

MS *in focus*

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● Employment and MS



multiple sclerosis
international federation

Editorial Board

Multiple Sclerosis International Federation (MSIF)

MSIF's mission is to lead the global MS movement to improve the quality of life of people affected by MS and to support better understanding and treatment of MS by facilitating international cooperation between MS societies, the international research community and other stakeholders.

Our objectives are to:

- Support the development of effective national MS societies
- Communicate knowledge, experience and information about MS
- Advocate globally for the international MS community
- Stimulate and facilitate international cooperation and collaboration in research into the understanding, treatment and cure of MS

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Letter from the Editor



Work provides opportunities for maintaining or sometimes improving one's standard of living, for forming new relationships, for learning new things, as well as providing a sense of satisfaction and purpose. In industrialised countries, participating in the workforce also signifies health and unfortunately, this concept leads to discriminatory treatment of people with MS and others with impairments far too often.

A diagnosis of MS is often made when a person is either just entering the workforce, or is in the process of making decisions about job interests and possibilities. A diagnosis at a later age is not uncommon either, when an individual may be well integrated into work, with an established work history of ten or more years.

Studies involving people with MS have reported high rates of unemployment and job loss. Reports from the United States, Norway, the United Kingdom, Australia, Spain, Israel and other countries have all found that a large number of those working at the time of diagnosis leave the workforce prematurely, many even before they have symptoms that might impede their ability to work. Certainly these countries have very different cultural and legal conditions, although job risk for people with MS appears to be a common theme.

Why is it that some people with MS leave employment shortly after being diagnosed? The decision to maintain one's job is complex and is likely to depend on a number of factors that are more complicated than specific symptoms or the disease itself.

In this issue of *MS in focus* a number of themes related to employment are discussed, including workplace modifications, post-employment planning and issues related to disclosure. While we have not delved into legislative issues due to the diversity across countries, this issue provides a comprehensive presentation of employment and involves experts from a number of universities and MS societies.

We look forward to receiving your comments.

Michele Messmer Uccelli, Editor

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The next issue of *MS in focus* will be on MS research. Please send questions and letters to michele@aism.it or marked for the attention of Michele Messmer Uccelli at the Italian MS Society, Via Operai 40, Genoa, Italy 16149.

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. 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 healthcare professional. For specific, personalised information, consult your healthcare 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 employment and MS – key concerns

Phillip D Rumrill, Jr PhD CRC, Professor and Director, Center for Disability Studies, Kent State University, Kent, Ohio, USA

Arnold is a 44-year-old man who works as an academic advisor at a community college. He works with students in person, over the telephone and online to help them to select major courses of study, choosing classes pursuant to those majors and preparing for their careers after graduation. Arnold works full-time, 40 hours a week, on a 12-month basis. His job requires periodic car travel to meetings and conferences in the

community, and airplane travel to conferences once or twice a year.

Arnold was diagnosed with MS at the age of 32. His symptoms are periods of extreme fatigue, numbness and tingling in his left hand, gait problems and problems with short and long-term memory. During exacerbations, Arnold uses accrued sick leave when he is unable to work, a quad-cane for mobility, and a hand-held electronic planner to combat his problems with memory. In fact, he has taken to using the hand-held device at all times. Arnold also asks his employer to make minor scheduling modifications on days when he is working and experiencing fatigue. One such modification involves an extended lunch break so he can go home to have a one-hour nap, returning to work in the afternoon and staying after hours to make up the time.

Arnold has disclosed his MS to his employer, and his supervisor is very supportive. He has chosen not to disclose his MS to his co-workers, although they express concern for his well-being when he takes sick leave. One colleague asked him if everything was okay when he came to work with his quad-cane, to which Arnold casually replied, "It's a nerve thing, the cane helps me walk straight."

Like the vast majority of people with MS across the globe, Arnold is an experienced and well-trained worker who has much to contribute to the labour force. He hopes to work through to



retirement age, and he consults his neurologist regularly and adheres strictly to his medication regimen. Thanks to advances in medicine, technology, and laws in his country protecting workers with disabilities and entitling them to reasonable accommodations at work, Arnold's long-term career prospects are good.

Many people with MS have a successful employment history, just like Arnold. Around 90-95 percent have worked at some time in their lives. Some two-thirds of people with MS were still working at the time of diagnosis. However, as time and the illness progress, there emerges a precipitous decline in labour force participation. In the US, only about 40 percent of people with MS are currently employed for pay, and estimates indicate that only 20-25 percent will continue working until age 65. Some of the reasons that have been cited for this seeming "mass exodus" from employment include negative attitudes on the part of employers, difficulties in arranging transportation to and from work, functional limitations associated with MS symptoms, the availability of disability benefits, and lack of access to assistive technology and other on-the-job accommodations that could enhance productivity and reduce turnover. Studies also show that women, people with lower levels of education, those with more severe and persistent symptoms (such as people with progressive forms of MS), and workers whose jobs require significant physical exertion are more likely than other individuals to disengage from the work force following a diagnosis of MS.

