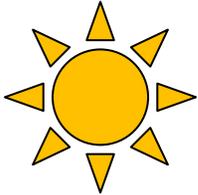




World Federation for Mental Health



CARING FOR THE CAREGIVER:

WHY YOUR MENTAL HEALTH MATTERS
WHEN YOU ARE CARING FOR OTHERS

*An educational booklet describing
the needs of those with neurological
conditions – and how to best care for
yourself while caring for them*

*An International Awareness Packet
from the
WORLD FEDERATION
FOR MENTAL HEALTH
www.wfmh.org*

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TABLE OF CONTENTS

Introduction: The Global and Personal Impact of Caregiving	1
Section I. The Needs of Those with Neurological Conditions: A Focus on Alzheimer's Disease and Multiple Sclerosis	3
Section II. Common Issues Faced by Caregivers	16
Section III. Caring for the Caregivers: Taking Care of Yourself	27
Section IV. Resources	39
Section V. References	63

Introduction: The Global and Personal Impact of Caregiving

Caregiving affects us all. Regardless of language, culture, or country, caregiving has become an everyday part of life for millions of people around the globe. Though differently named on each continent, these millions of “carers,” or “caregivers,” provide care to family members, partners or friends each year because they are sick, elderly or have a disability. The care they provide is unpaid, and often, unrecognized and under-supported. In most countries, family care is the primary means of caregiving – with immediate or extended family, rather than institutions – responsible for caring for loved ones who are ill or aged.

Caregiving affects us all. Regardless of culture or country, all people have been – currently are – or will need a caregiver during the course of their lifetime.

Today, a global caregiver’s movement is gaining momentum, driven by the needs of the millions of people, like you, who care for others with neurological disorders, such as Alzheimer’s, multiple sclerosis, dementia, cerebral palsy, epilepsy, muscular dystrophy or Parkinson’s. This caregiver’s movement – fueled by non-governmental organizations (NGO’s) and non-profits all over the world – is working to get carers like you **recognised and supported**.

Caring for loved ones with neurological disorders can be rewarding, and has many positive, life-giving rewards. Many caregivers report tremendous *personal satisfaction* giving back to those who have given to them. Other caregivers are grateful for a deeper, more meaningful relationship that develops over the course of caregiving. Beyond the *personal satisfaction* gained from caregiving, the *economic impact* of caregiving is enormous. Caregivers are the backbone of the long-term care systems in many countries, saving governments millions of dollars each year.

Invisible yet Valuable Care

- Carers provide an estimated £110 billion each year of care in the **UK**¹
- **U.S.** family caregivers provided \$375 billion worth of care in 2007²
- In **Taiwan**, 90% of elders are cared for by family members³
- In **European** countries, 80 percent of long-term care is provided by informal caregivers who are predominantly women⁴
- In **Africa**, scores of older Africans are caring for grandchildren orphaned by HIV/AIDS, resulting in enormous health and economic burdens estimates.⁵

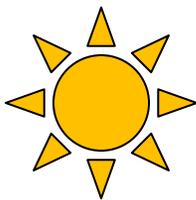
The Impact of Caregiving

Caring for those with neurological disorders requires tireless effort, energy and empathy, and indisputably, greatly impacts the daily lives of caregivers. There are physical, social, emotional, and financial impacts of caregiving. As caregivers like you struggle to balance work, family, and caregiving, **physical and emotional health is often ignored**. Your emotional and physical health is important not only for your own quality of life, but affects the person you care for; the risk of institutionalization of a loved one increases with a decline in your own physical and mental health.

Beyond managing the practical day-to-day issues of caregiving, perhaps the biggest struggle you may face is letting go of the person you used to know. As a caregiver of a loved one with a neurological disorder, losing your ability to connect with them is deeply distressing.⁶ This inability to make a daily connection with them, in combination with the lack of personal, financial, and emotional resources many caregivers face, often results in tremendous stress, depression, and/or anxiety in the year after caregiving begins.

This booklet provides new caregivers with an overall roadmap of the **care needed** by those diagnosed with a neurological disorder, with a focus on Alzheimer's disease and MS. This booklet also outlines some of the **common issues** faced by caregivers, including the emotional impact that caregiving can have, and provides recommendations on **caring for yourself as you care for others**.

This booklet, Caring for the Caregiver, includes four sections:



Section 1: The Needs of Those with Neurological Conditions

Section 2: Common Issues Faced by Caregivers

Section 3: Caring for Yourself

Section 4: Resources to Help You Cope

Section I. The Needs of Those with Neurological Conditions

Caring for someone with Alzheimer’s disease, dementia, multiple sclerosis, or other neurological disorder can be difficult, and in most cases, is a long-term and often full-time job. The first place to start is getting all the **information** about the disorder(s), the **possible disease course** and **stages**, and the **kind of care that will be needed throughout its course**. Arming yourself with this roadmap of where you are going, when, and how, will provide needed certainty in likely uncertain times, and may result in better caregiving outcomes.

This section outlines the needs of those with neurological conditions, with a focus on Alzheimer’s and MS.

Get all the Information you can about the Disorder

There are hundreds of neurological disorders, each with disease-specific symptoms and a different progression. The first step in caring for someone with a neurological disease is **learning as much as you can about the illness** in general, and working with your healthcare provider to understand the possible course the disease will take for your loved one. Multiple resources are available for gathering information about neurological disorders, including healthcare providers, librarians, non-governmental organizations or non-profits; many online resources can provide useful information for you and your loved one. [Click here](#) for the types of potential resources that may be available in your community; [click here](#) for a list of organizations that may be in your area.

The next section summarizes the disease courses and stages of those with Alzheimer’s disease and MS. Some of this information will also be useful for caregivers who are looking after loved ones with other neurological conditions, such as Parkinson’s disease.

A. ABOUT ALZHEIMER’S DISEASE

Alzheimer’s disease (AD) is the most common form of dementia, a term used to describe a group of symptoms affecting intellectual and social abilities severely enough to interfere with daily functioning. Memory loss generally occurs in dementia, but memory loss alone doesn't mean you have dementia. Dementia indicates problems with at least two brain functions, such as memory loss along with impaired judgment or language. Dementia can cause confusion and an inability to remember people and names.

A Global Scourge
Barring a medical breakthrough, the World Alzheimer report projects dementia will nearly double every 20 years. By 2050, it will affect 115.4 million people worldwide.⁷

Dementia may also cause changes in personality and social behavior.⁸ The second most common form of dementia is called vascular dementia, which is an umbrella term used to describe a series of conditions caused by problems in the supply of blood to the brain, often as a result of stroke(s) or small vessel disease.⁹

Alzheimer's disease occurs in one in ten people over the age of 65.¹⁰ According to recent assessments, the rate of Alzheimer's disease is going to nearly double every 20 years.¹¹ By 2050, 43 percent of those with Alzheimer's disease will need high-level care, equivalent to that of a nursing home. The largest increase in the prevalence will occur in Asia, where the number of Alzheimer's cases is expected to grow from 12.65 million in 2006 to 62.85 million in 2050.¹²

Alzheimer's disease is often thought about in three stages:

- **Mild Alzheimer's disease** (also called early-stage). In mild AD, the first stage, people often have some memory loss and small changes in their personality. They may have trouble remembering recent events or the names of familiar people or things. They may no longer be able to solve simple math problems or balance a checkbook. People with mild AD also slowly lose the ability to plan and organize. For example, they may have trouble making a grocery list and finding items in the store.
- **Moderate Alzheimer's disease**. This is the middle stage of AD. Memory loss and confusion become more obvious. People have more trouble organizing, planning and following instructions. They may need help getting dressed and may start having problems with incontinence. This means they can't control their bladder and/or bowels. People with moderate-stage AD may have trouble recognizing family members and friends. They may not know where they are or what day or year it is. They also may lack judgment and begin to wander, so people with moderate AD should not be left alone. They may become restless and begin repeating movements late in the day. Also, they may have trouble sleeping. Personality changes can become more serious. People with moderate AD may make threats, accuse others of stealing, curse, kick, hit, bite, scream or grab things.
- **Severe Alzheimer's disease** (also called late-stage). This is the last stage of Alzheimer's and ends in the death of the person. In this stage, people often need help with all their daily needs. They may not be able to walk or sit up without help. They may not be able to

talk and often cannot recognise family members. They may have trouble swallowing and refuse to eat.¹³

B. ABOUT MULTIPLE SCLEROSIS

Researchers believe multiple sclerosis (MS) is an autoimmune disease of the central nervous system where communication between the brain and other parts of the body is disrupted due to a break down in the insulating myelin that surrounds a person's nerves. The manifestation of this disease for each individual is different, depending upon where the damage occurs in the individual's central nervous system, and how extensive the damage is.¹⁴

Common symptoms include fatigue, weakness of arms and legs, numbness, lack of coordination, loss of balance, visual problems, loss of bladder or bowel control, depression and emotional changes, cognitive problems and difficulty speaking. MS is not contagious or fatal, but a small number of people have a severe type of MS that may shorten life expectancy.¹⁵

Today over 2,000,000 people around the world have MS.¹⁶ Women are more likely to develop MS than men. There are four commonly-discussed disease courses for MS. For those newly diagnosed, it may not be clear what type you have for some time.

- **Relapsing/Remitting.** The majority of people diagnosed with MS—approximately 90%—are diagnosed with the relapsing/remitting type. The symptoms affect most people in their early 20s, after which there are periodic attacks (relapses), followed by partial or complete recovery (remissions). A relapse can last for a few days to several months. The severity can also vary. Symptoms may remain after relapse due to nerve damage. The pattern of nerves affected, severity of attacks, degree of recovery, and time between relapses all vary widely from person to person. Eventually, most people with relapsing/remitting MS will enter a secondary progressive phase of MS.¹⁷
- **Secondary Progressive.** People with this type of MS may have started with a diagnosis of relapsing/remitting and then started to experience a worsening of symptoms over many years. In this type of MS, the course of symptoms steadily progress, without relapses or remissions. The transition typically occurs between 10 and 20 years after the diagnosis of relapsing/remitting MS. Progression occurs at a different rate in each person and generally leads to some disability.
- **Primary Progressive.** In this form of MS, the disease begins with

a slow progression of neurological deficits where symptoms appear and gradually worsen over time, without significant plateaus or remissions. A person with primary progressive MS, by definition, does not experience acute attacks.

- **Progressive Relapsing.** Progressive relapsing MS is the least common form of disease—approximately 5 percent of people with MS have this form. Relapses or attacks occur periodically. However, symptoms continue and are progressive in between relapses.¹⁸

The above list represents very broad categories for MS. It does not definitively or adequately describe the experiences *everyone* has with the disease. It is difficult to predict who will remain relatively stable over time and who will progress or how quickly. The final stages of MS vary greatly for each individual with the disease, although most will see an increase in symptoms.

C. ABOUT OTHER NEUROLOGICAL DISORDERS

There are literally hundreds of neurological disorders that require care at various stages and different care as they each progress. If you or someone you know is a caregiver for a loved one with a neurological disorder, the first step is to find out as much as you can about the disease and its course. The next step is to connect with people who are involved in caring for individuals with the disease. There are multiple caregiving support groups across the world, as well as disease-specific support and advocacy organizations that have caregiver information and/or support available. Talk to your healthcare provider or go to your local health agency or library, or search online for relevant resources and support. See Section 3 for more information on taking care of yourself while caring for another.

D. WHAT TO EXPECT

Caring for someone with a neurological disorder can be a rewarding experience, but it can also have a significant impact on a caregiver's own life and health, both physical and emotional. Taking an educated and balanced approach to this important work will serve you and your loved one best over the course of the illness. Seeking input and support from friends and others who have done this work can prove invaluable, and lessen the stress or anxiety you might feel from not knowing what to expect.

For most neurological disorders, recognizing the ever-changing nature of the illness is a critical first step. Very often, the path will be unpredictable or will appear to be heading in one direction, only to suddenly change. As a caregiver, learning to accept these uncertainties

may be the most difficult part of your work — and is very stressful, in and of itself. At the same time, making future plans is also important. This may seem counter-intuitive, as it is hard to plan when you don't know what to expect, but there are many parts of caregiving that can be predicted, such as planning for regular doctor's appointments and daily routines such as mealtimes and other care. Learning all you can about the disease provides an anchor as the disease course begins to unfold.

