

# MS *in focus*

January 2015

## Ageing with MS



multiple sclerosis  
international federation

## Editorial Board

### Multiple Sclerosis International Federation

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- Stimulate and facilitate international cooperation and collaboration in research into the understanding, treatment and cure of MS
- Support the development of effective national MS organisations
- Communicate knowledge, experience and information about MS
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ISSN1478467x

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## Letter from the Editor



This issue of *MS in focus* is dedicated to ageing with MS. This seems appropriate because *MS in focus* was launched 13 years ago and while this is certainly not to be considered “old”, we have established quite a history over the years. There have been a number of innovations to the magazine since the first issue on fatigue was published back in 2003. Since then, 23 issues have been produced, with the number of translations, countries reached and readership increasing over time.

After long consideration, MSIF has announced that it will continue with a theme-specific series, with some significant changes that will include a quarterly rather than biannual production cycle, accessible exclusively online as individual articles and translated into Arabic and Spanish.

As editor of *MS in focus*, I would like to thank the members of the Editorial Board, past and present, who have each contributed to the success of the magazine over the years. Some of these individuals will continue to participate in the direction of the new format.

With this final issue of the magazine in its current format I will be stepping down as editor. I would like to take this opportunity to thank all of the people with MS, family members, health care professionals and scientists who have shared their experiences, challenges and successes in facing MS with us. Their contributions have helped to make the magazine the success that it has been.

In line with every previous *MS in focus*, this issue includes an international group of experts, with research, clinical and personal experience in the field of ageing and MS. We have attempted to cover the wide range of concerns a person faces while living with MS later in life. We hope that this issue can be a learning and information resource for health care professionals and people with MS and their families.

I look forward to receiving your comments.

Michele Messmer Uccelli, Editor

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This is the final issue of *MS in focus*. Back issues can continue to be downloaded free at [www.msif.org](http://www.msif.org). Please send questions or comments to [info@msif.org](mailto:info@msif.org).

## Editorial statement

The content of *MS in focus* is based on professional knowledge and experience. The Editor and authors endeavour to provide relevant and up-to-date information at the time of publication. The views and opinions expressed may not be the views of MSIF. Information provided through *MS in focus* is not intended as a substitute for advice, prescription or recommendation from a physician or other health care professional. For specific, personalised information, consult your health care provider. MSIF does not approve, endorse or recommend specific products or services, but provides information to assist people in making their own decisions.

# Introduction to ageing with MS

Marcia Finlayson, School of Rehabilitation Therapy, Queen's University, Kingston, ON, Canada

We all grow older - including people with MS. Yet, until fairly recently, it was not common to see research about the issues or challenges of ageing with MS, or to have access to resources and services specifically designed for older adults with MS.

Even though MS is often described as a disease of young and middle aged adults, about 10% of all people who are living with MS are over the age of 65. Although the proportion of people with MS who are older is relatively small, the general and disability-specific trends towards increasing life expectancy suggest that their numbers are likely to increase over time.

In the past, it was commonly believed that MS reduced life expectancy. Over the past 40 years, longer life expectancies in the general population plus improvements in MS-specific care have contributed to longer average survival times for people with MS. In addition, it has been recognised that reductions in life expectancy of people with MS tend to be associated with advanced disability, progressive disease course, and related complications.

Perhaps as a consequence of these changes, interest in and questions about ageing with MS have been growing over the past 10-20 years among basic, clinical and applied scientists as well as among people who deal with the daily management of the disease and its consequences (including individuals, families, health care providers). This issue of *MS in focus* is a reflection of the growing interest in ageing with MS and recognition that attention must be given to this important aspect of a person's life and health care.

Many factors will influence a person's experience of ageing with MS, and several of them are addressed

in this issue including general concerns about ageing, comorbidities, self-management, cognitive and emotional changes, and planning for end-of-life.

In considering each of these topics, one must keep in mind that there are a wide range of normal age-related changes that all people will experience to a greater or lesser degree, regardless of whether they have MS. For example, with age, it is normal to experience some reduction in muscle strength, reduced cardiopulmonary reserve, and impaired temperature regulation. Furthermore, many of the symptoms experienced by people with MS (such as pain, fatigue, depression, cognitive changes, visual disturbances and mobility losses) are also commonly experienced by people ageing without MS. Normal age-related changes, together with MS symptoms, contribute to the functional challenges of an older adult with MS.

In comparison to younger people with MS, those who are older adults with MS (over 65 years) report greater activity limitations in the areas of bathing, dressing, toileting, getting out of bed, getting around a room, taking medication, shopping, and getting around the community. Consistent with these limitations, they also identify transportation, accessible housing, professional home care, social wellbeing programmes, pharmaceutical services, nutrition programmes, and physical wellness/exercise programmes as the most important services they needed to maintain their health and wellbeing.

Several studies have examined the concerns of people with MS, from their own perspective. Some of these common concerns are summarised in this issue. Declines in mobility, becoming a burden on family and friends, and requiring more care are common concerns expressed by people ageing with MS.



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As people with MS grow older, they may experience other health conditions, in addition to their MS and this can add to their concerns. Common examples include heart disease, diabetes or arthritis. These other conditions are called comorbidities. These common comorbidities, their potential impact and consequences are also discussed. Both health care providers and people with MS must be attentive to the possibility of these other conditions in the course of comprehensive care.

Living with MS, with or without a comorbid condition, requires a person to find ways to manage variable symptoms and adapt habits and routines in order to continue to engage in meaningful everyday tasks. The self-management article in this issue of *MS in focus* discusses the critical skills involved in taking an active role in one's own health care. Self-management is important for everyone, including people with MS. Yet, development and use of self-management skills may be particularly important as people ageing with MS learn to cope with both MS and age-related challenges. Some of these challenges may be related to the cognitive and emotional issues associated with ageing with MS, as discussed later.

The final article in this issue defines palliative care and addresses end-of-life issues that everyone must consider. While this article addresses a sensitive topic, the principles of palliative care generalise very well to all aspects of high-quality care and services for people ageing with MS: the importance of focusing on quality of life, considering the whole person and their family, ensuring choice and control, and emphasising open communication.

Keeping a focus on these principles in all interactions with older adults with MS, across the full continuum of care - from home and community care and services to hospital and long-term care - will hopefully reduce their concerns, support their families, and promote quality of life and high quality services and care.

As our ability to effectively treat MS and its symptoms continues to advance, people with the disease can expect to live well into old age. With increasing numbers of older adults with MS, health care providers must be attentive to the interactions between MS and normal age-related changes, and be prepared to address them when working with older adults.

# Normal ageing processes

## Skin and hair

- The skin's oil glands gradually produce less oil, making the skin drier and more flaky.
- The skin becomes less elastic, thinner, more fragile and less sensitive.
- Skin may become paler but appear more blotchy, and blemishes are more common.
- Fingernail growth slows.
- Fingernails and toenails become tougher, brittle and thick.
- Hair gradually thins on the scalp, pubic area and underarms.
- As hair pigment cells decline in number, grey hair growth increases.