By their own reports, people with MS are gravely concerned about their long-term employment prospects. Surveys of people with MS in a number of countries repeatedly document concerns related to workplace discrimination, the need for information regarding home-based employment, interest in learning more about legal protections and employment-related resources, issues surrounding health insurance coverage and MS speciality care, the need for more widespread availability of assistive technology in

the workplace, and the desire for more effective self-advocacy strategies to aid in continuing one's career.

For specifics about the laws and customs in one's own country, it is best to contact the MS society and ask for legal and vocational help. Support from other people with MS who have found ways to stay at work could be the most important element, no matter what the local situation is.

Taken in aggregate, the articles in this issue of *MS in focus* address virtually every employment concern voiced by people with MS as they attempt to resume or maintain their careers while coping with such an intrusive and unpredictable chronic illness. Given the extensive work history that many people with MS can claim to their credit, issues of job retention often arise in vocational services for people with MS. Perhaps the single most common employment-related question posed by people with MS is "What do I have to tell my employer about my condition?" The decision whether to stop working or to continue one's job as long as possible is an extremely complex one for people with MS and their families. And, considering how MS might affect avocational pursuits, volunteer work or community activities is a critically important part of the effort to live well with MS.

Therefore, articles in this issue related to job retention, disclosure of disability, the decision to stop working, and avocational concerns are especially timely. Experts on these subjects have been commissioned to share their knowledge, and all stakeholders in the employment and quality of life of people with MS are heartily encouraged to thoroughly examine the many and complex work-related issues that accompany an MS diagnosis. Seamless coordination of services among medical, social service and vocational rehabilitation professionals is the ultimate end goal for this journal's interdisciplinary readership, and people with MS and their families stand to benefit greatly from the enhanced awareness of employment issues that can be gleaned from this issue of *MS in focus*.

MS and barriers to keeping a job

Sarah Westlake, editor of Worklife website (www.yourworkhealth.com), UK MS Society

Despite legislation in many countries to protect against it, there are barriers for people with MS when they are trying to find work, or when they want to stay in the job they currently have. Living with all the effects of MS can make continuing to work difficult, but there are ways to overcome some of the barriers.

MS symptoms

The fluctuating nature of MS can make it particularly difficult to find and retain employment. It is hard for someone to commit to working in shifts or even for a full day when they are unsure how they will feel tomorrow or next week.

MS affects people differently, but fatigue is one of the most common reasons reported as to why people with MS stop working. Fatigue can be difficult to treat and is an 'invisible' symptom, so it is often misunderstood. There are many other symptoms that can impact on working, like vision issues, pain, balance, tremor, problems with memory and thinking, continence problems, and the side effects of certain medications. These symptoms could also make it difficult for someone to feel confident when they are seeking work.

Having a relapse while employed can highlight all kinds of issues. There may be concerns over how much sick leave someone can take, or if time off is allowed for medical appointments. If someone has to take a long time off work, they can become isolated and fearful that their job is not safe. And when they return, it can be stressful if work has piled up in their absence or they find themselves out of touch with

changes that have occurred. There can also be a lack of confidence or other issues that can get in the way of work.

Working environment

For someone with MS, there may be a time when they can no longer physically manage their current role because their work environment does not support them. It may be that a workplace is unsuitable for a wheelchair or for a person with mobility issues. Some people with MS may find the heat in an office, or an outside job, a problem in warmer weather. Even getting to work using public transport or driving a car could be a major barrier.

Public perceptions

There may also be ignorance about MS in the general public and about how it might affect someone at work. This could make an employer less likely to employ someone with MS, often citing other reasons why they may have been unsuccessful at an interview or at the time of an evaluation for a promotion.

Often employers simply lack information about MS and about what they can do to help, and may only find out once the condition has already had an impact and there is friction or problems at work. This highlights the importance of finding the right way to educate employers – in some countries, healthcare professionals or MS societies may be able to assist people with MS to provide information for their employer.

But telling others about MS can be difficult. Some people choose not to say anything until they have to because they are worried about how people will react. Will they start treating you differently, or be afraid that they will say the wrong thing? This can

put a strain on the relationship between the person with MS and people they work with. There are many misconceptions about MS and some people might not feel like being the person who has to educate everyone.

If an employer and colleagues do not know that a person has MS, they may wrongly interpret symptoms, such as a problem with balance as being related to alcohol. MS can be difficult to explain to colleagues because of its relapsing-remitting nature, and because many symptoms, such as fatigue, are 'hidden', there could be a perception that someone is 'making it up' leading to bad feelings. Open

communication and education can be a good way to clarify misconceptions.