E. PROVIDING LOVING AND INFORMED CARE

Regardless of the neurological disease your loved one is facing, there are some basic *guidelines* to consider that may be helpful for you, as a caregiver, to consider in providing the best possible care for your loved one:

- **Maintaining dignity.** Always remember that the person you are caring for is an individual human being with feelings.
- **Establishing routines.** A routine decreases decisions that you need to make and can provide an added sense of security to a person with a neurological disorder. Create a schedule for meals and activities.
- **Supporting independence.** It is important to encourage someone with a neurological disorder to remain independent for as long as possible. This helps maintain their self-respect and decreases your burden as a caregiver. Independence can be as simple as getting dressed, or as considerable, as managing finances and going to work.
- **Simplifying tasks and assistance with daily life.** Make day-to-day activities as simple as possible. Remove the burdens of household chores and maintenance, as necessary, by taking them over yourself, and/or seeking additional help.
- **Improving safety.** Take steps to make your home as safe as possible. This means locking up or removing medications and dangerous chemicals in your home, eliminating small rugs, clutter and extra furniture, and ensuring smoke detectors are in working order. It may also mean you need to make home modifications, such as installing safety railings, gates across stairways, and other assistance devices or equipment.
- **Keeping active.** Planned activities can enhance a person's sense of dignity and self-worth by giving purpose and meaning to life, as well as maintaining physical and mental capabilities.

- **Communicating.** Keep your communication simple and calm. Always speak clearly, slowly and face to face. Be aware of your body language. Make sure you have the person’s attention before speaking.
- **Treatment monitoring and adherence.** Ensure medications are taken regularly and as directed. Monitoring response and side effects can also be helpful. Long-term adherence to some of the treatments can be critical for positive outcomes.
- **Provide love and emotional support.** The mental well-being of your loved one is critical to their overall health. Create a loving and nurturing environment.¹⁹

As the neurological disease progresses, there are other considerations for caring for people as their physical and mental capabilities decline. These include:

- **Eating and Nutrition**

Ensuring proper nutrition and fluid intake is critical. Talk to your healthcare provider about diet recommendations. Focus on nutrient rich foods, especially if your loved one has limited appetite or tolerance. Serve high protein foods, add vitamin supplements as necessary, and avoid excessive sugar, salts and fats. Serve bigger portions at breakfast. Try to make mealtime as enjoyable as possible.

- **Swallowing and Choking Hazards**

People with neurological disorders can often develop trouble swallowing. It is important that mealtime is calm and not rushed, and that the person is not drowsy or lying down. It is also important to make sure the food is cut into small pieces and is soft enough to eat. There are many tips for helping someone eat who has difficulty swallowing. Talk to your healthcare practitioner if swallowing becomes compromised, and seek online resources for additional information.

At first, Mom would forget to eat. This was easy to manage by making her a plate of food and she’d eat. Then she started eating less and more slowly. Verbal reminders while she was eating handled this situation. Then Mom declined to where my father or I would feed her. This too eventually became a struggle as she would take bites of food, chew for a short time, and then forget to finish chewing or to swallow. We finally went to blended foods and liquid supplements. Mom had always made it clear that she didn’t want “artificial means to keep her alive-this included a ventilator and/or feeding tubes”. We honored her wishes and did the best we could. Feeding Mom would take an hour or more per meal.

- **Mental Health**

Depression and/or anxiety commonly occur alongside many chronic disorders. For some of the neurological disorders, their pairing is more likely. As a caregiver, watching for signs of mental health problems is critical in the overall well-being of your loved one, and to the prognosis of their neurological disorder. There has been substantial research looking at poor health outcomes due to co-occurring depression and anxiety. In most cases, the severity of depression or anxiety of your loved one can be eased with medication and/or talk therapy.

- **Moving Around**

If your loved one can no longer move around on his or her own, it may be helpful to talk with a nurse or home health practitioner who can show you how to move the person safely and make them more comfortable. There are various medical supplies and devices that can help with immobile patients, both in making them more comfortable and in helping to move them. You will also need to consider your own safety when moving your loved one.

- **Pressure or Bed Sores**

Skin problems, specifically pressure or bed sores resulting from staying in one place for too long, are common for people who are no longer mobile. Moving your loved one often (every hour or two), whether sitting up or lying down, and getting the appropriate seat padding and mattress, are critical in preventing skin problems. It is also important to consistently check their body for any redness or irritation. Talk to your healthcare provider if you see any signs of sores.

- **Sleep Problems**

Changes in sleep patterns are common for people with neurological disorders. They may be caused by physical discomfort, confusion or mental anguish, or medications. Encouraging some form of exercise each day is helpful, planning an outing, limiting naps, maintaining a normal routine and setting a quiet mood in the evenings before bedtime are all strategies to help your loved one get a good night's sleep.

- **Incontinence**

Neurological disorders or their treatments can lead to incontinence. It is important to bring any bladder or bowel problems to the attention of your health care provider. It could be a sign of something wrong, or it could be treatable with alterations in medication or additional

medications. As a caregiver, taking care of someone who is incontinent can be difficult, but there are many products available to ease this burden. Talk to a pharmacist or healthcare specialist for help.

- **Dental Hygiene**

It is important as the disease progresses, and as your loved one ages, to pay close attention to their dental hygiene. Make sure the teeth are brushed daily and a dentist is seen on a regular basis. Also check for decay or mouth sores.

- **Foot Care**

Taking care of feet is also important. If your loved one is no longer capable, you will need to make sure his or her feet are kept clean and free of cuts, calluses, or cracks, with the toenails trimmed. Talking to a foot doctor (podiatrist) is important if there are any signs of foot sores or problems.

F. CARING FOR SOMEONE WITH ALZHEIMER'S DISEASE OR DEMENTIA

Research has shown that most people with dementia live in their own homes and are cared for by a female caregiver, and that care is associated with substantial psychological and financial strain.²⁰ In contrast to developed countries, more than a quarter of people with dementia in developing countries live in a multigenerational household with their children and grandchildren.²¹

Taking care of someone with Alzheimer's disease (AD) or dementia can impact every aspect of your daily life. There are several major challenges that you may face, most prominently changes in **communication, personality and behavior**.

Communication is difficult for people with AD and dementia, simply because they have trouble remembering things. This means they have:

- Trouble finding the right word when speaking

Lee is constantly asking me where I am going, and follows me around the apartment. I have to tell him the same things over and over again, and he jumps every time I come into the room. He refuses to take a shower, and when I tell him it is time to take one, he lies and says he just did it. Yesterday, when our daughter came to visit with her children, he couldn't remember their names. I kept saying, Lee, you remember, these are Maya's children. He said he felt dizzy and went to his room. I feel as though I am living with a stranger.

- Problems understanding what words mean
- Problems paying attention during long conversations
- Loss of train-of-thought when talking
- Trouble remembering the steps in common activities, such as cooking a meal, paying bills, getting dressed or doing laundry
- Problems blocking out background noises from the radio, TV, telephone calls or conversations in the room
- Frustration if communication isn't working
- Sensitivity to touch, tone, and loudness of voices²²

Being sensitive to the communication challenges of people with AD or dementia is important. Be aware of your tone and body language, use touch while talking to show you care, make eye contact and be encouraging and try to remain calm even during angry outbursts.

Personality and behavior changes are also common over the course of AD or dementia. Your loved one may:

- Get upset, worried and angry more easily
- Act depressed or not interested in things
- Hide things or believe other people are hiding things
- Imagine things that aren't there
- Pace a lot of the time
- Exhibit unusual sexual behavior
- Hit you or other people
- Misunderstand what he or she sees or hears
- Stop caring about how he or she looks, stop bathing, and want to wear the same clothes every day.²³

Some of the most difficult aspects of caring for someone with AD or dementia are the changes in behavior or personality. It can be frightening to see your loved one become paranoid or aggressive. Working with your healthcare practitioner to get appropriate medication and assistance in coping with these behaviors is important.

Wandering away from home or getting lost is not unusual for people with AD or dementia. Make sure your loved one has an ID bracelet with your phone number, especially if he or she walks alone. Keep doors locked, and consider putting a bell or other noise-making device on your door to know when it opens. Let neighbors and local police know you are caring for someone with AD or dementia. There are also cell phones you can purchase that can function as tracking devices for someone who is lost.

Home safety is vital for your family. Over time, people with AD will be less able to manage simple tasks, such as turning the water off, how to

use the telephone, or where things are in your home. You will need to continually address your home environment to ensure it is safe for your loved one.

G. CARING FOR SOMEONE WITH MULTIPLE SCLEROSIS (MS)

The most common caregivers for people with multiple sclerosis (MS) are spouses, children and aging parents.²⁴ Caring for someone with MS can be difficult because the disease is unpredictable, and thus, caregiving needs are continually shifting. Each person with MS has a different set of symptoms and disease course.²⁵ The most common type of MS is a disease that relapses and remits, meaning there are often times of high functioning and capability, and other times where the person will need significant support and assistance.

The needs of those with MS vary greatly and can change drastically over time, but often not in a progressive pattern. This can make caregiving very complicated, as there it is difficult to know when the person with MS will need care and how much. There are many advocacy and support groups, both online and across the world, that may be critical to you as a caregiver, to know how to deal with the ups and downs and the unpredictable nature of the disease. From these, a rich wealth of information may be garnered. In addition to the general caregiving guidelines and considerations listed above, some of the primary issues facing a MS caregiver include the following:

- **Visual**

The optic nerve is a common area for inflammation in MS. Because it is responsible for carrying vision signals to the brain, visual disturbances are common. They range from haziness and blurred vision to more serious visual impairment. Often, visual symptoms lessen or disappear after a period of weeks, upon remission. Blindness in MS is rare.²⁶

- **Movement problems, sensory feelings and spasticity**

People with MS will often have difficulty in controlling the strength and precision of movements, so that holding things can become a problem, and balance and coordination may be impaired. They also experience numbness, tingling, sensitivity to heat or cold. Approximately 85 percent of people with MS report some spasticity, which leads to increased stiffness or tightness in their muscles adversely affecting movement. They may or may not experience other components of abnormal muscle tone, such as spasms.²⁷ Complications from spasticity include pain, joint contractures, frozen joints, impaired bladder or bowel function, skin ulceration, and abnormal postures and falls.²⁸

Helping your loved one get some type of daily exercise can be critical to their well-being and may affect the course of their disease. Research has shown exercise achieves significant benefits: increased mobility, strength, energy output for daily activities and social interactions; as well as decreased disability levels, depression and anger.²⁹ Talk to your health care practitioner for recommendations. In planning, periods of exercise should be carefully timed to avoid the hotter periods of the day and prevent excessive fatigue.³⁰

- **Cognitive Problems**

It is now recognised that MS may cause problems with memory, planning, foresight and judgment. The most frequent cognitive abnormalities in MS are subtle defects in abstraction, memory, attention and word finding. Occasionally, a person experiences severe cognitive difficulties and is said to have "cerebral MS." There are many strategies to help in managing cognitive problems, including: making lists; using a calendar regularly; establishing a memory notebook to log daily events, reminders, or important messages; using a tape recorder; organizing your environment so that things remain in familiar places; avoiding distractions during conversations; repeating information and take notes; establishing good eye contact during any discussion.³¹

- **Fatigue**

Fatigue is one of the most common symptoms of MS, occurring in about 80% of people. Fatigue can significantly interfere with a person's ability to function at home and at work, and may be the most prominent symptom in a person who otherwise has minimal

With Amelia, it has been very hard to know when she will need our help. She will be totally fine for months at a time, and then suddenly, she will get double vision, or her left leg will go completely numb, and she will need constant help getting around and taking care of herself. And then just as suddenly as it came on, it will go away again, sometimes as a result of medication, of taking intense doses of steroids, and other times, it seems to just go away on its own. One day, we will be there making her breakfast, laying out her clothes, carrying her down the stairs of her apartment, staying with her throughout her days and nights, and the next day, she will be on her own again, completely capable of doing everything. We never know how long her episodes will last or even if, this time, they will go away at all. Sometimes, they last for weeks; other times, for months, and then we are all worrying that this time, it won't go away and she will be like this forever. Then, suddenly, the symptoms disappear. And we all REJOICE! Yet, it is very hard to not know what to expect and when you will be needed, or for how long.

activity limitations.³² Oftentimes, the person with MS may appear lazy when they are really coping with the fatigue often associated with the disease.

- **Speech**

Speech difficulties are common in MS and especially in people with advanced disease, and can result from damage to areas of the brain that control language, speech production, swallowing, breathing, and cognition. They can range from mild difficulties where the person takes extra long pauses between words or syllables to severe problems that make it difficult to speak and be understood, such as slurred speech. Losing the ability to communicate effectively through speech can be devastating for both you and your loved one. Be patient and kind with each other. There are assistive devices that may be helpful, everything from voice amplifiers to alphabet cards to computers.³³

- **Pain**

Pain is often an overlooked part of caring for someone with MS. Several recent studies have suggested that between 43-80 percent of people with MS experience pain, which significantly impacts quality of life and functioning in people with MS.³⁴ People in the advanced stages of MS can have pain related to spasticity, infection, pressure sores, headache, muscle contractures, as well as muscle and bone pain that can come from their limited ability to move.³⁵ Continued research is needed on effective pain management for people with MS,³⁶ but working with your healthcare practitioner to ensure you are doing your best to manage the pain your loved one is experiencing can be critical in his or her quality of life.