## Bones and joints

- Decreasing levels of calcium and other minerals reduce bone density, making them more susceptible to fracture.
- Osteoporosis becomes more common, especially in women after menopause.
- Some joints become stiffer and less flexible, and movement becomes more restricted.
- Osteoarthritis and rheumatoid arthritis become more common.
- Compression in joints, spinal bones and spinal discs may reduce height by several centimetres.

## Muscles and metabolism

- Typically the body uses less energy, and metabolism slows.
- Hormone changes result in a

shift to more body fat and less muscle mass.

- Muscles lose tone, strength and flexibility.
- Muscle weakness leads to increased fatigue and decreased endurance.
- Overall movement slows and becomes more limited.
- Involuntary movements, such as muscle tremors become more common.

## Heart and lungs

- The heart's pumping strength diminishes and the heart becomes less efficient.
- Blood vessels become stiffer, causing the heart to work harder, which can lead to raised blood pressure (hypertension).
- Heart rhythm irregularities become more common.
- The capacity of the lungs decreases and they become less elastic, reducing oxygen intake.

## Digestion

- Appetite gradually reduces.
- Indigestion becomes more frequent.
- Constipation becomes more common, and this may be associated with haemorrhoids.
- Oesophageal reflux, which causes "heart burn", may develop.

## Bladder control and passing urine

- Bladder control weakens.

- Decreased ability to hold urine means more frequent urination.
- Bladder and urinary tract infections become more common.
- In men, the prostate gland enlarges, which can lead to problems with urination.

## Vision and hearing

- Presbyopia – difficulty in focusing on close objects – means most people develop a need for reading glasses.
- Night vision and visual sharpness decline, and glare may interfere with vision.
- The eyes may become drier.
- Hearing may decline – it becomes harder to hear high-frequency sounds, and distinguishing between sounds may become more difficult.
- Tinnitus – persistent abnormal ear noise – is more common.
- The senses of smell and taste gradually diminish.

## Memory and mental changes

- Short-term memory may decline.
- Some cognitive functions tend to slow down and become less efficient.
- The ability to maintain selective and divided attention may decline.
- Risk of depression increases.
- The length of night time sleep is often reduced, as is the depth of sleep.

Sources: [www.webmd.com/healthy-aging/tc/healthy-aging-normal-aging](http://www.webmd.com/healthy-aging/tc/healthy-aging-normal-aging) ; [www.mayoclinic.org/healthy-living/healthy-aging/in-depth/aging/art-20046070](http://www.mayoclinic.org/healthy-living/healthy-aging/in-depth/aging/art-20046070) ; [www.who.int/ageing/publications/PPNormalAgeingfortoolkit.pdf](http://www.who.int/ageing/publications/PPNormalAgeingfortoolkit.pdf)

# Living with MS alongside age-related health issues

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MS affects more than 2.3 million people around the world, and many people with MS also have other health conditions, such as high blood pressure or asthma. These co-existing conditions are called “comorbidities”. Comorbidities differ from secondary conditions and complications, which are physical and mental problems that arise from MS. For example, osteoporosis that occurs due to reduced mobility is a secondary condition. Urinary tract infections due to a neurogenic bladder – problems with the nerves in the body that control how the bladder stores or empties urine – are complications.

It is important to know how these conditions differ, since the approaches to treating them are not the same. If a comorbid condition makes fatigue worse, the health care team would treat the comorbidity. If a complication such as a urinary tract infection causes increased symptoms, the health care team would treat the complication and the neurogenic bladder. This article will focus on comorbidities.

## Common comorbidities in ageing people with MS

Psychiatric comorbidities are common in MS throughout the disease course. Over a lifetime, half of people with MS will develop depression; about one in three people will develop anxiety; bipolar disorder, though a lot less common than depression and anxiety, affects about one in twenty people with MS.

Physical comorbidities are also common in MS. At the time of MS diagnosis, when most people are young, the risk of conditions like diabetes and high blood pressure is low. With increasing age, co-existing conditions are more common. At older

ages, the conditions that are most common in MS are those that are the most common in the general population. High blood pressure affects more than 45 percent of people with MS over 60 years old. High cholesterol and chronic lung diseases, such as asthma or chronic bronchitis, affect more than 20 percent of people with MS over 60. Diabetes and heart disease affect more than 15 percent, while autoimmune thyroid disease affects up to 10 percent of people with MS. Most of these conditions affect people with MS about as often as they affect people who do not have MS.



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## Impact of comorbidities

Comorbidities affect MS in many different ways. It has been reported that vascular comorbidities, including high blood pressure, high cholesterol, diabetes and heart disease appear to be common.

In one study, participants with vascular comorbidities had faster declines in walking ability than those who did not. About half of people **without** comorbidities needed a cane to walk within 18 years of having their first symptoms of MS. But as many as half of people **with** comorbidities needed a cane to walk within 12 years of having their first symptoms. In another study, people with MS who had higher total cholesterol levels had more disability after two years than those with lower levels. Higher cholesterol levels were also associated with greater shrinkage of the brain.

People with MS who are depressed or anxious are less likely to take their disease-modifying therapies as prescribed. Quality of life is lower in people with MS than in other people, and as the number of comorbidities increases, quality of life decreases. This is the case in people with MS who have comorbid depression and anxiety, while physical comorbidities also affect quality of life.

In a nation-wide Canadian study, quality of life was lower in people with MS who also had arthritis, high blood pressure, chronic fatigue syndrome or depression. Arthritis, high blood pressure and chronic lung disease merit clinical attention as they increase in frequency with age. Depression is a concern at all ages. It is not yet known whether treating a person's comorbidities improves quality of life. The effect of comorbidity on life expectancy in MS is poorly understood.



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## Management considerations

As people with MS get older and the disease progresses, symptom management is more important. Little is known about the impact of comorbidity on the management of MS. Generally, adults with multiple chronic conditions report many problems with medications. Coordinating multiple medications at different times is difficult, and taking more than one medication may be costly. These problems can make it hard to take medications as prescribed. This, obviously, reduces the benefits of the medications.

The presence of comorbidity in MS may pose management challenges. A person with MS and comorbidity may present with more than one clinical problem at the same time; or, a person may present with one problem due to several factors. For example, fatigue may be due to MS or another condition, such as a sleep disorder or thyroid disease. Symptoms that often occur with ageing can also be a challenge. For example, poor vision and memory are common symptoms in MS, but these symptoms also affect people without MS as they get older. Sometimes these symptoms simply reflect ageing. Sometimes these symptoms are due to comorbidities. Worsening vision in an older person with MS could be due to cataracts in some cases. Therefore, it is critical to identify the influence of alternative causes other than MS for worsening symptoms. This often requires coordination of care by different members of the health care team.