Overcoming the barriers

There are certainly barriers to staying in and finding work for people with MS so it is important to consider all the available options. These may include staying in the same role with adjustments to the workplace to make it more accessible, making changes to the way of working, changing jobs or career, or using available initiatives and benefits to enable job retention or job maintenance. These barriers do not have to stop a person with MS from working if they want to.



Disclosing MS at work

Deanna Groetzinger, Vice-President,
Government Relation and Policy, Multiple
Sclerosis Society of Canada

“Will I be able to keep working?” This is a commonly asked question after being told “you have multiple sclerosis”. The answer for most people with MS is “yes”. But this raises the question of whether or not to tell employers and colleagues.

Reasons for disclosing

There may come a time when a person with MS requires a number of changes in the workplace to be able to continue to do the job and therefore needs to disclose their MS. It may also mean the person is covered by insurance if an accident were to happen at work.

Points to consider before disclosing are:

- Know the legal rights in your country concerning amendments in the workplace for people with disabilities;
- Think about what workplace changes would make it easier to do the job;
- Seek advice from the local MS society or from others who have had similar experiences.

In many countries and for most jobs, people are not legally required to disclose the diagnosis or discuss their medical condition in order to be able to make amendments to their workplace. There are some occupations for which a medical exam is required as a condition of employment, for example an airline pilot or firefighter. Otherwise, the only questions an employer can legally ask about an illness or disability are those relating

to the ability of the employee to perform the essential duties of the job.

A good strategy for disclosure is to rehearse the main points in advance, and to consider the questions an employer might ask. This way, a disclosure can be prepared, positive and confident, not apologetic.

When requesting workplace amendments, a person with MS could describe the current limitations of the job and make suggestions as to how those limitations could be minimised by appropriate changes. For example, if fatigue is a problem, asking to be able to work from home one day a week or have flexible work hours to avoid traffic congestion are practical solutions with little or no cost.

It is positive that in many countries, there are laws to protect from on-the-job discrimination after disclosure. In addition, employers are beginning to appreciate the skills that people with MS bring to the job and are not just focusing on the disease or the disability.

When to disclose

The best time for a disclosure of MS is before the employer becomes aware that workplace changes might be necessary and before there is any concern about job performance. Lapses at work are more often noticed than not. Being proactive and positive should assist in preventing negative reactions and emotional stress.

Reasons for not disclosing

There are good reasons, as well, for not disclosing a diagnosis for MS. In most cases, these would apply to people whose MS symptoms are not visible. If MS does not affect job performance and no changes to the workplace are required, there is often no reason to share information.

In some cases, people with MS may be concerned their employer and co-workers will react negatively, and fear that disclosing their MS might jeopardise their job or adversely affect work relationships, even if they are protected by legislation.

Being a job candidate

It is far easier, in most cases, to continue in a job than to find a new one, but the issues facing a person with MS who is looking for a job are similar to those of other employees. For someone with invisible symptoms, there is no requirement to disclose the MS diagnosis, unless a medical examination is mandatory. For someone with visible symptoms, it is not necessary to disclose the diagnosis; discussion should focus instead on positive aspects including the skills the person would bring to the job. Accommodating any disability can also be broached in a positive manner.

Examples of disclosure issues

Carol has worked for a government agency all of her career. Diagnosed when she was 35, she disclosed immediately that she had MS as she had to take a month off work. "I'm lucky because my workplace is covered by an Employment Equity Act. They have to accommodate you," she said. "Some of the people in my MS support group don't have that. They worry about disclosing because they fear they could lose their jobs."

Carol's MS symptoms are invisible and most of the time she needs few adaptations. However, she did request and receive amendments when she was competing for another job within the organisation. Because she couldn't write with a pen, she was allowed to take the three-hour test separately and to use a computer. Carol obtained the promotion and now heads an eight-person team.



Sharon (pictured below) had her first MS attack at age 18 while working at a summer job. "I had to quit that job, and no, I didn't tell them why," she said. Sharon's approach has been not to disclose throughout her career, although she didn't hide the fact she has MS. To her, it was not relevant to the kind of work she did. She decided that self-employment and part-time jobs were best, especially after she became a single mother of three daughters.

"I taught part-time at colleges and did freelance writing and editing for many years. Even after I started using a cane, I didn't tell people it was because of MS," she said. Her most recent job was with an MS society where she had been a volunteer. "My symptoms were progressing, and I needed a steady job with benefits. They welcomed the fact that I had MS so it worked well."



Sharon chose not to disclose her MS to her employer.

Making a change

Richard T Roessler, PhD, University Professor, RHRC Department, College of Education and Health Professions, University of Arkansas, Arkansas, USA and **Steven W Nissen**, MS, CRC, Senior Director, Employment and Community Programs, National Capital Chapter, National MS Society, Washington, DC, USA

When it comes to multiple sclerosis, there are two things a person does not want to hear: the diagnosis itself and that it is time to quit work. Of course, no one can change the reality of the diagnosis, but it is possible to do something about the second piece of news. Maybe it isn't time to quit work, just time to think about working in a different way through the use of job accommodations or amendments.