- **Respiratory Problems**

MS can cause weakness of muscles used for breathing. When muscles are weakened, respiration can become labored. Decreased mobility can contribute to pneumonia. People with MS can have difficulty fighting bacteria and viruses.³⁷ Be watchful for signs of labored breathing or illness during all stages of the disorder, particularly when your loved one is otherwise compromised due to a relapse or other symptoms.

- **Emotional Disturbances**

Emotional issues are common in people with MS.³⁸ These include serious mental illnesses, such as anxiety, depression, and bipolar disorder, but they can also consist of frequent mood swings, or volatile moods, frequently called “emotional incontinence” by those with MS.³⁹ As a caregiver, educating yourself on the signs and symptoms of mental illness, as well as the common mood swings of

people with MS, will be helpful to both you and your loved one.

- **Hearing Loss**

While uncommon, hearing loss can be a result of MS and in some, is the first symptom of the disease. It is usually associated with other symptoms that suggest damage to the brainstem, the part of the nervous system that is involved in the control of vision, hearing, balance and equilibrium.⁴⁰

H. COMPOUNDING HEALTH PROBLEMS

People with AD, dementia, MS or other neurological disorders may have additional co-occurring illnesses, some a result of these illnesses, and some that are completely separate. They can be common ailments, such as the flu or constipation, or can include other serious diseases, such as Parkinson's, depression, heart disease. Ensuring proper treatment of *all* illness is critical to the health the care recipient. As a caregiver, acting as a liaison and communicator between doctors can be an additional, yet invaluable job.

Section II. Common Issues Faced by Caregivers

Globally, caregivers will continue to play an important and ever-expanding role as developments in medical care extend human life, and health and social services systems are resource-challenged. Now, more than ever, caregivers are needed to help care for those with neurological and other chronic disorders.

This section outlines how caregiving can contribute to the onset of stress, depression and anxiety.

Given this fact, the range of caregiving issues – including carers' situations and needs – are being more intensely studied so that the impacts of caregiving on caregivers are better understood. Indeed, research in the last decade has focused more specifically on how caregiving contributes to caregiver stress, depression, and anxiety.

A. A SNAPSHOT OF CAREGIVER SITUATIONS AND NEEDS

The majority of caregiving is provided by spouses, relatives, and friends like you. In most cases, carers receive little recognition for this valuable work, and policies in most countries do not provide financial support for the care services they provide. However, a caregiver's movement is gaining momentum in many countries, driven by the work of many non-governmental organizations (NGOs) trying to change government policies affecting caregivers. One initiative of a European-based NGO, Eurocarers, called EuroFamCare, surveyed carers about their caregiving needs.⁴¹ The survey of carers from 23 European countries reported that while the benefits of caring for a loved one outweigh the costs, the reality is this – caregivers face difficult and demanding issues and need more **resources and support**. According to the survey,⁴² caregivers report that they:

- Need **more information and advice** on diseases, and availability and access of support services
- Are **overburdened**
- Are at **high risk to falling ill oneself**
- Have difficulty **combining care and paid work**
- Have a **loss of income**
- Feel like they are **all alone**
- **Do not feel appreciated** in their care work

- Have an often **hidden, but high risk for physical, psychological, sexual, financial abuse and neglect**

Clearly, caregivers face many issues when caring for a loved one with a neurological disorder. Indeed, a large and expanding set of scientific evidence confirms that caregivers carry a significant burden and face many potentially serious health problems.⁴³ The impact of caregiving on emotional health can be significant. Without good emotional health, shouldering the increased burdens of caregiving (e.g. managing medical, financial and legal issues), in addition to managing paid work and caregiving, becomes nearly impossible.

B. THE IMPACT OF CAREGIVING ON YOUR MENTAL HEALTH

Several factors impact a caregivers' mental health, including his/her relationship with the care recipient, the nature of the disability, the stage of disease⁴⁴ and the lack of social support/social network.

- **Relationship with the Care Recipient**
Caring for a loved one, particularly a parent, spouse, or child is especially difficult as you are faced with the decline in the person's cognitive and physical capabilities. Watching the day-to-day decline in the thought processes, such as those seen in Alzheimer's disease or dementia, can be especially painful as they perhaps struggle to remember your name and face. Watching someone's memories slowly disintegrate, especially someone that you love, with whom you have shared so many of those memories, can be a devastating experience. It has been described as a series of grief experiences as you watch the memories disappear. Caring for someone with multiple sclerosis (MS), perhaps your child who is now an adult, watching them struggle with relapses and hope for recovery, can be heart-wrenching. The emotional toll that this takes is indescribable.
- **Nature of the Disorder/Disability**
Neurological disorders, like Alzheimer's and MS, can be by nature, significantly disabling. The nature of the disorders is such that the needs of those cared for can be intense, from the cognitive breakdowns of Alzheimer's, which is often accompanied by the physical wearing down and aches and pains of old age, to the unpredictable and often progressive disabilities seen in those with MS.
- **Stage of the Disease**
Providing caregiving for those with neurological disorders can be particularly difficult as the diseases progress. For Alzheimer's or

dementia, it is hard to care for someone you love while watching them slowly slipping away or even become volatile or paranoid. For a disease like MS, it can be a struggle to not know the course the disease will take, when your loved one may relapse, how long it will last, and if the disability will continue or worsen. The intensity of care needed for those with neurological disorders such as MS and Alzheimers can be overwhelming as the diseases progress and the care recipient becomes increasingly oblivious, unable to communicate, and/or disabled.

- **Lack of Social Support/Social Network**

Caregivers frequently become isolated from family and friends as they are caring for a loved one. Little time is often left to devote to maintaining friendships and social networks. This social isolation can increase as the disease(s) progresses and caring demands increase. Caregivers who don't have sufficient social support from family and friends often feel isolated and alone in their caregiving, increasing stress.

Family conflicts further exacerbate the isolation and loneliness many caregivers feel. For those living in a rural community, this can be doubly hard, as they are *geographically* removed from support and services. While social support may not affect the primary stress caused by the disease, it can change the caregiver's response to the illness. Feeling supported by family and friends can improve your psychological responses to stress and boost the caregiver's sense of well-being.

C. STRESS, ANXIETY AND DEPRESSION: YOU ARE NOT ALONE

Caregiving can take a tremendous toll your emotional as well as physical health. Stress, depression and anxiety are very common among caregivers. Watching a loved one struggle, and for many, caring for them without enough resources, especially emotional and financial support, is directly related to the caregiver's health, both emotionally and physically. Worldwide, caregivers are impacted by the daily care that they provide. Some examples from research include:

- An Italian study reported that **caregivers' quality of life is directly related to the severity of behavioral disorders and duration of Alzheimer's disease**. The increase in anxiety and depression is directly proportional to the severity of the illness, affecting the patients.⁴⁵

- A Norwegian study of **caregivers of patients with MS experienced high levels of distress and reduced quality of life** related to caregiving.⁴⁶
- A Kuwaiti study found that **caregiver quality of life was more affected by their fear of having MS than their feelings about the illness and caregiving role.**⁴⁷
- A London study found that **23.5% of caregivers had anxiety and 10.5% had depression.**⁴⁸

The emotional impact of caregiving is well-documented, worldwide. Women, minority, and low-income caregivers can be especially affected by the demands of caregiving.

D. THE IMPACT OF CAREGIVING ON WOMEN AND MINORITY CAREGIVERS⁴⁹

Caregivers are more likely to be women (in almost 80% of the cases); perhaps a daughter, wife, sister or daughter-in-law of the person being cared for.⁵⁰ Women tend to stay home to provide time-consuming care to one or more ill or disabled friends or family members, while men respond to loved one's needs for support by delaying retirement, in part to shoulder the financial burden associated with long-term care.

The impact of the women's intensive caregiving can be substantial. Middle-aged and older women who provided care for an ill or disabled spouse were almost **six times as likely** to suffer depressive or anxious symptoms as were those who had no caregiving responsibilities. It's not only care for a spouse that can affect mental health, however; the same study found that women who cared for ill parents were twice as likely to suffer from depressive or anxious symptoms as noncaregivers.

A particularly strong factor in determining the mental health impact of providing care is the *amount of care per week* that a woman provides. One study found a marked increase in risk for mental health problems among women who provided 36 or more hours per week of care to a spouse. Researchers concluded that there may be a threshold of time involvement beyond which the likelihood of mental health consequences rapidly escalates.

Some common hallmarks of women's caregiving experience include:

- A higher level of hostility and a greater decline in happiness for caregivers of a family member;

- Greater increases in symptoms of depression, less “personal mastery” and less self-acceptance;
- High caregiving-related stress.

Compounding this picture, physical ailments are not uncommon. Researchers found that **more than one-third of caregivers** provide intense and continuing care to others while suffering from poor health themselves. Additionally, a 1999 study indicated that as compared to noncaregivers, women caregivers were twice as likely not to fill a prescription because of the cost (26% vs. 13%). Elderly women caring for a loved one who has dementia may be particularly susceptible to the negative health effects of caregiving because they receive significantly less help from family members for their own disabilities.

Despite the personal impact of caregiving, women caregivers are simply less likely to meet their own health needs. For example, compared to non-caregiving women:

- 25% (vs. 17%) rated their own health as fair or poor;
- 51% (vs. 38%) exhibited depressive symptoms;
- 16% (vs. 8%) were twice as likely in the past year not to get needed medical care.

Caregiving can have negative health effects. Taking care of yourself will allow you to enjoy your role as a caregiver, which can be rewarding. Some women caregivers reported a caregiver “gain”: more purpose in life than their noncaregiving women peers, and reported beneficial effects including more autonomy, more personal growth and more self-acceptance when caring for friends.

Minority and Low-Income Caregivers in the U.S.

Like women, minority and low-income caregivers may face additional challenges. Forty-one percent of single African American women ages 65+ are poor; for elderly Hispanic women, the poverty rate is 49%. For these caregivers, accessing paid sources of care may be particularly difficult. In fact, lower-income caregivers are **half as likely** as higher-income caregivers to have paid home health care or assistance available to provide support for and relief from their caregiving functions. This is important, because the caregiving time burden is reported to fall heavily on lower-income women: 52% of women caregivers with incomes at or below the national median of \$35,000 spend 20+ hours each week providing care.

Men as Caregivers: A Gender Role Reversal

Recent estimates indicate that the majority of caregiving is done by females (approximately 80%). However, as additional carers will be needed worldwide in the future, more males are likely to become caregivers. Less research on the male caregiving role has been done, and as a result, the number of reported male caregivers in each country varies widely – from 10% of the caregivers in Japan and Uganda, to nearly 50% in the US, Israel, Sweden).^{51, 52}

In many countries, the increased need for caregivers is changing social norms and traditional gender roles within families.⁵³ Research indicates that men and women share some common caregiving experiences. For example:

- A US study of men caring for the partners with Alzheimer's revealed similar experiences to female caregivers: commitment, social isolation, the loss of companionship, control, sense of accomplishment, a problem-solving approach, burden lessening with years of caregiving, and limited expectations of children.⁵⁴
- A study in Japan indicated that there was little difference in the care burden among male and female caregivers.⁵⁵

New research conducted in this area has focused on the different approaches and experiences of male caregivers, with some studies finding that male caregivers are less stressed and better at task management and seeking outside resources. This research has met with controversy, and a recent meta-analysis has found that contrary to common perceptions, gender differences in caregiving are small.⁵⁶

As more men are likely to take on caregiving roles in the future, additional research needs to be conducted to see how the male caregiving role – a role reversal in many if not most countries – impacts their physical and emotional lives and their financial livelihood.

E. CAREGIVING'S MENTAL HEALTH IMPACT: STRESS, DEPRESSION, ANXIETY AND OTHER ILLNESSES

Caregiver Stress

Caregivers are at risk for many different **physical and mental health challenges**. In general, they suffer from high levels of stress and frustration, show higher levels of depression than the general population, sometimes exhibit harmful behaviors, from increased use of alcohol or other substances to higher than normal levels of hostility. Caregivers are also **physically less healthy** than noncaregivers, and have more chronic illnesses like high blood pressure, heart disease, diabetes and arthritis than their noncaregiving peers. They may also suffer from poorer immune function and from exhaustion. They neglect their own care (have lower levels of self care and preventive health behaviors than others), and have higher mortality rates than noncaregivers of the same age.⁵⁷ Given these odds, caregivers need to take good care of themselves, and reduce their levels of stress, depression, and anxiety.