It is important that people with MS continue to be followed by their primary care or family physician, since many ageing-related issues are not associated with MS and are better evaluated and managed by a general practitioner rather than by a neurologist.

## MS treatment and comorbidities

Many treatments exist for managing the chronic symptoms of MS. However, clinical trials of these treatments often leave out people with comorbidities for safety reasons. Therefore, sometimes it is not known if these treatments are as safe, effective or well-tolerated in people with comorbidities. In a trial of a fatigue management programme, participants with MS and diabetes improved more slowly than

other participants. Treatments and goals may need to be changed when comorbidity is present.

Treatments used for MS may affect the risk of comorbidities. For example, corticosteroids used to treat relapses may worsen the control of diabetes. As the number of comorbidities increases, it is more likely that a person with MS will be taking multiple medications at the same time. Use of multiple medications increases the risk of side effects and drug interactions. Some medications may cause blood pressure to get too low causing fainting or dizziness. Reaction times may be slowed. Balance may be impaired as well, leading to falls.

## Conclusion

Comorbidity is common in MS and increases in frequency with age. Comorbidity affects disability progression, quality of life and other outcomes. Also, it may affect the usefulness of symptomatic treatments, while it increases the chances that multiple medications will be used together. Therefore, any changes in management proposed for a person with MS should be considered in the context of their whole treatment regimen.

# Cognition and emotions

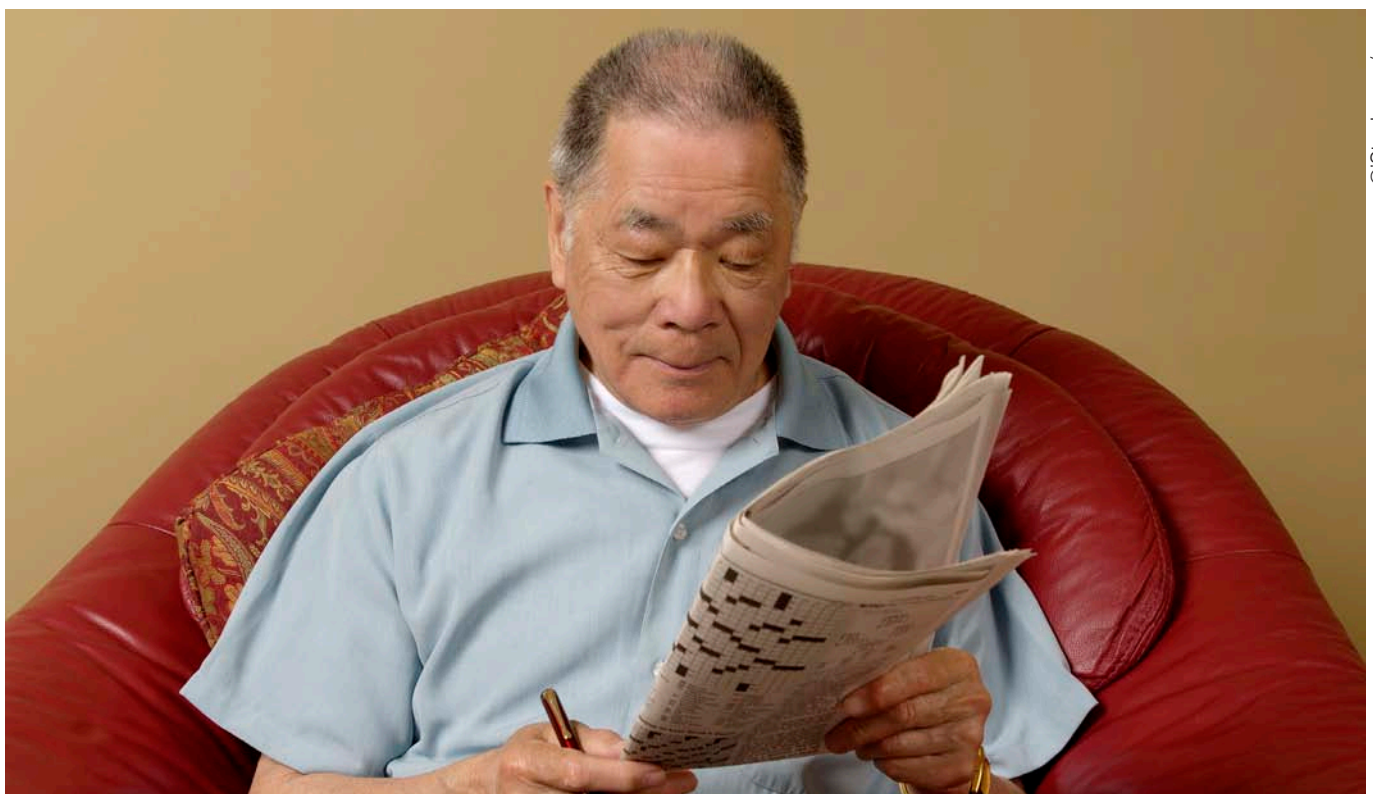
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MS can impact the life span by about 5-10 years, and the majority of people diagnosed will live to an age at which they will also experience age-related changes.

Differentiating between the effects of MS and age-related changes can be difficult, since many of the symptoms of MS – including fatigue, pain, depression, cognitive changes, visual disturbances and mobility difficulties – are common in normal ageing. Over the past 15 years, researchers have begun to explore the relationship between ageing and MS. Generally, two views have emerged. The first is that ageing and MS are two detrimental processes that exacerbate each other. The second is that as people age, they are better able to manage their disease and its symptoms.

## Experience of ageing with MS

Insightful information has been gathered from interviews asking individuals with MS directly about their experience with ageing. One study found that most older individuals with MS report feeling that they are ageing successfully. This perspective was ascribed to gained wisdom, established meaningful activities and relationships, and the ability to deal with changing capabilities that comes with age. Additionally, many individuals in this study reported that being older made it easier to cope with their MS symptoms, as there are reduced societal expectations for physical and cognitive fitness in older adults. For example, there is less pressure for older adults to participate in physical activities, such as helping a friend to move home, or to have high cognitive performance, such as perfect



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memory. A long-term study found that individuals with MS reported that over time, their disease felt more predictable as they became accustomed to their symptoms and how their bodies functioned with them.

This same study found that social engagement, access to health care, healthy lifestyle habits, and maintaining independence at home were critical components of health-related quality of life in older people with MS. Generally, interview based studies suggest that individuals who report ageing successfully with MS have established adaptive mind-sets and appropriate support systems.

### Cognitive functioning

In a survey study looking specifically at cognitive functioning, more than half of people with MS between 45 and 88 years old reported that cognitive difficulties interfered somewhat with their daily life. Remarkably, individuals who reported cognitive difficulties were, on average, younger than individuals who did not, suggesting that cognitive difficulties may have less impact with age. This study also asked caregivers to evaluate individuals' cognitive functioning. About one third of the caregiver-patient pairs disagreed on the presence of cognitive difficulties. Half of these disagreements were that the caregiver reported cognitive difficulties in a patient who did not report them. Interestingly, the longer the individual had been diagnosed with MS, the more likely there was to be a discrepancy between them and their caregiver in reporting cognitive difficulties. These findings suggest that as individuals with MS age, they may become accustomed to their cognitive difficulties, and thus become less aware of them.

