartment building. If more personal assistance is needed, sometimes several renters choose to share the services of an aide, reducing the time and expense of having an aide travel to several locations. Of course a schedule of who is going to have the aide at what time needs to be negotiated and managed.

Supportive housing often targets particular populations such as the elderly, the developmentally disabled, the mentally ill, the homeless, or those with adult onset disability such as MS. An MS membership organization should be able to advise you if appropriate supportive housing is available in your area.

FAMILY CONVERSATION PRIOR TO SEEKING ASSISTIVE LIVING OR SUPPORTIVE HOUSING

1. Why do we need to think about this option now? What are we not able to provide at home?
2. Are we seeking a place just for the person with MS, or will other family members be moving too?
3. What particular accessibility features or services must be available?
4. Are there appropriate programs available near where we live?
5. What financial resources do we have to work with?
6. How can we find out if we are eligible for any housing subsidy, rental assistance, or Medicaid coverage for some assisted living or adult foster care expenses?
7. Who can do phone or Internet research to learn more?
8. Who would be willing to make on-site visits when the time comes?

WHERE TO START?

When trying to identify supportive housing options it is always important to gather information from those who have made this search in the past. The MS Association of America, the MS Foundation, and the National MS Society all have staff who can share with you what they know about programs in their area, particularly those that currently serve people with MS. Do a search on Supportive Housing, Assisted Living, and Adult Foster Homes on the Internet. Many times you will be guided to a state site.

There are three assisted living provider organizations that have helpful websites: the Assisted Living Federation of America, the National Center for Assisted Living, and LeadingAge. All assisted living and adult foster care centers are licensed by the state, so checking with your local Area Agency on Aging or your State Department of Health and Human Services should prove helpful.

MAKING VISITS

It is very important to make at least one visit, and preferably several, to evaluate whether a particular living option is the right one. Note the physical features and atmosphere, particularly in the individual living space and the social/recreational areas. How accessible are the building and the grounds? Go at meal time so you can observe food service and its presentation. Are snacks available during the day? Is the staff attentive to resident needs?

Are licensing certificates and other credentialing recognitions posted? Do they provide a place for exercise or rehabilitation? How would you describe the interaction between residents and staff? Are residents actively engaged in activities?

If you have an opportunity, talk to some of the residents and staff. The more you can engage them in conversation, the more you will get a sense of how people are feeling about living and working there.

QUESTIONS TO ASK OF ASSISTED LIVING OR ADULT FOSTER HOMES

1. What are your admission criteria?
   Are there restrictions on whom you can admit into your facility?
2. What level of independence is necessary?
3. How much personal assistance is provided as part of the monthly fee?
4. How much privacy do the residents have?
5. Who provides medical oversight?
6. How is transportation handled?
   Do you have accessible transportation?
7. What is the age range of the residents?
8. Do you have any residents with MS,
   or have you had some in the past?

9. If additional personal assistance is needed, is a resident free to hire someone to come in and provide that service?
10. Do you work with any home care agencies?
11. If powered mobility is needed, are you equipped to keep a wheelchair charged and stored?
12. What kind of training does your staff receive?
13. Do you offer formalized social programs and activities? What kinds of activities do you offer? Are they age-appropriate for a younger resident?
14. How is medication managed and administered?
15. How is conflict handled, either between residents, or between residents and staff?
16. What is covered in the monthly fee? Do you have a listing of additional services and what each costs? Can these costs increase? How often and why?
17. Do you work with Medicaid?
18. Could you show me a resident agreement?
19. What are your discharge criteria? When might a resident be required to leave?
20. If a person must leave, do you assist with finding another place for that resident?
21. Do you permit pets to visit or live there?
22. If a smoker, do you accommodate smokers?
23. Have any formal complaints been filed with state regulatory agencies in the last 2 years? What was the nature of the complaints? What was their disposition?