In countries where employees with disabilities are protected by law, rehabilitation professionals can encourage workers to think about how changing equipment, job duties or location of their work can enable them to be more productive. In the US for example, the basic principle is as follows: a person with a disability cannot be discriminated against in the processes of job acquisition or job retention if he or she can perform the essential functions of the position with or without reasonable accommodations.

We know many things about reasonable accommodations based on workplace experiences.

- They cost very little; for example, the majority cost nothing at all and the vast majority cost no more than US\$600/€475. Examples of no-cost accommodations include use of a parking spot adjacent to the workplace, flexible work hours, options to work at home, job sharing, work locations near the toilets or a rest area, as well as encouragement to have regular rest breaks.
- Many types of accommodations exist, ranging from the installation of an automatic door opener,

to a raised work area ensuring wheelchair or scooter access.

- Although the choice of the accommodation typically rests with the employer, the worker is advised to research the range of feasible accommodations themselves.
- The cost of the requested accommodation must be reasonable in relation to the employer's available resources.
- The accommodation cannot change the basic nature of the business. For example it may be unreasonable for a staff member of a restaurant to request brighter lighting to compensate for visual impairment related to MS.
- The accommodation cannot constitute harm to others, as may be the case for a machinery operator with MS who, due to coordination problems, may endanger co-workers.

The majority of accommodation costs nothing at all.

Even with this vast array of accommodations, the employee with MS may not be able to perform satisfactorily in his or her job due to new or more severe and frequent symptoms. Decisions with respect to leaving one's current employment must be based on an accurate self-assessment of the impact of MS, which often requires feedback from family, friends and treating physicians and therapists. The alternative is not necessarily one of unemployment, but possibly one of different employment.

Different employment means a career change, and career change is best understood in terms of the timeless vocational counselling equation of “interests + abilities = feasible career choice”. In other words, vocational interests, or what the person likes to do, must be compatible with the activities of the job, and the abilities of the person – as affected by MS or not – must be compatible with the tasks of the job.

Vocational interests are often thought of in terms of work reinforcers. Does the person prefer to work alone or with others? How important are security, creativity, achievement and compensation to the person? Vocational interests are also defined in terms of preferences for different types of work activities. Does the person enjoy working with data, people or things? Obviously, when thinking about

career changes, people with MS must consider the extent to which an array of career options satisfies their vocational interests. They must also consider carefully the extent to which these “vocational hypotheses” are consistent with their current skills.

People with MS must consider the extent to which career options satisfy their vocational interests.

Current skills may or may not be affected by MS. Obviously the goal is for the person to identify career possibilities requiring their unchanged skills (for example data analysis, customer service, spatial and mechanical skills). But the person must also keep in mind the impact of MS on



functional abilities – which skills remain or could be developed to be compatible with the impact of MS? Again the secret to successful career change lies in the match between job tasks and stable and changeable skills. But this match is by no means static; over time the quality of the match can be enhanced by utilising job accommodations in terms of physical access to the workplace or modifications in the ways work is done.

In conclusion, the news “you have MS” is not synonymous with the recommendation “and you should quit work”. More realistically, the news that one must cope with MS means that creative solutions are needed to preserve that person’s role

of worker. At first these solutions may only require enhanced vigilance and responsiveness if MS symptoms are negatively affecting job functioning. In other situations the diagnosis of MS may signal the need for reasonable accommodations in the way the person completes work or accesses the workplace.

Finally, the presence of MS in a person’s life may necessitate a more extreme change such as a new career. Career change is all about finding work that one likes to do (interests) and can do (skills and abilities) because, when it comes to MS, one thing a person does not need to hear is “it’s time to quit working”.

Karen provides a good example of someone who navigated the career change path. After receiving a degree, Karen worked as an athletic trainer for more than 15 years in a clinical setting, as well as in the field treating high school athletes’ injuries. Diagnosed with progressive MS, Karen began having more significant mobility difficulties. She could not run out onto the field or court quickly anymore and began using a scooter or a cane. She felt, that for her students’ safety as well as her own, being an athletic trainer was no longer appropriate. Karen spent time researching other vocational fields, networking and conducting a realistic self-assessment of her interests and abilities. An opportunity presented itself to be the administrative assistant and office manager for an orthopaedic surgeon. The job responsibilities include scheduling appointments, filing with insurance companies, entering patient information into the database and maintaining the physician’s calendar – all sedentary activities. Her employer allows her to work from home two days a week as a way to manage fatigue and to minimise her lengthy commute. She is able to utilise her extensive experience and knowledge of orthopaedics, medical terminology and familiarity with sports injuries in a position that is not as physically demanding as her previous one. Karen shares openly that she wants and needs to work as long as she can.