This study also found that people who reported cognitive symptoms were also more likely to be depressed. This finding emphasises that depression should continue to be monitored throughout the lifetime of people with MS, as the relationship between depression and cognitive difficulties in MS has been reported in a number of studies. This topic will be further explored later on in the article.



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### Cognitive changes with ageing

Studies using neuropsychological measures of cognition have also illuminated how cognition changes as people with MS age. One study examining individuals aged 45 to 81 found that almost half of their sample exhibited some cognitive impairment. In this study, information processing speed, attention and learning/memory were more likely to be impaired than executive functioning (the mental processes that help connect past experience with present action, such as planning, organising, strategising).

However, according to a recent review, cognition appears to deteriorate fairly slowly in MS compared to other neurological conditions, such as Alzheimer's, with its decline predicted by a progressive course type and increasing disability. One study examining mental processing speed found that although individuals with MS had slower processing speeds than people without MS, the rate of slowing of their processing speed as they aged was comparable to that of non-MS ageing adults. Such findings suggest that individuals with MS are likely develop cognitive difficulties during the course of their disease, but their cognitive decline due to ageing will be similar to that of the general population.

## Ageing and depression

While 50 percent of people with MS will experience depression in their lifetime, only a few studies have examined depression as a function of age in MS. At least two studies have found results that suggest depression decreases with age. One of the studies found that in a large sample of people with MS, relatively younger age was associated with more symptoms of depression. A second study found that older adults with MS had fewer symptoms of depression than younger adults with MS. After examining measures of helplessness and psychological vulnerability in their sample, the authors concluded that the decrease in depression seen with ageing was not due to differences in thoughts or attitudes, but rather that older patients were less emotionally reactive.

Unfortunately, the results between ageing with MS and depression are mixed, as at least two recent studies have found that depressive symptoms increase with age. It is possible that both of these findings are valid, as MS affects people uniquely, and may be better predicted by how factors such as disability and coping (known

to relate to depression) change as individuals age. Fortunately, depression in MS is not inevitable, and it is highly treatable.

## Conclusion

Many individuals with MS report adjusting well to ageing and attribute this to factors including familiarity with their symptoms, gained wisdom, meaningful activities and relationships, healthy lifestyle choices, accessible health care, and reduced societal expectations.

Although cognitive difficulties affecting mental processing speed, attention and memory are present in most older adults with MS, rates of decline in these areas appear to be similar to rates of decline in healthy ageing.

How depressive symptoms change as a function of ageing remains unclear, with some studies indicating that depressive symptoms decrease with age and others suggesting the opposite. These studies suggest that depressive symptoms may be best explained by factors such as disability and coping, and how these variables respectively change during the ageing process.



# Common concerns about ageing with MS

Mette Harpsøe Nielsen and Marianne Kjærem Nielsen, Danish MS Society

The number of older people living with MS is predicted to grow proportionally with the general population. Today the percentage of people living with MS above the age of 55 is estimated to be approximately 28 percent in Canada and 30 percent in Denmark. Most of these people have lived with MS for more than 20 years.

Living with MS presents many kinds of challenges and concerns in all life phases. Ageing with MS is no less challenging, as most people with MS already have to adjust to progressing disability, the fact that their symptoms no longer remit in between relapses as they may have done previously, and to general age-related conditions.

One of the key differences between people with MS ageing and others experiencing normal ageing processes is the growing need of help from others in daily life and in social activities.

People ageing with MS may have more restricted options than other people their age due to physical or cognitive difficulties. These may reduce the person's freedom to do as they would like day-to-day, which can challenge the individual's sense of identity and self.

*“It's more than wrinkles! It is my whole life that I need to think differently about. People my age are still going strong. I often have to stay at home, so I need to learn new ways and to find out what can be beneficial for me”. Anna aged 62*



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## Characteristics of people with MS over the age of 55

Previously, research on ageing with MS has been limited. However, this is changing, and we are beginning to get a clearer picture of this group compared to both younger people with MS and the corresponding age populations without MS.

Recent surveys point to the following characteristics of people with MS above the age of 55. They are:

- More likely to have a secondary progressive form of MS.
- More likely to have a greater level of significant disabilities that require help from caregivers and/or help from a health care professional.
- More likely to be living without a partner.
- More likely to be unemployed or retired.
- Less likely to be engaged in leisure and outdoor activities.
- More likely to have cognitive problems and depression.

## Loss of independence and identity

Most people with MS over the age of 55 have reached the stage of disability and progression characterised as secondary progressive. This often means that the person requires more support and may be more dependent on others.

A recent survey by the Danish MS Society found that 64 percent of people with MS over 60 are dependent on help from others. This is roughly the same proportion given by a recent Canadian survey. Most of this help is given by an individual's partner and/or family members.

As Anna relates,

*“It is difficult! I have always been so independent, and consequently it is hard to be so dependent on your spouse... He [retired early and] makes everything at home and he takes care of me. I need him for everything...”*

Anna's husband concurs:

*“I would love to go visit our friends in Stockholm for a couple of days, but I can't leave Anna alone”.*

The help given from professional caregivers is often a supplement to the help of family members, and often involves personal and intimate care.

In the Danish survey, 28 percent of people with MS over 60 received professional help. Unfortunately the professional help is not always carried out in a supportive way. Anna says,

*“I do not feel as I am being recognised as a person. The other day one of the helpers asked the other, ‘Do we also brush her teeth?’. And I was sitting right there!”.*



Experiences related to dependence and ageing with MS are not only caused by physical problems, but may also be due to cognitive impairment.

Further, older people with MS may also be responsible for caring for elderly family members, such as a parent, or may be responsible for raising grandchildren. These situations can be a cause for added concern, particularly when the person with MS experiences disease progression or when their support system is limited.

### Cognitive changes

Cognitive changes and ageing are generally closely interrelated. For people with MS, cognitive changes also exist as a direct symptom of the disease. Cognitive disabilities are often hidden symptoms, and a person's family and friends can find them difficult to understand and deal with. Cognitive challenges can therefore be a threat to day-to-day social interaction. They can also affect an individual's capacity to do daily tasks, and many people with MS fear that this will cause a loss of independence.

### Being a burden

The most common concern of people with MS at any stage of the disease is the fear of becoming a burden on their partners and family members. They often express their fear that the prosperity and general well-being of their loved ones may be threatened by the potential changes and challenges caused by their MS.