Caregivers of people with Alzheimer's disease and other neurological disorders report that they frequently experience high levels of stress. Too much stress can be damaging to both a caregiver and to the care recipient. If you experience some of these signs of stress on a regular basis, consult your doctor. Ignoring them can cause your physical and mental health to decline. Some **symptoms of caregiver stress**⁵⁸ include:

1. **Denial** about the disease and its effect on the person who's been diagnosed. *I know Mom is going to get better.*
2. **Anger** at the person with the disorder or others, anger that no cure exists or anger that people don't understand what's going on. *If he asks me that question one more time I'll scream!*
3. **Social withdrawal** from friends and activities that once brought pleasure. *I don't care about getting together with the neighbors anymore.*
4. **Anxiety** about facing another day and what the future holds *What happens when he needs more care than I can provide?*
5. **Depression** that begins to break your spirit and affects your ability to cope. *I don't care anymore.*

6. **Exhaustion** that makes it nearly impossible to complete necessary daily tasks. *I'm too tired for this.*
7. **Sleeplessness** caused by a never-ending list of concerns. *What if she wanders out of the house or falls and hurts herself?*
8. **Irritability** that leads to moodiness and triggers negative responses and actions. *Leave me alone!*
9. **Lack of concentration** that makes it difficult to perform familiar tasks. *I was so busy, I forgot we had an appointment.*
10. **Health problems** that begin to take their toll, both mentally and physically. *I can't remember the last time I felt good.*

There are various tools, many available on the internet, to check on your own stress levels. The **Caregiver Stress Check** is one brief tool to determine your levels of stress, and provides resources to resolve this stress; [Click here to take the STRESS CHECK.](#)

Caregiver Depression and Anxiety

If stress builds up without being managed, depression and anxiety may result. As a result of the demanding and emotional work of caring for someone with a neurological disorder, caregivers tend to suffer clinical depression and anxiety more often than the general population.

Depression. Many caregivers—with some reports as high as fifty percent—experience depressive symptoms severe enough to need treatment⁵⁹. As a caregiver of someone with a neurological disorder, you should be aware of the signs of depression and talk to your doctor if you have symptoms. Providing the best care for your family member requires that you remain emotionally healthy and physically strong. The following symptoms in caregivers may indicate depression:

- Persistent **sad, anxious or "empty" mood**
- **Sleeping too much or too little**, middle of the night or early morning waking
- Reduced appetite and **weight loss**, or increased appetite and **weight gain**
- **Loss of pleasure and interest in activities** once enjoyed, including sex
- **Restlessness, irritability**
- **Persistent physical symptoms** that do not respond to treatment (such as chronic pain or digestive disorders)

- **Difficulty concentrating**, remembering or making decisions
- **Fatigue or loss of energy**
- **Feeling guilty, hopeless or worthless**
- Thoughts of **suicide or death**

GET HELP FOR DEPRESSIVE SYMPTOMS. Caregivers can benefit from maintaining their social support system. Keeping connected with those who **understand** the impact of caregiving – via support groups or caregiver networks – will help you to deal with your sadness and the isolation that can accompany caregiving. If you have five or more of these symptoms listed above, see your healthcare provider.

Typical treatment for depression includes talk therapy and/or antidepressant medication, which can help to alleviate the symptoms. Treating mild depression can make a big difference in the meeting the day-to-day caregiving tasks before you.

Anxiety. Many caregivers suffer from anxiety; for example, anxiety affects about a quarter of caregivers for people with dementia.⁶⁰ As a caregiver, you have a lot of responsibilities, and you have many details that cause you to worry much of the time. You should seek help for your anxiety if:

- Your worries have bothered you **most days** for the last six months
- You worry **about lots of things** at once even when there is no particular reason to worry
- You **can't stop** or even control worrying, however hard you try

This type of worrying can get in the way of your daily activities. For example, perhaps you're too anxious to make a phone call for appointments, or to even drive to an appointment. Or perhaps the constant caregiving has eroded your confidence in your abilities, and you are performing poorly at your job. If you have anxiety disorder, you will also have at least three of these other symptoms.

- You're **restless** and can't relax. You often feel keyed up or on edge.
- You get **tired** easily. You get worn out by a short trip to the shops. Or you feel like sleeping all the time, even when you have just got up.
- You **can't concentrate**. Your mind keeps going blank. You have trouble staying focused on what you are doing.
- You're **irritable**. Everyone gets grumpy sometimes, but some people with anxiety disorder feel cranky most of the time.

- Your **muscles are tense**. This can make you shaky. Your hands may tremble so much that you spill your coffee or can't write clearly. You may also get aches and pains in your muscles.
- You **sleep badly**. You have trouble falling asleep or staying asleep. Or if you do sleep, your sleep is restless and doesn't make you feel refreshed.

Anxiety can also cause physical symptoms. These symptoms can be very frightening, and people with anxiety disorders often think they have a physical illness. Many people with anxiety have heart palpitations (your heart beats faster than normal), making them think they are having a heart attack. Other physical symptoms include: cold, clammy hands, dry mouth, sweating, nausea, diarrhoea, and shortness of breath.

GET HELP FOR YOUR ANXIETY SYMPTOMS. You may be able to relieve your anxiety symptoms through relaxation techniques. Many self-help techniques like meditation and stress reduction help you cope with stress more efficiently. There are many online resources available to teach you how to reduce your stress; [click here](#) for one of these resources.

However, if anxiety still persists, it is typically treated with medication or talk therapy, or a combination of both. Consult your healthcare provider for the best treatment plan. Sometimes, a medical condition can also cause anxiety symptoms; check with your healthcare provider to be sure you do not have any other underlying medical conditions. In addition, other conditions, such as alcoholism or depression, can complicate treatment; be sure to talk to your healthcare provider about these other conditions so that they can be treated as well.

Caregiver Syndrome: Untreated Stress, Depression and Anxiety

Many over-exhausted – and perhaps even physically ill – caregivers do not seek help because they do not realize that they are as emotionally drained and physically ill as they really are. This state of exhaustion, though not officially recognized by the medical community worldwide, is called **caregiver syndrome**.

Caregiver syndrome is a result of “unrelieved constant caring for a person with a chronic illness or dementia.”⁶¹ It is the prolonged stress of caregiving and the resulting depression, anxiety, financial loss, physical strain and frustration of caring for someone that causes this chronic yet treatable condition. By managing your stress, anxiety or depression, you can prevent further significant illness like caregiver syndrome.

Summary: Take care of yourself. The stress, anxiety and depression that can result from caregiving are all treatable conditions. You are not alone, and there is help.

The remainder of this booklet outlines how to get the support you need to best care of yourself while you care for loved ones, and in particular, maintain good mental health and a positive outlook.

Section III. Caring for Caregivers: Taking Care of Yourself

Caregivers across the world, who are often unrecognised and under-supported, are deeply and personally impacted by the care they provide. Despite the burdens they shoulder, many caregivers report enormous positive feelings about the care they provide.⁶² Caregivers need resources and support to sustain this loving and valuable care of those with neurological disorders.

What do Caregivers Need?

The ten principles outlined in the box to the right were developed by EuroFamCare to assist governments and NGO's all over the world in developing programs to support caregivers. These principles directly outline some of the needs of caregivers, such as time off, support, and information. You may share some of the same needs.⁶³

As a caregiver, you need a plan. A “**Caring for the Caregiver Plan,**” described below, will help you to both navigate life during this uncertain time, and will help to maintain good emotional and physical health. The Caregiver Principles outlined to the right should be incorporated your own Caring for the Caregiver Plan. While it may take some work upfront, a “**Caring for the Caregiver Plan,**” will set the stage for a more positive caregiving experience.

Caregiver Principles:

- **Recognition**
- **Social inclusion**
- **Equality of opportunity**
- **Choice**
- **Information**
- **Support**
- **Time off**
- **Compatibility of care and employment**
- **Health promotion and protection**
- **Financial security**

This **Caring for the Caregiver Plan** should have three parts:

- **Coping** with day-to-day demands
- **Creating** a community of carers to support yourself
- **Caring** for your mental health

A. COPING WITH THE DAY-TO-DAY DEMANDS:

DEFINING AND GETTING THE HELP YOU NEED

In order to cope with the day-to-day demands of caregiving, you will need help. There are several steps in asking for and accepting help. These steps include: **understanding** why it is okay to get help; **defining** the help you need; and finding **resources for help**. If you are a caregiver caring for a family member(s), **holding a family meeting** at the outset of caregiving is crucial to not only your emotional and physical health, but the overall success you will have in providing care for a family member.

Step 1: Understand That it is Okay to Get Help

Often, as a carer, you may hear people ask how they can help; however, few carers actually follow-up on these offers of help. Just as paid workers get a lunch break or a week-long vacation, you too need these necessary and built-in breaks in care. In order to maintain good emotional and physical health, you must **ask for and accept help**, even if you don't think you need it. Caregivers may often have these feelings about getting help:

- **“It’s not okay to ask for help”**

Remember that everyone needs help at times. It's okay to ask for help and to take time for yourself.

- **“I feel guilty getting help”**

It is all right to leave the person in your care with someone else; just as paid workers get a regular holiday, you too need time off to care for yourself.

- **“I don’t think I can get help”**

Though you might think that no one will help even if you ask, try. Seek out resources in your community, and ask family and friends.

- **“If my family *won't* even help, maybe I don't really need it.”**

Understand that some family members *won't* be willing to help; each family member has a different family history that dictates their emotional capacity and willingness to provide help.

Understand that asking for help is a sign of strength and not of weakness. It is okay to get help, and likely, you can get the help you need. Step one is to clearly define the help you need; the next section describes in detail how to define the help you need.

Step 2: Define the Help you Need

Defining the help you need is a critical step, and it may be difficult at first. Recognise that caregiving, like all jobs, is made up of lots of individual tasks, not all of which are of the same importance. A critical piece is to write down all that you do, even the “little things.”

1. List all of your **care-giving related tasks** that need to get done during a typical week.
2. Group your list into **categories**: personal care for your loved one, transportation, household chores, healthcare activities.
3. List your **care-giving worries** (for example, who will care for my loved one if I get sick? What will happen to my loved one if she falls when I’m not home?)
4. **Show your list to others** (e.g. a family member, good friend, your health care provider or nurse, etc.) to generate more ideas and insights. The intent is first to get comfortable with the idea of talking about your need for assistance, and hopefully get some encouragement and good ideas in the process.
5. Finally do it! Take a deep breath and **actually ask someone to help** with one of the tasks on your list, or ask for guidance in resolving your most persistent worry. Start with something small, but start!⁶⁴

Though getting help takes work (and energy you might not have right now), it is worth doing. Keep in mind that the goal of getting help is better care for your loved one – and for yourself.

Step 3: Seek out Resources for Help in Your Community

Caregiver support programs vary from country to country, culture to culture. In some countries, families are now legally required to provide for the welfare of elders (e.g. Latin America). Recent laws in the UK give caregivers the right to request needs assessments, supportive services, and flexible work schedules. Other countries provide cash carer payments or carer allowances (e.g. Australia, Ireland, Israel, China). Many countries are still in the early stages of defining the challenges of caregiving, with progress and solutions influenced by internal resources and cultural traditions. [Click here](#) for an update on international caregiving laws.

In many communities, a range of services is available to assist and support caregivers. The following list, organized by **type of resource**,

while not exhaustive, provides a starting point for searching for resources in your area.

Table 1. List of Potential Support and Resources Available to Carers⁶⁵

Caregiver resources and support vary by country. Many new laws have been passed providing financial support and respite care, training, and education. Contact your local, regional, state or national government health or aging-related agencies for information on these supports.

Type of Support	Description	Who to Contact
Counseling	Counseling for caregivers	Healthcare Professionals
Government Financial Support	<ul style="list-style-type: none"> ➤ Income compensation (welfare or salary) ➤ Compensation for expenditures ➤ Time Compensation ➤ Paid respite ➤ Mandatory days off of care 	
Information, Advice and Emotional Support	Fact sheets, brochures and support groups	Non-profits, NGOs, libraries, universities and healthcare professionals
Other Support	Caregiver health check-ups	NGOs/Non-Profits
Peer Support	Online or group support	NGOs/Non-Profits
Respite Care Programs	Voluntary home-care, short-term day care, volunteer care	NGOs/Non-Profits
Recognition and Legal Rights	Formal government laws to recognise carers	Federal, regional, or state governments
Training/Education Programs	Provide “caring for the carer programs”	NGOs/Non-Profits

In addition, some programs designed to serve the care recipient can also help the caregiver (e.g. meals being brought in, medical alert programs, like Lifeline, chore or homemaker services, adult day care, or home health care). Check with your healthcare provider to determine the types of programs, information, assistance, training and respite care offered by governmental and non-governmental organizations in your area. Good

sources for this information also include the internet and your local library, or by contacting local, regional and state governments, as well as national programs.

You can also find additional resources from the **informal support network you may have already established**. For example, if you, or other extended family member like a mother or father, belong to a church, senior center, or service club, these organizations are often looking for ways to help others. Organizational newsletters are a great place to “advertise” your need for help.

Finally, while many services are available through local government agencies, service organizations, or faith-based organizations, **employers** are beginning to implement workplace support programs as one way to mitigate the impact that caregiving can have on workers.

Support Systems for Women Caregivers

Women are more than **twice as likely** as men to say that they would benefit from talking to someone about their caregiving experience.⁶⁶ As women’s role in the workforce grows, workplace-sponsored programs will become an important resource for women who both work and provide care to a loved one.