RESOURCES FOR SUPPORTIVE HOUSING

National Center for Assisted Living

www.ahcancal.org/ncal/Pages/default.aspx

National membership organization of assisted living providers that provides many resources for consumers on their website including "Choosing an Assisted Living Residence: A Consumer's Guide".

LeadingAge

http://leadingage.org

A national membership organization primarily representing non-profit providers of long-term care services…home care, assisted living and nursing home care. Their website has a significant number of resources geared to consumers.

Assisted Living Federation of America

www.alfa.org/alfa/default.asp

This provider organization website houses a searchable directory containing thousands of independent living, assisted living and senior living communities across the United States.

Disability.Gov

https://www.disability.gov/housing

This section of Disability.gov has information about housing vouchers and other assistance programs, home accessibility resources, and supportive housing that can help people with disabilities live independently in their communities.

WHEN SKILLED NURSING HOME CARE IS NEEDED

Making the decision that a person with MS needs the 24 hour skilled care provided by a nursing home is always difficult and complicated. Fortunately the culture of nursing homes is changing markedly from what existed in the past.

They are becoming more person-centered in their approach to care, and operate under increasing scrutiny to focus on enhancing the quality of care and quality of life of the people they serve. Consumer direction has come to the nursing home setting, and this is welcome news to anyone who needs to consider this level of care.

The decision that skilled nursing care is needed usually occurs when the person with MS experiences significant functional decline and/or challenging clinical issues that are beyond a family's capacity to address. Symptoms such as bowel or bladder incontinence, nutritional compromise, respiratory issues, and significant cognitive loss often require the specialized and complex clinical interventions and 24–hour/day monitoring provided by skilled nursing facilities. Serious complications such as skin breakdown and urinary tract infections can also become increasingly difficult to manage at home vs. a nursing home where nurses are available 24 hours a day.

MEDICARE AND MEDICAID

Medicare does not pay for ongoing nursing home care. It only pays for a limited number of days following an acute medical episode, usually following a hospitalization. Therefore, if your loved one with MS needs long-term nursing home care, Medicare will not be a resource.

Medicaid does cover nursing home costs, but only for those who have very limited assets, or who have spent down their savings and assets to the point that they are now eligible for Medicaid coverage. Some people with MS pay privately for nursing home care until their financial resources are depleted and they can no longer cover the costs. Then Medicaid becomes the payer. Others will be eligible for Medicaid upon admission due to the many expenses they have incurred up to that time; they have already spent down their assets. Most states do have protections for a healthy spouse who is not receiving Medicaid services. Some assets must be set aside for use by that spouse to support their continued life in the community.

It is important for families to understand the way that both Medicare and Medicaid work regarding the payment of nursing home costs. Information is available on both the Medicare and Medicaid websites. The Area Agencies on Aging and all three MS organizations can also direct families to more information.

Rick, diagnosed in 1991

FAMILY CONVERSATION PRIOR TO SEEKING NURSING HOME ADMISSION

1. What needs can no longer be met at home or in a supportive housing situation?
2. What are the primary medical and functional issues that now require 24-hour skilled nursing care?
3. Has our situation been discussed with the doctor of the family member with MS? Does he/she agree to write a doctor's order for nursing home placement?
4. Who will conduct an inventory of assets…property held (either singly or jointly), assets, insurance policies, insurance coverage, SSDI, SSI, pensions, passbook savings, retirement savings, etc.?
5. Who will lead the effort to research and explore nursing homes to be considered?
6. Who will do research on Medicaid to learn more about eligibility and when that eligibility might be reached?
7. Does the person with MS have mobility equipment that needs to be upgraded or replaced? It might be easier to get this done while still living at home.

WHERE TO START

Since word of mouth and personal experience are often most valuable, it is always wise to begin by reaching out to neighbors, friends, clergy, and health care professionals in your community for input about local nursing homes. Call an MS membership organization to see if there are any nursing homes in the area where other people with MS reside. Start a list!