Beyond paid employment – planning ahead

Judy Gregurke, (DAppSc, MHA) Regional General Manager – South, MS Australia

The experience of many people diagnosed with MS provides evidence that careers can continue to develop and grow and that employment choices often remain varied and exciting. The Australian MS Longitudinal Study has documented evidence that the majority of people with MS who leave paid employment do so due to their symptoms, especially fatigue, rather than any unwillingness by employers to negotiate changes to accommodate special needs. The first point of decision-making about employment may occur months, years or even decades after diagnosis. Whatever the timeframe, planning ahead is important.

Before deciding to leave employment

Prior to deciding on a change in employment, it is important to carefully consider many factors and to take some time to do so. A hasty decision following a diagnosis of MS may not lead to the best solution. It is also important to give oneself time to see if adaptations or accommodations could reduce the need to leave work.

Practical planning

Planning for the future is an accepted part of life today. People have plans for their future employment, their financial security, their recreation

and leisure activities, and for their family life. When people are diagnosed with MS, they are forced to review all their preconceived plans, and each person's journey with MS is as individual as they are.

It is important that each person carefully considers their particular financial circumstances as well as any government support available and how this will meet the financial commitments of the individual and their family. These vary from country to country, as do pensions and other income supports. Future housing and accommodation requirements are also an important consideration for some people with MS and their families. Help with financial planning may be available from MS societies or professional financial advisors.

It is also important to consider the emotional impact of stopping paid work. Some people miss the routine a job can provide, as well as the social side of working with other people. Planning ahead can help reduce the impact of finishing paid work on many levels.

Avocational planning

Avocational planning addresses those aspects of life beyond paid employment and becomes much more important to individuals who have been diagnosed with MS. For many, this diagnosis comes at a time when they are fulfilling their key

employment objectives and preparing for a long and rewarding career path leading to a retirement of travel, leisure and recreational activity. Financial investment, family, lifestyle and housing choices need to be reconsidered by many people with MS, as do current and planned recreational goals.

The importance of avocational planning

Like all aspects of life and career planning, planning for life beyond paid employment is important. It establishes non-employment goals that provide something to look forward to and a reason for getting up each day in retirement. For people with MS, retirement can come much earlier than their original plans or expectations, and with their diagnosis comes a need to re-evaluate those plans.

Avocational planning is most effective when undertaken with immediate family and other friends and supporters within each individual's networks. Ideally, the best planning is a team effort, involving the individual and those closest to them, in conjunction with relevant health and medical professionals, financial and career planning professionals, and individuals who can give advice on recreational and leisure activities. This ensures that the person with MS is able to make decisions with all the necessary information.

Planning for life beyond paid employment

Opportunities for continued participation in community life are an important part of avocational planning. Individual characteristics such as personality, existing hobbies and recreational passions, and family responsibilities should be considered along with accessibility and availability of a range of activities in the local area. Alongside a person's hobbies and recreational pursuits, more "formal" avocational options can fall into two broad categories: activity programmes for ongoing personal development and volunteering for the benefit of others.

Recreation and personal development

Many local communities provide a range of creative and purposeful avocational opportunities for individuals to explore and experience, for example



creative arts programmes (see page 16). Others enjoy spending more time on hobbies and adjust their expectations to suit their ability levels. Another key area of personal development could be physical activity and health and wellness. People with MS are generally aware of the health benefits of being physically active. Planning ahead to identify activities and programmes, such as swimming and exercise groups, which are local and suited to individual mobility and support needs, can be very rewarding.

Volunteering

For people with MS, volunteer roles within MS societies and other community organisations can provide a sense of purpose and fulfilment that matches or exceeds that which has previously been associated with paid employment. Generally, volunteering activities can be done on a part-time basis and can be tailored to the available time and skill of each person, regardless of whether their time constraints are related to other commitments or fatigue.

Avocational planning can help link volunteer activities with the person and their skills. Attributes that characterise an individual's work life may still be relevant in their non-work activities. For example, "workaholics" may be highly valued by volunteer coordinators because they are reliable and available and willing to maximise their involvement within the limitations of their disease if there are any.

Fundraising events provide a range of opportunities for people with time and energy to contribute. Most MS events have a dual focus on raising funds to expand services for people with MS, as well as enabling people with MS to participate. Other non-profit or charity groups may also offer opportunities for fulfilment.

Conclusion

Successful avocational planning ensures that individual needs and aspirations are the focus of activity rather than disability, barriers and limitations. At some point along the journey with MS, each person becomes aware that life and living still provide valued and valuable life experiences, beyond paid employment.



Person Centred Planning (PCP) is an approach that develops individualised, natural and creative supports to achieve meaningful life outcomes based on each person's strengths and preferences.

This approach ensures that a team of people, who know and care about the person with MS, work together to develop a shared vision for the future, and to provide the supports necessary to make that vision a reality.

MS Australia provides a range of services for people with MS and has a dedicated Planning and Facilitation Team using PCP. This involves all aspects of employment planning, including paid employment, recreational planning and current and future lifestyle planning.