Although many people with MS do not progress to the point of serious disability, the impact of the disease may still cause radical changes in lifestyle and a growing dependency on care providers. The Danish survey showed that all of the married people with MS above the age of 60 depended on their spouses for help. Single people with MS depend primarily on professional caring services for their needs and many felt this restricted their social activities and freedom.



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### Ageing together

Some of the common age-related changes in all people are similar to changes caused by MS, such as less energy, weakness, pain or various kinds of mobility problems. An ageing couple needs to take into consideration that their joint health may be declining and that the partner may be less capable in the care giving role as time goes on. In these cases, receiving professional support and using assistive devices may be of even greater importance. It is vital that the needs and support of the partner are not forgotten. Space and time alone or attending support groups for family members who provide care can offer time to refresh as well as social opportunities.

### Conclusion

By anticipating that the disease may, over time, have wide-ranging consequences on them as well as their families, people with MS can plan for their potential needs when ageing, as well as those of their caregivers. They need to consider "what if?" and to be realistic about what may come. Planning ahead may offer a feeling of control and make the potential impacts of the disease less threatening. When thinking about ageing with MS, turning concerns into strategies for the potential future need can help people with MS and their families to stay on top of whatever may come.

# Self-management issues

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Treatment of MS is complex and often involves many health care professionals including neurologists, urologists, MS nurses, family doctors, psychologists, and physiotherapists. This type of care is called the “medical model”. The medical model aims to provide medically-based interventions such as medications, equipment and exercises. Because MS is often unpredictable, it is also important that people with MS acquire the knowledge of themselves and their disease to be able manage their everyday lives.

Having the confidence and skills to coordinate all the factors that affect one's health is the foundation of self-management. In studies that have tried to understand healthy ageing with MS, some older people have explained that it took them almost 10 years to understand their MS. However, once they gained the confidence in how to predict and manage their MS symptoms, such as fatigue or pain, they were able to cope better and focus on the other parts of their lives that were important to them – being parents, grandparents and professionals. Several wished that they could have learned about their MS and gained the confidence earlier.

Self-management focuses on the fact that knowledge of the disease, understanding of their emotions and their role in the family and society will help people with MS increase their overall quality of life. Having control and employing self-management skills empowers and provides optimism. People who are attentive and have good self-management skills may also be able to detect new symptoms or symptoms that are not due to MS. For example, someone with MS may notice a change in their bladder habits. Using self-management strategies they may detect that the change is not typical for them, and may bring it to the notice of their nurse or doctor.



## The ingredients of self-management

Self-management is a concept that was first developed to help people manage living with chronic conditions such as arthritis, pain and diabetes. Some of the messages may be useful in MS. One model of self-management describes how the task of self-management is three-fold in nature:

1. managing the medical symptoms; for example, regularly taking medicines
2. managing new life roles; for example, adapting to change and creating new activities with friends and family
3. managing emotions; for example, recognising stress and frustration and using techniques to manage them, such as deep breathing or time away.



This model outlines six fundamental skills that are used during self-management:

### **Problem solving**

This involves identifying the problem, determining potential ways to solve the problem and then choosing the best solution. For example, someone may find that standing and cooking meals is very taxing. Using problem-solving techniques, they would propose and then try out some ideas, such as cooking two meals at a time, testing simple recipes or eating out on certain days of the week.

### **Decision making**

This involves determining top priorities and then deciding what needs to be done to manage day-to-day activities. For example, when faced with a very busy day, a person may make a list of activities in order of priority – want to do and need to do – then postpone some that are low priority.

### **Using resources**

This involves organising oneself to use available resources as efficiently as possible. A person may decide to cluster similar chores together to save time, money and energy. For example in order to get more exercise, they may walk to the grocery store but get a bus back. They may also set up some tasks at home such as using online banking instead of travelling to the bank.

### **Communicating with health care providers**

This is a very important aspect of self-management. In one study examining the keys to healthy ageing with MS, older people with MS explained that it was more helpful when they engaged in a two-way conversation with health providers rather than simply being told what to do. Being prepared for medical visits, using a journal to keep track of issues and recording the outcome of the visits helps people to take ownership of their health.

### **Taking action**

Often, taking action is the most difficult step. For example, somebody may say “I intend to eat better”, however, this is not an action. After finding out how their diet could be improved and deciding to improve it, they then need to develop new habits. Dropping

old habits and replacing them with new ones is a challenge! They may need to routinely participate in the same, new behaviour in order to make it a habit.

### **Self-tailoring**

This means a person modifying things around them to suit their own needs and the resources available. For example, sleep is very important but a person may have to adapt their sleep to manage fatigue, to care for a baby or to work late. They would then try to arrange a time to get some extra sleep when it is convenient. Using self-tailoring, they can propose several ways to make the timing fit their schedule and check those modifications with their nurse or doctor.

### **Is self-management learned or innate?**

Can people learn to self-manage or are these skills they are born with? The answer is likely “yes” to both. Individuals can learn the skills and confidence to self-manage their MS but it also helps if they already have some techniques. For example, being intuitive of MS symptoms is likely to be very easy for some people. They can detect change – for example discomfort in an area that is not usually bothersome – determine the best course of action and follow through with the action. However these steps can also be learned. There are self-management courses and resources that can teach people to be more mindful (see list at the end of this article).

### **What can get in the way of self-management?**

Effective self-management can be a challenging process that may involve overcoming a combination of different obstacles.

#### **Denial**

Ignoring a change in health or a troubling situation can get in the way of a person with MS taking steps to manage the situation. If they use the self-management techniques described above, they should analyse the problem, plan a course of action and take steps to stay healthy. Delaying action extends the time it takes to find a solution.

#### **Self-defeating thought**

Our thoughts are connected to our behaviours. Therefore an unhelpful thought will lead to an



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Sometimes when we discuss health conditions, we focus on the physical conditions and ignore mental health. Attending to mental health as well as physical health is important. Self-management techniques can be used to note changes in sleeping or eating habits and reduced energy levels, as well as mood changes, especially any feelings such as hopelessness. Having a conversation with a doctor or nurse can often help too.

unhelpful behaviour. For example, someone may focus on a single negative detail, dwell on it exclusively and ignore all the other aspects that have been positive. Another example of self-defeating thoughts are “should” statements. This is when someone tells themselves that things “should” be the way they hoped or expected them to be and then feel hopeless or angry if they are not.

### **Worry rather than reflection**

Thinking about health and other issues does not mean brooding over them. Anyone concerned about their health must be attentive. Using self-management, a person takes steps beyond just worrying: they reflect on the symptom, recognise patterns, understand limitations and plan alternatives.

### **Managing other health problems while ageing with MS**

Many health conditions such as cancer, heart disease and osteoporosis are more common among older people. Prevention and management of other health conditions is important for everyone but it is especially important for people with a disease like MS. Routine screening for cancers such as breast cancer and colon cancer and attending to unusual symptoms is important. In fact, in one study of older people with MS, participants explained that they were more concerned about their other health conditions than their MS. Using self-management techniques prepares people to identify issues and take action to maintain good health.