Summary: Because the needs of those with neurological disorders are likely to be complex and constantly changing, caregivers need a range of support services and programs (outlined above in Table 1) to remain physically and emotionally healthy. Utilizing these resources where available will allow you to be able to maintain your role as a caregiver, whether providing care at home or assisting with out-of-home care. Some basic caregiver support services available in many areas include information, counseling, and support groups. Caregivers should take advantage of these support services; research has shown that using these services keeps caregivers healthier and in their caregiving roles longer, and with less stress and greater satisfaction.

SPECIAL SECTION FOR FAMILY CAREGIVERS: THE IMPORTANCE OF FAMILY MEETINGS

Providing care for a family member with a neurological or other disorder is emotional in and of itself. Each family member has a long history of with the family, and likely carries conflicting expectations of what each family member should do with regard to caregiving. There is also often anger at things that have happened in the past, which may interfere with family members’ willingness to help share the caregiving tasks.

Holding family meetings is important in discussing and understanding everyone's perspective and availability to help in the care. Research has shown that family meetings can reduce depressive symptoms in caregivers and result in postponement of institutionalization.⁵⁹

Though difficult, the caregiver meetings should focus on current caregiving needs, rather than dwell on past conflicts. If this is not possible, a trained professional may be hired to lead the family meetings to be sure that a successful caregiving routine is established, and anger and resentment are not deepened. Failure to find a neutral party to assist in developing a fair caregiving plan may result in divisive actions among family members.

Talk Early. If you are caring for a family member with a neurological disorder, it is *essential that you hold a family meeting at the outset of the caregiving situation.* Talking about the caregiving situation in honest and open terms will allow everyone to **contribute** to developing a plan to provide the best care for your loved one, and in a way that maintains the primary caregiver's physical and emotional health.

Listen Carefully. A family meeting is an important opportunity for everyone to best **hear and understand** the current caregiving demands, to identify potential problems and solutions, and to work through defining and sharing caregiving tasks. The caregiver needs should be outlined (see Define the Help you Need, above) by the group. In addition, family members who are out-of-town should be included via phone to insure that they understand the current caregiving situation (and that the caregiving needs may change while they are away). Listen to each other and determine the best fit for the caregiving tasks you have defined. Be sure to also listen to what the person being cared for has to say. Make sure that each person hears the feelings of all involved. Develop a written plan listing what each person will do and when he or she will do it; utilizing an online website (e.g. [Lotsa Helping Hands](#)), discussed below in Section B, will facilitate the sharing of tasks.

Talk often. It will take more than one meeting to establish and maintain a good caregiving routine. Schedule a family meeting at least several times per year; this way, if a crisis arises, you are all more likely to all be on the same page. If the emotional toll of caregiving makes it difficult for you as the primary caregiver to hold a family meeting, contact your healthcare provider for the names of those who can help. A social worker, case manager, counselor, trained facilitator or mediator, or member of the clergy trained in

family counseling can help bring the family together to insure that the primary caregiving burden does not fall too heavily on one family member, endangering their emotional and physical health.

B. SUPPORT YOURSELF: CREATING A COMMUNITY OF CARERS

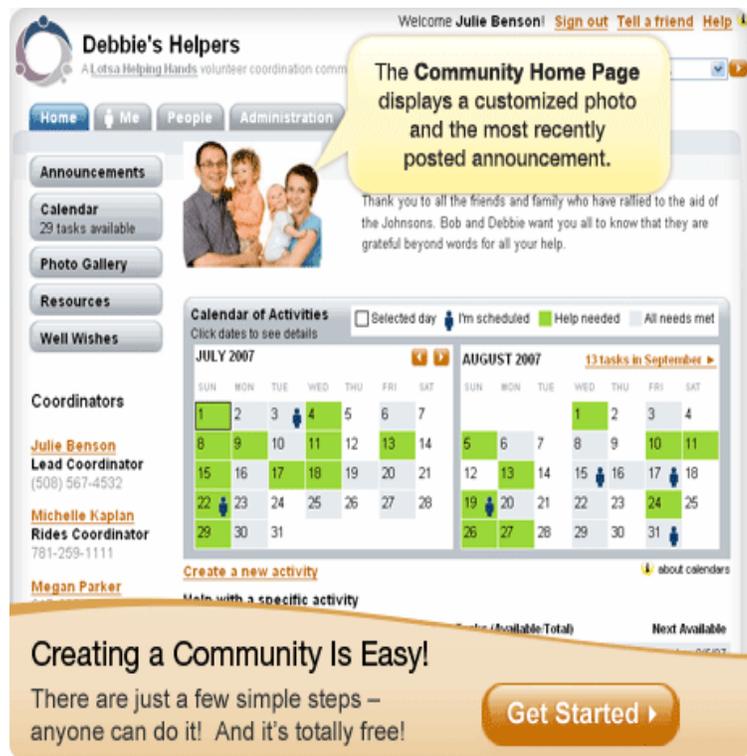
Hopefully, you are surrounded by many family and friends who can offer help. Having this help at hand will be invaluable to you. But how to coordinate this help? One way caregivers can coordinate offers of help is by using a web-based caregiving coordination service, such as Lotsa Helping Hands.

Lotsa Helping Hands is a web-based caregiving coordination service that allows family, friends, neighbors and colleagues to create a “community of caregivers” to assist with daily tasks. This service was developed in partnership with dozens of national nonprofit organizations in the U.S., and helps to bring together community members who can help caregivers with meals, rides, errands, childcare and other activities of daily living.

[Click here](#) to see and use this **free service**.

Each community you create includes an easy-to-use group calendar for scheduling tasks such as coverage or transportation to medical appointments, a platform for securely sharing vital medical, financial, and legal information with designated family members, and customizable sections for posting photos, well wishes, blogs, journals, and messages.

Now when someone offers to help, ask for their email address; from there, the system takes over and allows people to sign up and start helping.



Another more low-tech way to achieve a similar goal – creating a community of carers – is by using paper calendars to record scheduled doctor’s appointments and other routine, necessary tasks that must be

done (e.g. meals, laundry), and distributing these on a monthly basis to all those who offer to help. During the first week of each month, distribute these calendars and collate responses, assigning tasks for that month.

C. **PROTECT YOURSELF: CARING FOR YOUR MENTAL HEALTH**

Without good emotional health, the day-to-day tasks of caregiving – of managing doctor’s appointments, preparing meals and handling finances, perhaps on top of an already-demanding worklife – can lead to stress, and even perhaps depression or anxiety. You may be so busy caring for the person with a neurological disorder you don’t have time to think about caring for your own emotional health.

A substantial body of research shows that family members who provide care to individuals with chronic or disabling conditions are themselves at risk for emotional, mental, and physical health problems.⁶⁵

As a caregiver, you will need great emotional resilience as you meet the increasing caregiving demands of a loved one or friend with a neurological disorder under your care. Taking care of your emotional health means first and foremost, managing the stress of caregiving so that you can avoid caregiver burnout.

WATCH FOR CAREGIVER BURNOUT

As the Alzheimer’s or MS or other neurological disorder progresses, the carer’s role can become more involved. It is important to take steps to avoid becoming burned out as the disorder progresses. Below are some tips to help you along the way.

1. **Set boundaries.** As a carer you have enough to do already. Don’t feel like you have to say “yes” to the requests of others.
2. **Set realistic limits.** Accept that you cannot do it all. No one should expect you to. You should not expect it of yourself.
3. **Delegate responsibility and create a care team.** If you have others around you who are willing to help, take advantage of it.
4. **Seek and accept help.** If you have realistic limits you’ll know when it is time to ask for help – ask before you find yourself in a crisis. If someone offers help, take advantage of it.
5. **Celebrate success.** Celebrate your own success, no matter how seemingly small. Celebrate the successes of your loved one.

6. **Take breaks.** Taking periodic breaks to do something that gives you enjoyment and peace, even if it's only a 10-minute break, can help recharge you for the rest of the day.
7. **Utilise respite care and adult day care.** Accept that getting away from the care-giving situation helps you and your loved one. If you feel guilty about leaving your loved one talk your feelings over with someone.
8. **Identify what external resources are available, including carers' training courses and physical aids.** Resources for people dealing with neurological disorders day-to-day will vary from country to country.⁶⁶

Caring for a person with a neurological disorder will require significant time and effort. The job may become especially difficult, particularly if you are caring for someone with Alzheimer's, who may forget who you are, becomes angry with you for no reason, or lashes out and hurts your feelings. Handling these emotions is very difficult. You might feel extremely sad, and even mad that the disorder has stolen this person from you. These feelings are normal; seek out others, via a peer support group, or through counseling, who can understand your feelings and situation. Peer support groups or counseling will help to lessen sadness, anxiety, or anger that you may be feeling.

WATCH FOR SIGNS OF ANXIETY AND DEPRESSION

Many caregivers become depressed or anxious over the course of caring for someone with a neurological disorder. The increase in anxiety and depression is directly proportional to the severity of the illness affecting the care recipient.⁶⁷ As you continue on your journey of caregiving, care for your emotional health by **watching for signs or symptoms of anxiety and/or depression.**

You should **seek help for your anxiety** if:

- Your worries have bothered you most days for the last six months
- You worry about lots of things at once even when there is no particular reason to worry
- You can't stop or even control worrying, however hard you try.

You should **seek help for depression** if you have five or more of the symptoms listed below for two weeks or more. See your healthcare provider or mental health professional for help.

- Persistent sad, anxious or "empty" mood

- Sleeping too much or too little, middle of the night or early morning waking
- Reduced appetite and weight loss, or increased appetite and weight gain
- Loss of pleasure and interest in activities once enjoyed, including sex
- Restlessness, irritability
- Persistent physical symptoms that do not respond to treatment (such as chronic pain or digestive disorders)
- Difficulty concentrating, remembering or making decisions
- Fatigue or loss of energy
- Feeling guilty, hopeless or worthless
- Thoughts of suicide or death

Remember that stress, depression, and anxiety are common among caregivers – you are not alone. Depression and anxiety are very treatable conditions. Even small improvements in the symptoms of anxiety or depression will help to lessen the strain of caregiving, and insure that you can maintain your caregiving role.

Summary: The Importance of Caring for Yourself, the Caregiver

Today, millions of people around the world care for loved ones with neurological disorders such as Alzheimer’s and MS. For many caregivers around the globe, the impact of unaided and often lengthy caregiving can be significant. Caregiving can create enormous strain on carers, many who are trying to juggle paid work, family demands, and caregiving. As a result, caregiver stress and caregiver burnout are common. And, all too often, the daily toll of caregiving results in depression and anxiety for many caregivers. But there is **hope** – and there is **help**.

It is our **hope** here at the World Federation for Mental Health that this educational packet begins a global dialogue on the impact of caregiving, and the importance of caring for caregivers. It is essential that policies and programs be developed in all

**FOR CAREGIVERS
CARING FOR THOSE AT
THE END OF LIFE**

One final caregiving issue that must be considered by caregivers is how to manage end-of-life issues. Having a plan for managing these end-of-life issues will lessen the stress of a very difficult time. [Click here](#) if you are caring for someone at the end-of-life.

countries to recognise and support caregivers. These caregiver programs and policies – available in some countries – are crucial to maintaining caregivers’ emotional and physical health, and will be essential as the cadre of caregivers grows worldwide. As the numbers of those with Alzheimer’s increase, and modern medicine extends human life, more caregivers will be needed, and the issue of caring for caregivers will be of great public health importance to every country. It is essential that researchers around the world continue to explore the link between caregiving and its impact on a carer’s emotional and physical health.

There is also **help**, to support you, the caregiver. There are steps you can take to lessen the impact of caregiving. One of the best ways that caregivers can care for themselves is to develop their own “Caring for the Caregiver Plan.”

This **Caring for the Caregiver Plan** has three components:

1) Cope with day-to-day demands by getting the help you need

- *Understand that it is okay to get help*
- *Define the help you need*
- *Seek out resources in your community for help*

2) Create a community of carers

- *Utilize a web-based caregiving coordination service, or a paper-and-pencil calendar method, to organize offers of help*

3) Care for your mental health

- Watch for signs of caregiver burnout
- Watch for signs of anxiety and if necessary, seek help
- Watch for signs of depression, and if necessary, seek help

Take the time to write out a **Caring for the Caregiver** plan for yourself. By doing so, you can help sustain – or even improve – your own good mental and physical health, while at the same time providing excellent care for loved ones. Maintaining good mental and physical health will help you generate a positive attitude, and allow you to continue to provide needed and valuable care to loved ones.

Appendix 1 CAREGIVERS CARING FOR THOSE AT THE END OF LIFE**FOR CAREGIVERS CARING FOR THOSE AT THE END OF LIFE**

Caring for someone in the final stage of life is always hard. It may be even harder when the person's mental capacity is limited, and you are required to make decisions about their life course without their input. Of course, you want to make the person as comfortable as possible, but he or she can't tell you how. You may become frustrated because you don't know what to do. Also, it can be upsetting because you want the person to talk with you, share memories and feelings, and say goodbye. While the person with AD or dementia may not be able to say these things, you can. It's really important to say the things in your heart, whatever helps you to say goodbye.