Since nursing homes are licensed by the state, go to your State Survey Agency, which is usually located on the Department of Health and Human Services' website, and look for information about the nursing homes you are considering.

At the same time go to the 'Nursing Home Compare' website that is provided by Medicare and see how each nursing home on your list compares with others in terms of a number of quality indicators. Start visiting those nursing homes that look most promising to the family and compare each in terms of physical plant and atmosphere, staff morale, and the appearance and demeanor of the residents. For those nursing homes that seem most promising, go back for a few visits if you can, try to be around at mealtime, spend some time in the activities and rehabilitation programs, and chat with staff and residents.

It is very important that you have completed a financial inventory of family resources prior to any discussions with the Director of Admissions at any nursing home. It makes a difference whether you are paying privately or will need to rely on Medicaid. Sometimes nursing homes only allot a limited number of beds for Medicaid residents. Therefore, whether a person is admitted at a specific time could depend on the payer of services.

QUESTIONS TO ASK AT THE NURSING HOME

1. Are nursing home beds available now?
2. Do you accept Medicaid?
3. What is the age range of your residents?
4. Do you have any residents with MS?
5. Are speech, physical, and occupational therapies available?
6. Are there social workers on staff?
7. What kind of training does your staff receive? Would they be willing to learn more about MS if they have not had a lot of experience with this disease?
8. Are you experienced with power mobility? Do you have adequate storage for the equipment and the ability to keep it charged? How would you handle repairs?

9. How would you describe your activities program? What activities could you provide that would be age-appropriate for a younger population?
10. Who is your medical director? Can residents keep their own personal physicians if they wish?
11. Do you have private areas where residents can meet with family and friends?
12. What kind of preventive care do you offer...dental, immunizations, eye care, foot care, cancer screenings, etc.?
13. Does staff work with the same residents or rotate?
14. Do the rooms have individual climate controls?
15. What kind of off-site activities do you offer? Do you have accessible transportation equipment?
16. Is there a resident or family council?
17. Can you design activities to fit the interests of residents, such as computer, music, gardening, photography, etc.?
18. Do you have staff members who can do positioning and range of motion exercises?
19. Describe your dining program. Is it scheduled or open seating? Is there choice? Are there snacks?
20. Do you offer religious services?
21. Have any formal complaints been filed with state regulatory agencies in the last 2 years? What was the nature of the complaints? What was their disposition?

RESOURCES FOR SKILLED NURSING

Nursing Home Compare

http://www.medicare.gov/NHCompare/home.asp

Evaluates nursing homes around the country in terms of several key indicators.

LeadingAge

http://leadingage.org

Membership organization for non-profit nursing home providers.

American Health Care Association

http://www.ahcancal.org/Pages/Default.aspx

Membership Organization for for-profit nursing home providers.

AFTERWORD

The decision to seek supportive in-home services or an alternative living arrangement affects everyone in the family. Therefore the entire family should be engaged in the planning of these possibilities. Planning avoids crises and leads to better decisions.

This booklet was designed to assist in that process by providing information on some of the government programs, organizations, and services that can be of help and by providing questions and helpful hints to aid in assessing the appropriateness of service options that you are considering.

This booklet was a collaborative effort of MS professionals, people with MS, family members, caregivers, and long-term care providers representing the Multiple Sclerosis Association of America, the Multiple Sclerosis Foundation and the National Multiple Sclerosis Society. We hope that the information provided here will be helpful to you. Please feel free to reach out to any of these organizations for assistance and information about local resources.

Multiple Sclerosis Association of America

706 Haddonfield Road
Cherry Hill, NJ 08002

www.msassociation.org

800-532-7667

Multiple Sclerosis Foundation

6520 North Andrews Avenue
Fort Lauderdale, Florida 33309-2130

www.msfocus.org

888-MSFOCUS

National Multiple Sclerosis Society

733 Third Avenue
New York, New York 10017

www.nationalMSsociety.org

800-344-4867

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