## **Conclusion**

In summary, self-management is part of an overall effective long-term management plan that includes health care providers, which aims to help people with MS improve and maintain their health and quality of life. Taking charge does not mean that they become their own doctor. It means that because they are in a unique position as the expert in their own experience of MS, they become a partner, rather than just a recipient, in their health care.

### **Useful internet resources:**

#### Website:

- <http://patienteducation.stanford.edu/research/> (self-management checklists and questionnaires)
- <https://bc.selfmanage.org/onlinebc/hl/hlMain> (Online Chronic Disease Self-Management Program)
- <http://selfmanagementuk.org/what-self-management> (Self-Management UK)
- <http://www.mstrust.org.uk/information/publications/msandme/> (A self-management guide to living with Multiple Sclerosis)
- <http://www.nationalmssociety.org/Living-Well-With-MS/Health-Wellness> (Living Well with MS/Health and Wellness)

#### Mobile Apps:

- Multiple Sclerosis Self-Care Manager
- My Action Planner App

# Palliative care and MS

Simone Veronese, Palliative Medicine, FARO Onlus, Turin, Italy and Alessandra Solari, Foundation Neurological Institute Carlo Besta, Milan, Italy

## Defining palliative care

Palliative care is defined as the active total care of a person whose disease is not responsive to curative treatment. Management of pain and other symptoms, and of psychological, social and spiritual problems is paramount. The goal of palliative care in MS is to achieve the best quality of life for the person with MS and their families once their symptoms no longer respond effectively to treatment or management.

Palliative care, with its focus on the all-round needs of individuals and their families, and their active involvement in medical decisions, also aims to improve the quality of care and reduce the use of emergency and acute care services.

The five key principles underpinning palliative care which should be practised by all health professionals in primary care, hospital and other settings are:

1. a focus on quality of life
2. a whole-person approach, taking into account the person's past life experience and current situation
3. care encompassing both the person with the life-threatening disease and those individuals who matter to that person
4. respect for patient autonomy and choice (including preferred place of care and access to specialist palliative care)
5. emphasis on open and sensitive communication, extending this to the person with the disease, informal carers and professionals.

## Palliative care in neurological conditions

The National Service Framework for Long Term Conditions includes the following quality requirement for end of life care: "People in the later stages of long-term neurological conditions are to receive a





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comprehensive range of palliative care services when they need them to control symptoms, offer pain relief, and meet their needs for personal, social, psychological and spiritual support, in line with the principles of palliative care.”

However, many issues can affect the provision of palliative care in people affected by progressive neurological conditions such as MS. Among these, it is worthwhile mentioning long disease duration, lack of a predictable course, or presence of a fluctuating course; coexisting behavioural and cognitive compromise; complex multidisciplinary care, management of special treatments/devices (for example, a PEG tube for nutrition or a baclofen pump for severe spasticity). Most people with MS die with, but not from, their disease.

One solution to delivering appropriate care to people with such complex needs and unpredictable end-of-life trajectories is to provide input at different times during the disease course, and not to focus only on end-of-life care. Palliative

care might offer skills during diagnosis, different options when the progression of the disease exposes people with MS and their families to difficult choices, being a constant help in symptom control and psychosocial care, and being a known resource when a person with MS approaches the end of life. It can also provide bereavement care to family members who had been previously involved in the care of the person with MS.

In practise, palliative care can be integrated alongside neurology and rehabilitation services. The interaction between neurology and palliative care throughout the duration of rapidly progressive conditions is very close, with a relatively smaller role for rehabilitation medicine physicians. However, rehabilitation plays a major role in providing long-term care and support, often over many years, in the more slowly progressive or stable conditions. As a person’s MS becomes more advanced, rehabilitation and palliative care approaches often overlap.

## Lifelong care for people with MS

It is difficult to anticipate life expectancy in people with MS due to the variability between individuals and the unpredictable nature of the disease. People with advanced MS may need palliative care over decades. Informal carers are an essential source of support for people with MS, and in advanced disease they may take responsibility for meeting most of their loved one's needs. Caring for someone with MS can sometimes lead to a reduced quality of life for the carer, and may adversely affect carer employment and finances if care is needed over a long period. Ageing and other illnesses combined with MS can affect both the person with MS and his or her carer.

Recent studies on adults with advanced MS and their carers and newly-diagnosed people with MS indicate similar areas of concern. These include insufficient time spent with health professionals, lack of information exchange, and discontinuity of care.

However, unlike those in the early phases of MS, there are no disease-modifying treatments for people with advanced MS. It is therefore all the more important that appropriate recognition and

management of symptoms and co-ordination of care is achieved. Including disease-directed treatment and supportive care from the time of the diagnosis of MS should more effectively prevent and treat symptoms, as well as initiate communication regarding goals of care and future planning.

## Conclusion

Palliative care is a complex concept that aims to promote both physical and psychosocial well-being towards the end of a person's life. It is a vital and integral part of all clinical practice, whatever the illness or the stage of the illness progression.

Exploring preferences for future care should be carried out sensitively and at a pace suited to the person with MS and their family.

## Useful resources:

- [www.mssociety.org.uk/ms-support/for-professionals/palliative-care](http://www.mssociety.org.uk/ms-support/for-professionals/palliative-care)
- [www.nationalmssociety.org/For-Professionals/Clinical-Care/Managing-MS/Continuum-of-Care/Palliative-Care](http://www.nationalmssociety.org/For-Professionals/Clinical-Care/Managing-MS/Continuum-of-Care/Palliative-Care)

## Advance care planning

The challenge for specialist palliative care services is working within cultures and societies where many people are uncomfortable talking about death and dying. Over time, death has become increasingly medicalised and institutionalised. However, the vast majority of people with a life-threatening illness say they would prefer to die at home. Ensuring people with MS, family members and health care professionals are informed and share in decisions about end-of-life and critical care is crucial.

Advance care planning (ACP) is at the core of palliative care. It respects the goals and values of the person with the disease, and promotes a truthful and meaningful exchange between that person, his/her loved ones and the care provider.

Studies have shown that people who engage in ACP with their care providers and surrogates are more likely to have decisions made in accordance with their preferences, and to receive better health care at the end of life. Nevertheless, ACP should be a flexible and continuous process, as an individual's health and circumstances are ever-changing.

In addition, a person's readiness to engage in ACP may vary throughout the course of their illness. A three-step approach for preparing a person for future decision-making has been proposed, which involves choosing an appropriate surrogate, clearly articulating values and preferences, and establishing some leeway in surrogate decision-making given the complexity of a situation.

# Results of the ageing with MS online survey

1,948 people from 70 countries around the world took our survey about ageing with MS during October and November 2014. Read the full results at [www.msif.org](http://www.msif.org)

More than one third of people who took the survey were aged between 51 and 60, while a quarter were aged 41-50. Most respondents were female (80%), and 57% had relapsing-remitting MS, 5% had progressive-relapsing MS, 22% had secondary progressive and 11% had primary progressive MS. The majority of respondents had had MS for more than 20 years (29%), reflecting the topic.