Planning for the end of a person's life and knowing what to expect can make this time easier for everyone. Geriatric care managers, grief counselors, and hospice care staff are trained to help you through this time. You might want to contact hospice staff early for help on how to care for the dying person. These professionals can help make the person more comfortable.⁶⁹

*With Mariano, the end of his life was so difficult. I knew it was time to let go, but it was so hard to make the decision all alone, without his input. He could no longer communicate with me, and I was the person who had to tell the doctors to turn off his life support. **I have never felt so alone as during those few days**, as I struggled with this decision, even though Mariano and I had talked about this time long before we got here. I wanted his suffering to end. But I was not ready to say goodbye. I wanted my husband back to say goodbye to me, to say it was okay, and that I could go on without him. A friend came to be with me, and told me I should let him go and feel proud of everything I was able to give to him, that when he needed me, I was there. He said Mariano was thankful and ready for me to look toward the future.*

Section IV: Resources for More Information

This section contains resources for further information on caregiving and mental health; please note that there is an abundance of information available, and not all resources are listed here.

Major International Resources for Mental Health Information

Beyond Blue

(Bipartisan initiative of the Australian, state and territory governments)

PO Box 6100

Hawthorn West 3122

Website: <http://www.beyondblue.org.au/>

Anxiety Disorders Association of America (ADAA)

8730 Georgia Avenue

Suite 600

Silver Spring, MD 20910

Phone: 240-485-1001

www.adaa.org

Anxiety Disorders Association of Canada (ADAC/ ACTA)

P.O. Box 117

Station Cote St-Luc

Montreal, Quebec

H4V 2Y3

Phone: 514-484-0504/1-888-223-2252

Fax: 514-484-7892

Email: contactus@anxietycanada.ca

Website: www.anxietycanada.ca/

American Psychiatric Association

1000 Wilson Boulevard, Suite 1825

Arlington VA 22209-3901 USA

Phone: 703 907 7300

www.psych.org

Brazilian Association of Psychiatry -- Rio de Janeiro

Secretaria Geral e Tesouraria

Av. Presidente Wilson, 164 / 9º andar.

CEP: 20030-020

Telefax:(0xx21) 2199.7500

www.abpbrasil.org.br/

Canadian Mental Health Association

180 Dundas Street West, Suite 2301

Toronto ON M5G 1Z8
Phone: (416) 484-7750
Fax: (416) 484-4617
Email: info@cmha.ca
<http://www.cmha.ca/bins/index.asp?lang=1>

Clinical Research Unit for Anxiety and Depression

299 Forbes Street,
Darlinghurst, Sydney
NSW, 2010, Australia.
Phone: +612 8382 1730, clinic info line 8382 1749
Research Phone: +612 8382 1720
Fax: +612 8382 1721
Website: www.crufad.com/cru_index.html

Mental Health America (MHA)

2000 N. Beauregard Street
Sixth Floor
Alexandria, VA 22311
800-969-NMHA (6642)
Website: www.mentalhealthamerica.net

Mental Health Association of Hong Kong

Mental health info hotline: 2772-0047
Website: www.mhahk.org.hk

National Institute of Mental Health (NIMH)

Science Writing, Press, and Dissemination Branch
6001 Executive Boulevard, Room 8184, MSC 9663
Bethesda, MD 20892-9663
Website: www.nimh.nih.gov
E-mail Address: nimhinfo@nih.gov
Phone: 301-443-4513 (local) or 1-866-615-6464 (toll-free)

National Institute of Mental Health and Neuro Sciences (NIMHANS)

Hosur Road
Bangalore - 560029, India
Phone: 91-080-26995001/5002, 26564140, 26561811, 26565822
Fax: 91-080-26564830
Website: www.nimhans.kar.nic.in/psychiatry.htm

National Alliance for the Mentally Ill (NAMI)

Colonial Place Three
2107 Wilson Blvd.
Suite 300

Arlington, VA 22201-3042
703-524-7600
Information Helpline:
800-950-NAMI (6264)
Website: www.nami.org

South African Federation for Mental Health

267 Long Avenue
Ferndale Randburg 2194
Phone: +27 (11) 781 1852
Fax: +27 (11) 326 0625
Website: www.safmh.org.za/index.htm

The World Federation for Mental Health (WFMH)

12940 Harbor Drive, Suite 101
Woodbridge, VA 22192
USA
Phone: 703.494.6515
Fax: 703.494. 6518
Website: www.wfmh.org
Email: info@wfmh.com

World Health Organization

World Health Organization
Avenue Appia 20
CH - 1211 Geneva 27
Switzerland
Phone: +41 22 791 2111
Fax.: +41 22 791 3111
Website: www.who.int

World Psychiatric Association

WPA Secretariat:
Geneva University
Psychiatric Hospital
2, ch. du Petit-Bel-Air
1225 Chêne-Bourg
Switzerland
Tel.:+41 22 305 57 37
Fax: +41 22 305 57 35
E-mail: wpasecretariat@wpanet.org

INTERNATIONAL RESOURCES for Alzheimer's Disease and MS

ALZHEIMER'S DISEASE

Alzheimer's Disease International
The Alzheimer's Disease Portal
Web: <http://www.healthandage.org/html/min/adi/page2.htm>

MULTIPLE SCLEROSIS

Multiple Sclerosis International Federation
Web: http://www.msif.org/language_choice.html

International Journal of MS Care

Web: <http://www.msicare.org/cmssc/Journal-of-MS-Care.html>

MS World

Web: <http://www.msworld.org/html/resources.htm>

GENERAL CAREGIVING RESOURCES*

(*listed by country, primarily for Alzheimer's and MS)

ARGENTINA

Asociación de Lucha contra el Mal de Alzheimer
Lacarra No 78 1407 Capital Federal, Buenos Aires Argentina
Tel/Fax: +54 11 4671 1187
Email: info@alma-alzheimer.org.ar Web: www.alma-alzheimer.org.ar

AUSTRALIA

Alzheimer's Australia
P.O. Box 4019 Hawker ACT 2614 Australia
Tel: +61 2 6254 4233 Helpline: 1800 100 500 Fax: +61 2 6278 7255
Email: glenn@alzheimers.org.au Web: www.alzheimers.org.au

Carers Australia

Unit 1, 16 Napier Close, Deakin ACT 2600 Australia
Web: <http://www.carersaustralia.com.au/>

AUSTRIA

Alzheimer Angehorige Austria
Obere Augartenstrasse 26-28 1020 Vienna, Austria\
Tel: +43 1 332 5166 Fax: +43 1 334 2141
Email: alzheimeraustria@aon.at
Web: www.alzheimer-selbsthilfe.at

BAHRAIN

Alzheimer Support Group
 Dr Adel Al-Offi Psychiatric Hospital, P.O. Box 5128
 Kingdom Of Bahrain
 Tel: +973 17 279 326 Helpline:+973 39425525
 Email: alzbahrain@gmail.com
 Web: www.moh.gov.bh/alz

BANGLADESH

Alzheimer Association of Bangladesh
 Head Office Salander
 Post office: Thakurgaon- 5100
 Bangladesh
 Tel: +880 172 049 8197
 Email: alzbangladesh@yahoo.com

BARBADOS

Barbados Alzheimer's Association Inc
 PO Box 398
 Bridgetown Barbados
 Tel: +1 246 438 7111
 Email: barbadosalzheimersassociation@caribsurf.com

BELGIUM

Ligue Alzheimer Clinique
 Le Perî
 4B Rue Montagne
 Sainte Walburge
 Belgium B-4000 Liège
 Tel: +32 4 225 8793
 Helpline: 0800 15 225
 Fax: +32 4 225 8693
 Email: henry.sabine@skynet.be
 Web: www.alzheimer.be

Faculteit Politieke en Sociale Wetenschappen, Onderzoeksgroep Welzijn
 en de Verzorgingsstaat, Universiteit Antwerpen
 Faculty of Political and Social Sciences, Research team Welfare and the
 Welfare State, University of Antwerp, Sint-Jacobstraat 2, 2000 Antwerp
 Belgium
 Tel: + 32 3 275 55 25 Fax: + 32 3 275 57 98
 Web: http://www.ua.ac.be/main.aspx?c=*OWV

Werkgroep Thuisverzorgers vzw
 Workgroup Homecarers, Groeneweg 151, B-3001 Heverlee, Belgium

Tel: +32-1622 7337 Fax: +32-1622 0673

Email: werkgroep.thuisverzorgers@mantelzorg.be, info@mantelzorg.be

Web: <http://www.mantelzorg.be/>

Ons Zorgnetwerk vzw, Vereniging van gebruikers en mantelzorgers

Belgian Carers Association, Remylaan 4b, 3018 Belgium

Tel: +32-1624 4949 Fax: +32-1624 3972

Email: onzorgnetwerk@kvlv.be Web: <http://www.onzorgnetwerk.be/>

Ziekenzorg CM, Vereniging van gebruikers en mantelzorgers

Flemish Carers Association, Haachtsesteenweg 579, 1031 Brussels

Belgium

Tel: +32-2246 4776

Fax: +32 2246 4779

Email: mantelzorg@cm.be

Web: <http://www.ziekenzorg.be/>

BERMUDA

Alzheimer's Family Support Group

P.O.Box DV114

Devonshire DVBX

Bermuda

Tel: +441 238 2168 (pm)

Fax: +441 234 1765

Email: JulieKay@ibl.bm

BOLIVIA

Asociación Boliviana de Alzheimer y Otras Demencias

Casilla N° 9302

La Paz Bolivia

Tel: +591 224 941 43

Email: elvio904@gmail.com

BRAZIL

FEBRAZ - Federação Brasileira de Associações de Alzheimer

c/o ABRAZ - Associação Brasileira de Alzheimer

Caixa Postal 3913

Sao Paulo - SP - Brazil

01160-970

Tel/Fax: +55 11 270 8791

Helpline: 0 800 55 1906

Email: abraz@abraz.org.br

Web: www.abraz.com.br

BULGARIA

Compassion Alzheimer Bulgaria
zanko Djustabanov 30, fl.3
9000 Varna Bulgaria
Tel: +359 52 505 873
Fax: +359 52 505 873
Email: compassion.alz@abv.bg

CANADA

Alzheimer Society of Canada
20 Eglinton Avenue, W., Suite 1200
Toronto, Ontario M4R 1K8 Canada
Tel: +1 416 488 8772
Helpline: 1800 616 8816
Fax: +1 416 488 3778
Email: info@alzheimer.ca
Web: www.alzheimer.ca

Alberta Caregivers Association
Web: <http://www.elderpost.com/Alberta-Caregivers-Association.html>

CZECH REPUBLIC

Česká alzheimerovská společnost
Czech Alzheimer Society, Šimunkova 1600, 182 00 Prague 8 – Kobylisy
Czech Republic
Tel: 00420 283 880 346 Fax: 00420 286 882 788
Email: martina.rokosova@gerontocentrum.cz
Web: <http://www.alzheimer.cz/> <http://www.gerontologie.cz/>

CHILE

Corporación Alzheimer Chile
Desiderio Lemus 0143(alt 1400 Av.Peru
Recoleta Santiago, Chile
Tel: +56 2 7321 532
Fax: +56 2 777 7431
Email: alzchile@adsl.tie.cl
Web: www.corporacionalzheimer.cl

CHINA

Chinese Association of Alzheimer's Disease and Related Disorders
Department of Neurology
Beijing Hospital
Ministry of Health
#1 Da Hua Road
Dong Dan Beijing 100730
China

Tel: +8610 6521 2012
Fax: +8610 6521 2386
Email: wyh@medmail.com.cn
Web: www.adc.org.cn

COLOMBIA

Asociación Colombiana de Alzheimer y Desordenes
Relacionados Carrera 10A No 120-30
Apto 708 Bogota Colombia
Tel: +57 1 619 9402
Fax: +57 1 521 9401
Email: alzheimercolombia@live.com

COSTA RICA

Asociación Costarricense de Alzheimer y otras Demencias Asociadas
Apartado 4755
1000 San José
Del Parqueo del ICE
Sabana Norte 300 mts al Norte
Costa Rica
Tel: +506 237 7527
Fax: +506 260 1716
Email: ascada@ice.co.cr
Web: www.fundalzzheimer.com

CROATIA

Alzheimer Disease Societies Croatia
Croatian Institute for Brain Research (HIIM) Att. Secretary - Kristina
Stipetic Šalata 12
HR-10000 Zagreb Croatia
Tel: +385 1 23 88 176
Fax: +385 1 23 88 176
Email: alzheimer@alzheimer.hr
Web: www.alzheimer.hr