An example is Ehsan (above), 55, who lives in Melbourne, Australia. He gave up work as a motor mechanic when he could no longer stand for long periods and started falling at work. He looked for alternative employment that was manageable with his symptoms and became a salesman, while continuing to explore hobbies with small business potential. In 1998 Ehsan opened a shop with the support of friends. This kept him busy, but he had to close the store when he could no longer manage the work, due to MS worsening.

Ehsan heard about one of MS Australia's Creative Arts groups from a friend and has been attending for ten years – he particularly enjoys painting. His love of creative art has sustained him through the loss of the shop and into enjoying life beyond paid employment.

Your questions answered

Q. As an employer, I am keen to ensure an employee with MS can continue working as a teacher. We are working together to find solutions but can you suggest any changes we can make?

A. If the employee and employer are willing to cooperate in identifying and implementing on-the-job accommodations for workers with MS, effective solutions usually fall into place. The first step is determining which MS symptoms are affecting the worker's job duties, and which job duties are affected. Where MS symptoms create difficulties with job performance, a reasonable accommodation is warranted. Encouragingly, employers report that accommodating workers with MS is often a no-cost or low-cost proposition, often amounting to scheduling modifications or flexible arrangements at the workplace that enable the worker to take full advantage of the abilities he or she has that are not compromised by MS.

Prof Phil Rumrill, Kent State University, Ohio, USA

Q. I need to tell my boss that I have MS as my symptoms are interfering at work, but I am frightened. I can't afford to lose my job because I am a single parent and my government does not provide any assistance. What advice can you give?

A. Depending on where you live, it is important to determine whether you have any legal obligation to tell your employer. In many countries, the employer does not have the right to know your diagnosis of MS, only that you are a person with a disability who requires an accommodation to do your job. If MS is not affecting your job performance or your attendance and if there is no law in your country that you must disclose, I generally advise people to keep their health information to themselves. If you do need to disclose something about your health to your employer, I recommend telling only as much as you need to in order to arrange the accommodation you need. Once you relinquish your privacy, you can never get it back, and I try to discourage people from disclosing things that the employer has no right to know.

However, you may want to investigate if your place of employment has a policy regarding accommodations, if there is a personnel office that has a qualified person who can help you or if there are other employees who have had to make changes to their work due a disability/health condition. In any case, it's important to understand your rights as an employee before making any decision about when, how and what to say to your employer. Your MS society may be able to give you more detailed guidance.

Prof Phil Rumrill, Kent State University, Ohio, USA

Q. I find fatigue a big problem at work. My boss has allowed me to reduce my hours, but I'm still struggling on some days. Are there any medications or therapies that might help?

A. There are medications that can help (Amantadine and Modafanil are commonly prescribed), but these are never entirely successful if taken in isolation – it is important to integrate some fatigue management strategies into your daily routine as well. The strategies you may want to consider involve pacing yourself. It is important to take breaks at work – we often sit within our work environment during break times, but it is advisable to have a complete break away. It is also important to build a ten minute break into the morning and the afternoon. If you can't do this, you may want to consider relaxing for 10 minutes or taking an extra long toilet break.

It is also important that you eat regularly. Foods that are full of slow releasing carbohydrates are particularly good, such as a cereal bar or crackers. You may also want to consider the heat in your work environment – a fan or sitting near an open window can be helpful. Even having ice cold drinks can make a difference.

Finally, fatigue is usually worse as the day goes by so try to plan important activities or meetings in the mornings.

Nicki Ward, Lecturer Practitioner in MS, Birmingham City University, UK

Employment and MS: global survey results

Dr Dhia Chandraratna, MSIF's International Medical and Scientific Officer, summarises the results and recommendations of the World MS Day Employment and MS survey.

Work is a fundamental aspect of our lives.

It provides not only a salary, but a sense of self worth, an opportunity to lead an independent life and to be a fully integrated member of society. A study commissioned by MSIF into the global economic impact of MS highlighted the loss of employment or early retirement as the single largest cost factor in the total cost of MS. This represents not only a direct cost in terms of loss of earnings, but indirect costs in terms of quality of life, and affects not only the person with MS and their family but also society as a whole.

In order to gain a global perspective of the impact of MS on employment and to raise awareness of work-related issues faced by people with MS, we designed an online survey on 'employment and MS' in ten languages. It was linked to the World MS Day website and Facebook page and also advertised through MSIF member societies. Respondents were therefore a self-selecting sample.

MS and employment

- 59% of participants with MS were employed. More than two-thirds of these were in full-time employment.
- 67% said that having MS had at some stage impacted on their work (by reducing working hours, taking short-term leave, or changing jobs or type of work). 33% reported no change.