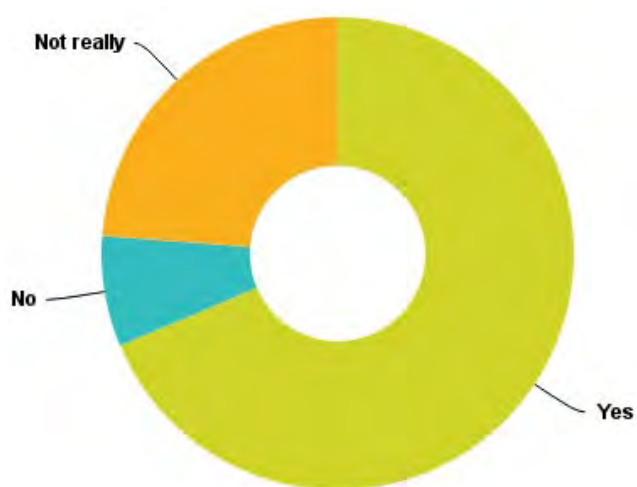
When asked if they thought that their MS had changed as they had got older, 69% said yes, 24% said not really, and 8% said no.

*“Luckily, 60 is the new 40.”*

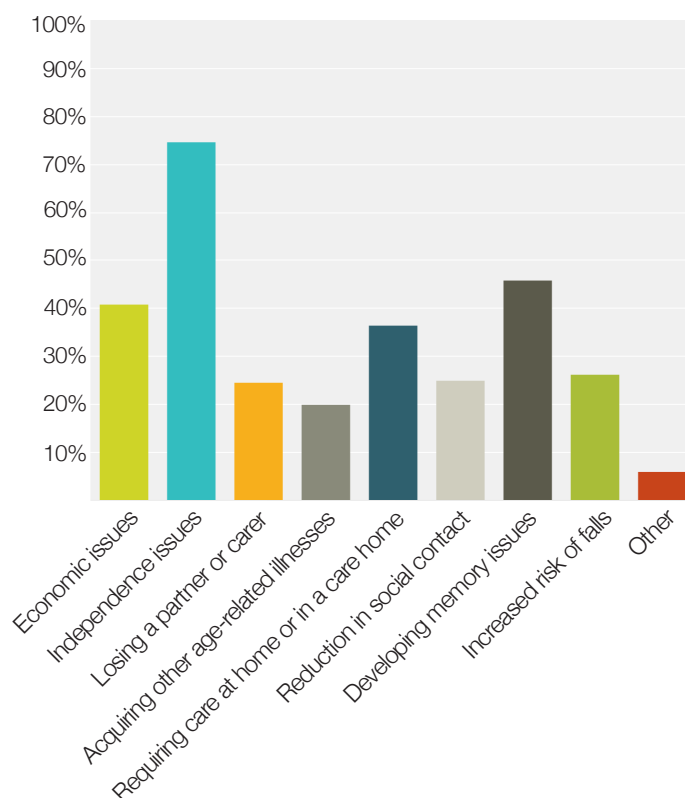
Respondents were asked to choose their three main concerns about ageing with MS. Independence issues (becoming less independent) was chosen by three quarters of those who took the survey.

Respondents came from Albania, Argentina, Armenia, Australia, Austria, Bahamas, Barbados, Belgium, Bosnia and Herzegovina, Brazil, Canada, Chile, Colombia, Croatia, Cyprus, Czech Republic, Denmark, Dominican Republic, Egypt, El Salvador, Estonia, Finland, France, Georgia, Germany, Greece, Haiti, Hong Kong, Hungary, Iceland, India, Indonesia, Iran, Ireland, Israel, Italy, Kenya, Kuwait, Lebanon, Luxembourg, Macedonia, Malaysia, Malta, Mexico, Morocco, Nepal, Netherlands, New Zealand, Norway, Pakistan, Palestinian Territory, Peru, Poland, Portugal, Puerto Rico, Romania, Russian Federation, Saudi Arabia, Serbia, Slovenia, South Africa, Spain, Sweden, Switzerland, Trinidad and Tobago, Turkey, United Kingdom, United States, Uruguay and Venezuela.

Has your MS changed with age?



Main concerns about ageing with MS



*“I fall a lot. I also worry about how I would cope if my husband was not there to support me.”*

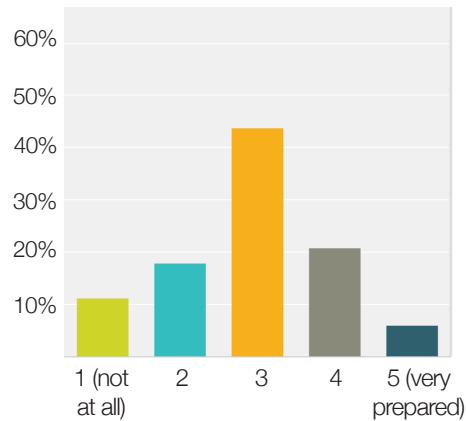
*“Not being able to do the things grandparents do when I (hopefully) get grandchildren in the future.”*

When asked how they would rate themselves on keeping up with regular screening for other non-MS issues as they age – for example, cervical smear test, colonoscopy, blood pressure, mammogram or skin examination, the majority (32%) rated themselves as very diligent.

*“My partner is more concerned about my health in future than I am.”*

Respondents were asked how prepared they felt for getting older with MS and only a small percentage felt very prepared.

How prepared respondents felt about getting older with MS



42% of respondents have considered but not carried through with making a will or advanced directives. About one-third have these measures in place.

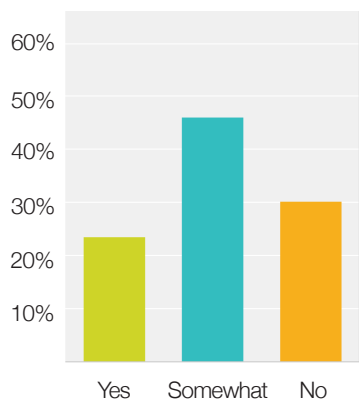
*“I have made a will but have not made, or even considered, any advanced directives.”*



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Almost half said that they had budgeted “somewhat” financially for older age, while 30% said no, that had not prepared financially.