CUBA

Cuban Section of Alzheimer's Disease and Related Disorders
Calle 146 No 2504 e/ 25 y 31
Cubanacan Playa
Ciudad de la Habana Cuba
Tel: +537 220 974
Fax: +537 336 857
Email: inmo@teleda.get.tur.cu
Web: www.scual.sld.cu

CYPRUS

Pancyprian Association of Alzheimer's Disease 31A Stadiou 6020
Larnaca Cyprus
Tel: +357 24 627 104 Fax: +357 24 627 106
Email: alzncyprus@yahoo.com

CZECH REPUBLIC

Ceska Alzheimerovska Spolecnost Centre of Gerontology Simunkova
1600 18200 Praha 8 Czech Republic
Tel: +420 286 883 676 Fax: +420 286 882 788
Email: martina.roksova@gerontocentrum.cz Web: www.alzheimer.cz

DENMARK

Alzheimerforeningen Sankt Lukas Vej 6, 1 DK 2900
Hellerup Denmark Tel: +45 39 40 04 88 Fax: +45 39 61 66 69 Email:
post@alzheimer.dk Web: www.alzheimer.dk

DOMINICAN REPUBLIC

Asociacion Dominicana de Alzheimer Apartado
Postal # 3321 Santo Domingo Republica Dominicana
Tel: +1 809 544 1711 Fax: +1 809 544 1731
Email: asocalzheimer@codetel.net.do

ECUADOR

Fundacion Alzheimer Ecuador
Avenida de la Prensa #5204 y Avenida de Maestro Quito Ecuador
Tel: +593 2 2594 997 Fax: +593 2 2594 997
Email: gmatute@uio.satnet.net

EGYPT

Egyptian Alzheimer Group c/o Professor A Ashour 233 26 July
Street Giza 12411 Cairo Egypt
Tel: +202 334 70 133 Fax: +202 330 23 270
Email: ashour200835@yahoo.com

EL SALVADOR

Asociacion de Familiares Alzheimer de El Salvador
Asilo Sara Zaldivar Colonia Costa Rica Avenida Irazu San Salvador El
Salvador
Tel: +503 237 0787
Email: ricardolopez@vianet.com.sv

ESTONIA

Sclerosis Multiplex'I Ühing
Estonian Multiple Sclerosis Association

Paldiski Mnt. 68, 10617 Tallinn, Estonia
Tel: +372-335 0453 Fax: +372 6507 395
Email: vladislava.vassitshkina@smk.ee Web: www.smk.ee

ETHIOPIA

Ye Ethiopia Alzhiemers Beshitegnoch Mahber
P. O. Box 28657/1000 Addis Ababa Ethiopia
Tel: +251 91 113 8547
Email: ninates2002@yahoo.com

FINLAND

Alzheimer Society of Finland
Luotsikatu 4E 00160 Helsinki Finland
Tel: +358 9 6226 200 Fax: +358 9 6226 2020
Email: toimisto@alzheimer.fi Web: www.alzheimer.fi

Omaishoitajat ja Läheiset -Liitto ry
Association of Care Giving Relatives and Friends in Finland
Hämeentie 105 A 18, 00550 Helsinki, Finland
Tel: 00358 207 806500 Fax: 00358 207 806555
Email: tiina.autio@omaishoitajat.fi
Web: <http://www.omaishoitajat.fi/english/php>

Suomen Omaishoidon Verkosto
Finnish Network for Organisations Supporting Family Caring
Folkhälsans Förbund r.f., Paasikivigatan 4, 00250 Helsingfors
Finland
Tel: 00358 9 315 5537
Email: jonna.skand@folkhalsan.fi
Web: <http://www.omaishoidonverkosto.fi/>

FRANCE

France Alzheimer et Maladies Apparentées
21 Boulevard Montmartre 75002 Paris, France
Tel: +33 1 42 97 52 41 Fax: +33 1 42 96 04 70
Email: contact@francealzheimier.org Web: www.francealzheimier.com

Aidants, Association française des Aidants familiaux
French Association for family carers
B.P. 10336-75229, 75005 Paris Cedex 05, France
Tel: +33-143265788
Fax: +33-143260416
Email: aide@aidants.fr Web: <http://www.aidants.fr/>

GERMANY

Deutsche Alzheimer Gesellschaft Friedrichstr. 236 10969
Berlin Germany Tel: +49 30 315 057 33 Helpline: 01803 171
017 Fax: +49 30 315 057 35
Email: deutsche.alzheimer.ges@t-online.de
Web: www.deutsche-alzheimer.de

BIVA (Bundesinteressenvertretung der Nutzerinnen und Nutzer von
Wohn- und Betreuungsangeboten im Alter und bei Behinderung) e.V.
Vorgebirgsstrasse 1, 53913 Swisttal-Heimerzheim, Germany
Tel: +49 2254-7045
Email: info@biva.de Web: <http://www.biva.de/>

Universitätsklinikum Hamburg-Eppendorf, Zentrum für Psychosoziale
Medizin, University Medical Center Hamburg-Eppendorf
Department of Medical Sociology, Working Group Social Gerontology
Martinistraße 52, D – 20246 Hamburg, Germany
Tel: 0049-40428034528
Fax: 0049-40428034056
Email: doehner@uke.uni-hamburg.de
Web: [http://www.uke.uni-hamburg.de/institute/medizin-
soziologie/index_9453.php](http://www.uke.uni-hamburg.de/institute/medizin-soziologie/index_9453.php)

GREECE

Greek Association of AD and Related Disorders
Petrou Sindika 13 Thessaloniki Hellas Greece
Tel/Fax : +30 2310 810 411 Helpline: +30 2310 909 000
Email: alzheimer@the.forthnet.gr Web: www.alzheimer-hellas.gr

Athens Association of Alzheimer's Disease and Related Disorders
Markou Mousourou 89, 11636 Athens, Greece
Tel: + 30 210 70 13 271
Email: Kentroalz@ath.forthnet.gr
Web: <http://www.alzheimerathens.gr/>

GUATEMALA

Asociación Grupo
ERMITA 10a. Calle 11-63 Zona 1, Apto B P O Box 2978 01901
Guatemala
Tel: +502 2 381 122 Fax: +502 2 381 122
Email: alzquate@quetzal.net

HONDURAS

Asociación Hondureña de Alzheimer
PO Box 5005 Tegucigalpa Honduras
Tel: +504 235 9193 Fax: +504 232 4580

Email: Alzheimerhn@ashalz.org Web: www.ashalz.org

HONG KONG SAR

Hong Kong Alzheimer's Disease Association
G/F, Wang Yip House Wang Tau Hom Estate Kowloon, Hong Kong
SAR China
Tel: +852 23 381 120 Carer Hotline: +852 23 382 277
Fax: +852 23 38 0772
Email: info@hkada.org.hk Web: www.hkada.org.hk

HUNGARY

Hungarian Alzheimer Society
Csaba u. 7A H-1054 Budapest 1122 Hungary
Tel: +36 1 214 1022 Fax: +36 1 214 1022
Email: ehimmer@axelero.hu Web: www.tar.hu/alzheimer

ICELAND

FAAS Austurburn
31 104 Reykjavik Iceland
Tel: +354 533 1088 Fax: +354 533 1086
Email: faas@alzheimer.is Web: www.alzheimer.is

INDIA

Alzheimer's & Related Disorders Society of India
Guruvayoor Road PO Box 53 Kunnankulam Kerala 680 503 India
Tel: +91 4885 223 801 Fax: +91 4885 223 801/ 222 347
Email: office@alzheimer-india.org Web: www.alzheimer-india.org

INDONESIA

IAzA Secretariat
c/o Wahyudi Nugroho Sasana Tresna Werda "Yayasan Karya Bakti Ria
Pembangunan" jl. Pusdika RT 008 RW 07 KM 17 Cibubur, Jakarta
13720 Indonesia
Tel: +62 21 8730 179 Fax: +62 21 3989 9128
Email: nasrun@indosat.net.id

IRAN

Iran Alzheimer Association
Shahrak Ekbatan Maydan Noor Exit Next to Bassij Building Tehran
13969 Iran
Tel: +98 21 4651 122 Fax: +98 21 4651 122
Email: info@alzheimer.ir Web: www.alzheimer.ir

IRELAND

Alzheimer Society of Ireland National Office

Temple Road Blackrock, Co. Dublin Ireland
Tel: +353 1 284 6616 Helpline: +353 1 800 341 341 Fax: +353 1 284
6030
Email: info@alzheimer.ie Web: www.alzheimer.ie

Care Alliance Ireland
Coleraine House, Coleraine Street, Dublin 7, Ireland
Tel: 00353 1874 7776
Email: ndo@carealliance.ie Web: <http://www.carealliance.ie/>

Caring For Carers Ireland, National Office
2 Carmodystreet Business Park, Ennis, Co Clare, Ireland
Tel: 00353-656866515
Fax: 0035-3656867710
Email: bbarron@caringforcarers.org
Web: <http://www.caringforcarers.org/>

The Carers Association National Office, Market Square, Tullamore, Co.
Offaly Ireland
Web: <http://www.carersireland.com/>

ISRAEL

Alzheimer's Association of Israel P O Box 8261 Ramat Gan Israel
52181
Tel: +972 3 578 7660 Fax: +972 3 578 7661
Email: a-a-i@zahav.net.il Web: www.alz-il.net

ITALY

Federazione Alzheimer Italia
Via Tommaso Marino 7 20121 Milano Italy
Tel: +39 02 809 767 Fax: +39 02 875 781
Email: alzit@tin.it Web: www.alzheimer.it

AIMA - Associazione Italiana Malattia di Alzheimer
Italian Alzheimer's Association
Ripa di Porta Ticinese 21, 20143 Milano, Italy
Tel: 0039 33583 70541
Fax: 0039 2894 04192
Email: aimanaz@tin.it Web: <http://www.alzheimer-aima.it/>

JAMAICA

Alzheimer Jamaica
Suite 24 Seymour Park 2 Seymour Avenue Kingston 10 Jamaica
Tel: +1 876 927 8967 Fax: +1 876 927 6155
Email: alzheimerja@cwjamaica.com

JAPAN

Alzheimer's Association Japan
 c/o Kyoto Social Welfare Hall Horikawa-Marutamachi, Kamigyo-
 Ku Kyoto Japan 602-8143
 Tel: +81 75 811 8195 Fax: +81 75 811 8188
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Multiple Sclerosis Resource Center

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MS Society, Just Diagnosed Pathway, UK Web:

<http://www.mssociety.org.uk/just%5Fdiagnosed%5Fpathway/>

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Caring for Someone with MS, National MS Society, US
Web: <http://www.nationalmssociety.org/living-with-multiple-sclerosis/relationships/caregivers/index.aspx>

CareCentral
Web: <http://www.carecentral.com>

CarePages
Web: <http://www.carepages.com>

Caring Road Support Group
Web: <http://www.caringroad.org/viewpages.cgi?athome/index>

Care Pages, online support networks and blogs for patients caregivers of multiple diseases, including Alzheimer's and MS
Web: <http://www.carepages.com>

Family Caregiver Alliance
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Family Caregiving 101

Web: www.familycaregiving101.org

Lotsa Helping Hands

Web: <http://www.nfca.lotsahelpinghands.com>

MS in Focus: Special Focus on the Family

Web: <http://www.msif.org/docs/MSinFocusIssue3EN.pdf>

Multiple Sclerosis Caregiving

Web: <http://www.ms caregiver.com/2009/02/11/doing-your-best/>

MS Foundation

6350 North Andrews Avenue, Fort Lauderdale, Florida 33309-2130

Web: <http://www.msfacts.org/default.aspx>

National Caregivers Library

Web: <http://www.caregiverslibrary.org/Default.aspx?tabid=89>

National MS Society

Web: <http://www.nationalmssociety.org/index.aspx>

The National Family Caregivers Association

10400 Connecticut Avenue, Suite 500

Kensington, MD 20895-3944

Web: http://www.nfcacares.org/caregiving_resources/ and www.thefamilycaregiver.org

The Comfort of Home™: An Illustrated Step-by-Step Guide for Multiple Sclerosis Caregivers