Factors that enable people with MS to remain in employment

MS-related factors

- Having stable MS was listed by 56% as the most important factor. Both symptomatic and disease-modifying treatments were also listed as important in

- 8,681 people from 125 countries took part.
- 87% had MS. 73% of respondents were female, 27% were male.
- 96% of respondents were of working age.
- 42% had been diagnosed with MS for five years or less.

enabling people to remain at work.

- 42% of participants said that seated work was one of the most important enabling factors for employment and 38% of participants saw flexible working hours as important.
- Only 6% of participants thought that computer adjustments made a difference to their work and 4% said that adaptive aids may help them in the workplace.

The fact that having stable MS was listed as the most important factor highlights the importance of disease management and the challenge of managing common symptoms such as fatigue from an early stage. This is supported by the fact that symptomatic treatments and disease-modifying drugs were also rated as major factors. Studies have shown that the number of people remaining in employment has increased in the 2000s compared to the 1980s and this may, in part, be explained by improved treatments and better disease management.

Support-related factors

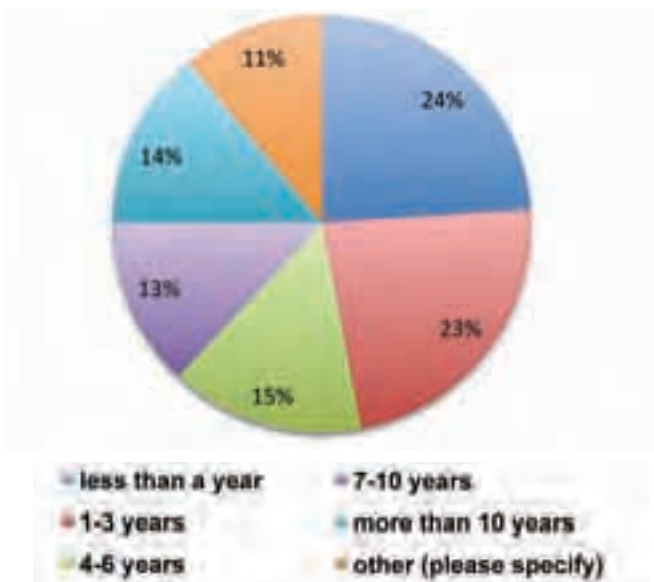
- 60% said that emotional support from family was important, and 49% identified a supportive employer and colleagues as the main factors enabling people with MS to remain in employment.

The importance of family support suggests that family counselling and emotional support can be of great benefit to people with MS and their families. These results also highlight the importance of educating employers and people in the workplace about MS.

MS and unemployment

- Of the 41% of people not working, 83% left work prematurely due to MS.
- Almost half (47%) of these, did so within three years of being diagnosed.

The number of years to stopping work after diagnosis



This last point was a significant result of the survey. The reasons for this are not clear but it poses many questions. Why do they leave work so early? Did they leave voluntarily? Was it due to the lack of knowledge of legal protection available to employees? Or to not fully exploring options to manage symptoms while remaining at work? Was it following advice to reduce stress or a reassessment of lifestyle and priorities? Although one would expect better disease management and treatment at the early stages of the disease to improve these figures, the high numbers leaving work so early suggests that drug treatments either may not be as effective as hoped for or are not being used to maximum benefit at this stage.

Factors that prevented people with MS from remaining in employment

Symptom-related factors

- 85% of unemployed participants identified fatigue

as being particularly detrimental to their ability to remain in work, while 72% said that mobility-related problems were difficult to overcome.

- More than 40% listed cognitive impairments as a barrier to work, while less than 20% said that tremors and speech impairments caused difficulty in remaining at work.
- Similar trends were seen in the individual language surveys. In addition, the Chinese and Russian surveys also listed urinary or bowel problems as an important barrier.

Other factors

- 49% listed unpredictable workloads as a major barrier.
- More than 30% of participants also said that a lack of support from an employer or work colleagues, lack of time off when needed, and their own attitude to work (e.g. a lack of confidence or motivation) had affected their employment.
- Less than 10% said that a lack of a lift in the office or limited help with childcare had made it difficult to remain in work.
- Access-related issues were rated highly in the global survey in some specific areas. The most important factor preventing people with MS from remaining at work in the Russian survey was access to transport, and access within the workplace in the Chinese and Arabic survey.

Changes that would have helped people with MS remain in work

Flexibility was a key factor in enabling people with MS to remain at work.

- 48% of unemployed participants said that flexible work hours would have made a difference.
- 42% said that the ability to take regular breaks to rest would have enabled them to continue working and 34% said that to do this, a place to rest would be necessary to support them at work.
- Better awareness of MS among work colleagues was also listed by 34% as being important.

Simple, inexpensive measures such as these can make a big difference and are relatively straightforward solutions. The last point stresses the importance of educating people in the workplace about MS.