### Financial preparation for ageing with MS



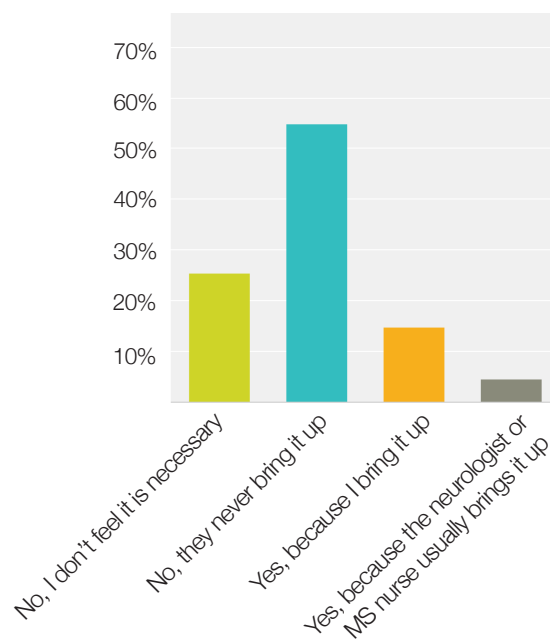
Approximately one-third of respondents felt their health care professionals were knowledgeable about ageing with MS. One-third felt that professionals were knowledgeable only partially or not at all.

*“I see my MS nurse twice a year but can contact her via e-mail or telephone if/when needed. Being able to talk, ask questions, [provides] invaluable support, I trust her more than my neurologist!”*

Respondents were asked if they discuss ageing issues with their MS neurologist, MS nurse and other health care professionals. More than half do not mention it.

*“The focus is always on mobility but mine is not affected. I have pain, fatigue, bladder, cognitive, spasticity and swallowing issues. I look great. I feel 80 years old.”*

### Discussing ageing issues with health care professionals



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# Your questions answered

**Q. I had my first symptoms when I was 21 and I am now 68. A neurologist told my husband that few seniors have active MS symptoms, which leads doctors to think that perhaps MS eventually stops on its own, leaving you with residual damage and ageing but nothing new. It's true that I have had no discrete symptoms for perhaps 10 years. What do you think?**

**A.** There is no evidence that MS stops on its own after a certain age or decade of life. What the neurologist told your husband about few older people having “active” MS is probably based on the fact that older individuals with MS who usually have a longer disease history are more likely to have converted to a progressive phase and are less likely to experience classic MS attacks, as seen in relapsing-remitting MS. We do know that about 75% of people with relapsing-remitting MS will convert to progressive MS after three decades. It may be that you are fortunate to have a very mild or even benign course. It might be helpful to discuss your specific situation with an MS neurologist.

**Q. I have secondary progressive MS and think I am starting the menopause as I have night sweats some nights. I have heard that it can affect me and my symptoms and I am rather apprehensive of this as I am unsure what to expect. Can you advise?**

**A.** There have been only small studies carried out on MS and menopause but they suggest that some women will experience little or no changes in their condition during menopause, whereas others may struggle. While the menopause does not necessarily bring on new symptoms, fatigue can worsen and 54% of women report an increase of some of their existing symptoms during this time. The reasons for this are unclear but is probably to do with the increase in body temperature that the menopause

causes, especially the hot flushes, and also due to the hormonal changes that occur with the reduction in oestrogen levels. It is thought that female hormones have a neuroprotective effect in MS and 75% of those who subsequently use hormone replacement therapy report an improvement in their symptoms. There is also an increased risk of osteoporosis, especially for women who have had repeated courses of steroids and are unable to do weight-bearing exercises. So it is important to ensure you have an adequate intake of calcium, that you reduce alcohol and smoking, and exercise for short periods of time throughout the day.

**Q. I am 66 years old and relatively healthy, despite having MS for 35 years. I am fortunate to live near an important MS research centre in my city. There are several clinical trials going on at any given time, but I am always told that my age excludes me from participating. Why is this and is there any hope for a trial in the future for older people with MS like myself?**

**A.** Each clinical trial has a set of inclusion and exclusion criteria. These are designed to insure that the study will be able to measure the effectiveness of the drug and to insure that the study is safe. Ageing means that people with MS often have additional age-related health problems, such as cardiac issues, diabetes, high blood pressure, vision problems and others. This makes it more difficult to determine whether it is the MS or other diseases or illness causing impairment. It also makes it difficult to determine which symptoms are side effects from the study drug and which are due to underlying health problems. Older people often take other non-MS medications, which may be criteria for exclusion from a study, as interactions between medications may not be known or could interfere with results.

With a renewed focus on finding effective treatments for progressive forms of MS, trials in the near future will necessarily require that the age limit for study inclusion be extended, since people with progressive MS are often older.

# Interview with Carol from Guatemala

## Please tell us about yourself

My name is Carol de León Reeves, I am 70. I live in Guatemala City, Guatemala, in Central America. I live in a house with my daughter and three of my grandchildren. I used to work as an interior decorator. I'm still doing small jobs here and there. I was diagnosed with MS when I was 38, so 32 years ago, but the symptoms go back 37 years.

## Did your disease course start out differently than it is today?

When I was diagnosed, it incapacitated me from the waist down and I was unable to walk. I didn't have control of my bladder. I had involuntary movements of my legs. I had pain in my legs and hips. To get around I used a wheelchair. Around six years after being diagnosed I started to regain some control of my legs and began to walk again. I still lose my balance but am able to walk. When I leave my home I use a cane to help me. I regained control of my bladder. About 15 years ago I started to see double and coloured light flashes. I also started to develop hearing loss. Otherwise things seem to be about the same.

## What are your most troublesome symptoms today and how do you manage them?

My double vision is the most difficult symptom today. When it happens I sit down, close my eyes and massage them. I feel burning sensations in patches on my skin around the lower part of my ribs in my front and on my back. The sensation lasts 2-3 hours and then leaves. I still have problems with balance but I have become accustomed to it and use my cane for support.

## Do you have any other diagnoses/health problems besides MS?

I have arrhythmia (a condition in which the heart beats with an irregular or abnormal rhythm).

## Have you done any financial planning for the future due to the fact that you are ageing with MS?

Unfortunately no, I don't have the financial capacity to do planning for the future.



Carol de León Reeves (front, centre) with her family

## Is it difficult for you to distinguish between normal ageing issues or problems and something that is related to MS?

I'm not sure whether my hearing loss is related to MS or not.

## Do you think having MS as an older person has created any limitations for you that other older adults wouldn't necessarily face?

I can't leave the house alone or drive a car. I have to rely on family for help.

## What do you worry about the most related to ageing with MS?

Honestly, nothing worries me about ageing with MS. I have learned to live with and manage my MS. Rather than worry, I accept that I have the disease and live a very happy and productive life. Having and maintaining a positive attitude has helped me a lot. I enjoy being with my family. I still keep as active as I can. Life is precious and I enjoy every minute that I can. I know that God is with me and there is nothing against me.



Asociación Guatemalteca de Esclerosis Múltiple provides information and support to people with MS and their families. Contact them at: [www.facebook.com/ASOGEMGT](https://www.facebook.com/ASOGEMGT) or email [asogem2@gmail.com](mailto:asogem2@gmail.com)

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## With many thanks

MSIF would like to thank Merck Serono for their generous unrestricted grant, which makes the production of **MS *in focus*** possible.