Web: <http://www.comfortofhome.com/bk/ms/>

Video Caregiving

Web: www.videocaregiving.org

Well Spouse Association

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References

- ¹ Retrieved from www.aarpinternational.org/resourcelibrary/resourcelibrary_show.htm?doc_id=728810
- ² Retrieved from http://assets.aarp.org/rgcenter/il/i13_caregiving.pdf, October 21, 2009.
- ³ Retrieved from http://www.aarpinternational.org/resourcelibrary/resourcelibrary_show.htm?doc_id=728810, October 21, 2009.
- ⁴ Retrieved from http://www.aarpinternational.org/resourcelibrary/resourcelibrary_show.htm?doc_id=728810, October 21, 2009.
- ⁵ Retrieved from http://www.aarpinternational.org/resourcelibrary/resourcelibrary_show.htm?doc_id=728810, October 21, 2009.
- ⁶ Retrieved from <http://www.uindy.edu/news/?p=577>, October 21, 2009.
- ⁷ The World Alzheimer's Report. Retrieved from <http://www.alz.co.uk/research/files/World%20Alzheimer%20Report%20Executive%20Summary.pdf> on October 21, 2009.
- ⁸ The Mayo Clinic, Dementia, <http://www.mayoclinic.com/health/dementia/DS01131>, retrieved October 21, 2009.
- ⁹ What is vascular dementia? Retrieved from www.alzheimers.org.uk/factsheet/402
- ¹⁰ Alzheimer's Disease Symptoms and Stages. Retrieved from www.helpguide.org.
- ¹¹ The World Alzheimer's Report. Retrieved from <http://www.alz.co.uk/research/files/World%20Alzheimer%20Report%20Executive%20Summary.pdf> on October 21, 2009.
- ¹² Brookmeyer R, Johnson E, et al. (2007). Forecasting the global burden of Alzheimer's disease. *Alzheimer Dementia: J Alzheimer Association*, 3,3:186-191.
- ¹³ Excerpted from the National Institute of Aging publication, Caring for a Person with Alzheimer's Disease. Retrieved from <http://www.nia.nih.gov/Alzheimers/Publications/CaringAD/>.
- ¹⁴ National Institute for Neurological Disorders and Stroke, Fact Sheet. Retrieved from http://www.ninds.nih.gov/disorders/multiple_sclerosis/multiple_sclerosis.htm
- ¹⁵ Plaintiff: A Booklet about MS for Families. National MS Society. Retrieved from <http://www.nationalmssociety.org/about-multiple-sclerosis/index.aspx>

- ¹⁶ Atlas of MS Statistic, Multiple Sclerosis International Federation. Retrieved from <http://www.atlasofms.org/index.aspx>
- ¹⁷ WebMD, Multiple Sclerosis Health Center. Retrieved from <http://www.webmd.com/multiple-sclerosis/multiple-sclerosis-understanding-the-differences-in-ms>
- ¹⁸ Excerpts from Four Disease Courses Have Been Identified in MS, National Multiple Sclerosis Society. Retrieved from <http://www.nationalmssociety.org/about-multiple-sclerosis/what-is-ms/four-disease-courses-of-MS/index.aspx>
- ¹⁹ Extrapolation of “Living with and caring for a person with dementia” from Alzheimer’s Disease International. Retrieved from www.alz.co.uk/carers/caring.htm.
- ²⁰ Prince M (2004). Care arrangements for people with dementia in developing countries. *Int J Geriatric Psychiatry*, 19:170-177.
- ²¹ The Global Impact of Dementia, Alzheimer’s Disease International, <http://www.alz.co.uk/media/dementia.html>
- ²² Excerpted from the National Institute of Aging publication, Caring for a Person with Alzheimer’s Disease, retrieved from <http://www.nia.nih.gov/Alzheimers/Publications/CaringAD/>.<http://www.nia.nih.gov/Alzheimers/Publications/CaringAD/>
- ²³ Excerpted from the National Institute of Aging publication, Caring for a Person with Alzheimer’s Disease, retrieved from <http://www.nia.nih.gov/Alzheimers/Publications/CaringAD/>.<http://www.nia.nih.gov/Alzheimers/Publications/CaringAD/>
- ²⁴ Caring for the Carers, Multiple Sclerosis International Federation. Retrieved from http://www.msif.org/en/resources/msif_resources/msif_publications/ms_in_focus/issue_3_family/caring_for_the_c.html
- ²⁵ National MS Society. Plaintalk: A Booklet about MS for Families. Retrieved from <http://www.nationalmssociety.org/about-multiple-sclerosis/index.aspx>
- ²⁶ Excerpted from Family Caregiver Alliance: National Center on Caregiving. Retrieved from http://www.caregiver.org/caregiver/jsp/content_node.jsp?nodeid=576
- ²⁷ What is spasticity and what causes it? Multiple Sclerosis International Federation. Retrieved from http://www.msif.org/en/resources/msif_resources/msif_publications/ms_in_focus/issue_12_spasticity_in_ms/what_is_spastici.html
- ²⁸ Northrop DE, Frankel D, eds. Caring for Someone in the Advanced Stages of MS: A Guide for Families. Retrieved from <http://www.nationalmssociety.org/download.aspx?id=789>.
- ²⁹ Currie AS, Knox KB, et al. (2009). Physical Activity Levels in People with Multiple Sclerosis in Saskatchewan. *Int J MS Care*, 11:114-120.

- ³⁰ National Multiple Sclerosis Society, Exercise. Retrieved from <http://www.nationalmssociety.org/living-with-multiple-sclerosis/healthy-living/exercise/index.aspx>
- ³¹ Multiple Sclerosis International Federation,. Retrieved from http://www.msif.org/en/about_ms/ms_by_topic/cognitive_problems/
- ³² National Multiple Sclerosis Society, Fatigue. Retrieved from <http://www.nationalmssociety.org/about-multiple-sclerosis/symptoms/fatigue/index.aspx>
- ³³Northrop DE, Frankel D, eds. Caring for Someone in the Advanced Stages of MS: A Guide for Families. Retrieved from <http://www.nationalmssociety.org/download.aspx?id=789>.
- ³⁴ Clint D, Wollin JA, et al. The impact of pain on the quality of life of people with multiple sclerosis: a community survey. *Int J MS Care* 2009;11:127–136. Retrieved from http://www.ms-care.org/cm-sc/images/journal/pdf/ijms_fall_09final1_127-136.pdf
- ³⁵ Northrop DE, Frankel D, eds. Caring for Someone in the Advanced Stages of MS: A Guide for Families. Retrieved from <http://www.nationalmssociety.org/download.aspx?id=789>.
- ³⁶ Clint D, Wollin JA, et al. The impact of pain on the quality of life of people with multiple sclerosis: a community survey. *Int J MS Care* 2009;11:127–136. Retrieved from http://www.ms-care.org/cm-sc/images/journal/pdf/ijms_fall_09final1_127-136.pdf
- ³⁷ Northrop DE, Frankel D, eds. Caring for Someone in the Advanced Stages of MS: A Guide for Families. Retrieved from <http://www.nationalmssociety.org/download.aspx?id=789>.
- ³⁸Minden SL. (2000). Mood disorders in multiple sclerosis: diagnosis and treatment. *J Neurovirol*, Suppl 2:S160-7.
- ³⁹ Arnold C (2000). An Ocean of Emotion: Mood Swings, Anger, and Uncontrollable Laughing and Crying - multiple sclerosis, *Inside MS*. Retrieved from http://findarticles.com/p/articles/mi_m0850/is_2_18/ai_61881259/
- ⁴⁰ National Multiple Sclerosis Society, hearing loss. Retrieved from <http://www.nationalmssociety.org>
- ⁴¹ Döhner H, Kofahl C, Lüdecke D, Mnich E (Hg). 2008. Family Care for Older People in Germany. Results from the European Project EUROFAMCARE. LIT Verlag, Hamburg.
- ⁴² Ibid.
- ⁴³ Talley R & Crews JE (2007). Framing the Public Health of Caregiving. *American Journal of Public Health*, 97 (2), pgs 224-228.
- ⁴⁴ Savage, S. and Bailey, S. (2004) The impact of caring on caregivers' mental health: a review of the literature, *Australian Health Review*, Vol 27 No 1, pp. 103-109, Australasian Medical Publishing Company Pty Ltd, Australia.

- ⁴⁵ Ferrara M et al (2008). Prevalence of stress, anxiety and depression in with Alzheimer caregivers. *Health Qual Life Outcomes*, 6: 93.
- ⁴⁶ Figved N, Myhr KM, Larsen JP, Aarstrand D. (2007). Caregiver burden in multiple sclerosis: the impact of neuropsychiatric symptoms. *J Neurol Neurosurg Psychiatry*, 78(10):1097-102.
- ⁴⁷ Alshubaili AF, Ohaeri JU, Awadalla AW, Mabrouk AAFamily caregiver quality of life in multiple sclerosis among Kuwaitis: a controlled study. *BMC Health Serv Res*, 8:206.
- ⁴⁸ Mahoney R et al (2005). *Am Assoc Geria Psych*, 13, (9), pp. 795-801.
- ⁴⁹ Excerpted directly from Women's Caregiver Alliance National Center on Caregiving, Women and Caregiving: Fact and Figures. Retrieved from http://www.caregiver.org/caregiver/jsp/content_node.jsp?nodeid=892
- ⁵⁰ Family Caregiver Alliance (2007). **Caregivers at Risk: A Public Health Concern**. Caregiving in California: Issue Paper #1 (2007).
- ⁵¹ Working and caring for the Elderly: international perspectives. Lechner VM, Neal MB, Eds. Philadelphia, Brunner/Mazel: 2009. Retrieved from http://books.google.com/books?id=CJwu74fkCXIC&pg=PA103&lpg=PA103&dq=male+caregivers+sweden&source=bl&ots=v7b9F15XFz&sig=ZKq0H4isFiL1euZTrE1npYhk26Q&hl=en&ei=8cypSoa0JcfRIaE1JCABQ&sa=X&oi=book_result&ct=result&resnum=2&ved=0CA8Q6AEwAQ#v=onepage&q=male%20caregivers%20sweden&f=false
- ⁵² Survey done in 2004 by the AARP and the National Alliance for Caregiving. (AARP Bulletin, 23 Jan 2009. Retrieved from http://bulletin.aarp.org/yourhealth/caregiving/articles/the_new_face_of_caregiving.html
- ⁵³ Takagi, E. (2003). "Gender Dynamics and Family Caregiving in Japan" Paper presented at the annual meeting of the American Sociological Association, Atlanta Hilton Hotel, Atlanta, GA Online <.PDF>. 2009-05-26 from http://www.allacademic.com/meta/p107418_index.html
- ⁵⁴ Harris B (1993). The misunderstood caregiver? A qualitative study of the male caregiver of Alzheimer's disease victims. *Gerontologist*, 33; 4:551-556.
- ⁵⁵ Aoki Y, et al. (2003). Characteristics of Male-caregiver's Burden in Home Care for the Aged with Dementia: Comparative Analysis of Burden to Relevant Factor and Coping with Female-caregiver, *Hokuriku Journal of Public Health*, 30;1: 6-11.
- ⁵⁶ Pinquart M, Sorenson S. (2006). Gender Differences in Caregiver Stressors, Social Resources, and Health: An Updated Meta-Analysis. *Journals of Gerontology Series B: Psychological Sciences and Social Sciences*, 61:P33-P45.
- ⁵⁷ Family Caregiver Alliance (2007). **Caregivers at Risk: A Public Health Concern**. Caregiving in California: Issue Paper #1 (2007). Retrieved from http://www.caregiver.org/caregiver/jsp/content_node.jsp?nodeid=1962

⁵⁸The Alzheimer's Association. Take Care of Yourself: Ten Ways to be a Healthier Caregiver. Retrieved from www.alz.org/national/documents/brochure_caregiverstress.pdf, 2009.

⁵⁹Retrieved from

<http://www.aagponline.org/advocacy/testimony.asp?viewfull=2>.

⁶⁰ Caregiver Syndrome; retrieved from

<http://www.cnn.com/2007/HEALTH/conditions/08/13/caregiver.syndrome/index.html>

⁶¹ This section is adapted from The US National Family Caregivers Association (NFCA), *Defining the Help you Need*, 2003. Retrieved from www.nfcacares.org

⁶² Döhner H, Kofahl C, Lüdecke D, Mnich E (Hg). 2008. Family Care for Older People in Germany. Results from the European Project EUROFAMCARE. LIT Verlag, Hamburg.

⁶³National Alliance for Caregiving, & AARP. (1997). *Family Caregiving in the US: Findings from a national survey*. Washington, DC: National Alliance for Caregiving & AARP.

⁶⁴ Joling KJ et al. (2008). Cost-effectiveness of family meetings on indicated prevention of anxiety and depressive symptoms and disorders of primary family caregivers of patients with dementia: design of a randomized controlled trial. *BMC Geriatrics*, 8: 2.

⁶⁵ The Family Caregiver Alliance. Retrieved October 21, 2009, from http://www.caregiver.org/caregiver/jsp/content_node.jsp?nodeid=892

⁶⁶Excerpted from the Well Spouse Foundation, 2000. Retrieved from the MS International Federation website, http://www.msif.org/en/resources/msif_resources/msif_publications/ms_in_focus/issue_3_family/caring_for_the_c.html.

⁶⁷Joling KJ et al. (2008). Cost-effectiveness of family meetings on indicated prevention of anxiety and depressive symptoms and disorders of primary family caregivers of patients with dementia: design of a randomized controlled trial. *BMC Geriatrics*, 8: 2.

⁶⁸Excerpted from the National Institute on Aging, *Caring for a Person with Alzheimer's Disease. End of Life: Helping with Comfort and Care*