Recommendations

Extending the possibilities for people with MS to stay in work is a challenge for governments, employers, medical professionals and MS societies. The outcomes of this survey lead us to make the following recommendations:

- Provide information for people with MS and their carers to help them fully explore options to remain in employment, understand their rights and know what services and support (medical, financial and social) are available.
- Improve vocational rehabilitation services to advise people with MS on how symptom and disease management can help while staying in work.
- Ensure early intervention to enable people with MS to seek help before a crisis point is reached, and to provide information on employment to those newly diagnosed. Employment should be considered as part of the overall management of MS.
- Educate employers and people in the workplace on issues related to MS and how to support people with MS at work. Employers need to be given information on useful workplace adjustments and the benefits of flexible working, routine workloads and rest breaks.
- Provide social, emotional and financial support for people with MS and their carers.
- Ratify the UN Convention on the Rights of Persons with Disabilities (see page 21). All governments should ensure that national legislation is in place to provide support for people with MS and others with disabilities and ensure the absence of discrimination.

In summary, living with MS has profound implications on employment for many people from a very early stage. While there are no adequate measures yet to manage symptomatic factors such as fatigue, better information for people with MS on disability rights and availability of services, more research to provide better treatments and better disease management, and relatively simple changes in the workplace, such as flexible working practices, should help people with MS to continue working for longer. For a copy of the full report, including results of questions for carers of people with MS, please visit the MSIF website www.msif.org

Thousands take part in World MS Day 2010

World MS Day is an annual global day for action where MS societies, medical institutions, private companies and interested individuals come together to form a global movement to end MS for good. This year activities took place in 67 countries and ranged from fundraising to awareness raising, from public health meetings with key representatives of government, to complimentary therapy seminars for people living with MS and their families.

Activities were focussed around the 26 May, however many organisations held awareness weeks, months, or even launched an ongoing campaign to raise awareness about MS. Australians kissed goodbye to MS while Americans thought globally and acted locally. Canadians moved for MS, while Uruguayans danced and sang. South Africans took part in golf tournaments and dinner parties, while Italians discussed the issues facing people with MS with the Minister of Health. Activities were well supported with thousands of people attending events, and thousands more showing their support by signing up on the World MS Day website and joining the Facebook site.

To find out more and to join the global movement for World MS Day 2011 go to www.worldmsday.org



The Korean MS Society rallied support to end MS with marches and stands in Seoul.

UN Convention on the Rights of Persons with Disabilities

What is the United Nations Convention?

The purpose of the Convention is “To promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and to promote respect for their inherent dignity.” It is both a development and a human rights instrument, a policy tool which works across different disabilities, and once ratified by a country, it is legally binding.

Countries that adopt the Convention engage themselves to develop and carry out policies, laws and administrative measures for securing the rights recognised in the Convention, and abolish laws, regulations, customs and practices that constitute discrimination.

Why have a Convention?

The Convention was formed as:

- A response to an overlooked development challenge: approximately 10 percent of the world’s population are people with disabilities (more than 650 million people), approximately 80 percent of whom live in developing countries.
- A response to the fact that although pre-existing human rights conventions offer considerable potential to promote and protect the rights of people with disabilities, this potential was not being tapped. People with disabilities continued being denied their human rights and were kept on the margins of society in all parts of the world. The Convention sets out the legal obligations of countries to promote and protect the rights of persons with disabilities. It does not create new rights.

What does the Convention mean for employment and people with MS?

In relation to employment, article 27 states that people with disabilities have equal rights to work and gain a living. Countries are to prohibit discrimination

in job-related matters, promote self-employment, entrepreneurship and starting one’s own business, employ people with disabilities in the public sector, promote their employment in the private sector, and ensure that they are provided with reasonable accommodation at work.

Other related sections, or articles, of the Convention include article 24, on education, that would ensure that people with MS have equal opportunities for education to enable them to gain the skills they need for future employment. Transport to and from work can be a big issue in some countries, so article 20, on personal mobility, is also a key section. Mobility and physically getting around can mean the difference between being able to work and not being able to work.

Peer Baneke, MSIF’s CEO, comments that “In countries where there is no legislation protecting people with disabilities, ratifying the UN Convention will make a major difference to people with MS. A government will be required by law to promote suitable access to transport or to public buildings, helping to support the continuation of employment for people whose mobility is affected by MS.”

“In many respects, the Convention gives legal backing to our document, *Principles to Promote the Quality of Life of People with MS*. Once a country has ratified the Convention, MS societies or individuals can use the general standards in the UN Convention to advocate for more detailed national legislation; however, in many countries it will require persistent advocacy to get the government to implement in reality what it agrees to in principle,” suggests Peer.

For more information on the UN Convention, please visit www.un.org/disabilities.

Countries that have ratified the Convention:

Algeria, Argentina, Australia, Austria, Azerbaijan, Bangladesh, Belgium, Bolivia, Bosnia and Herzegovina, Brazil, Burkina Faso, Canada, Chile, China, Cook Islands, Costa Rica, Croatia, Cuba, Czech Republic, Denmark, Dominican Republic, Ecuador, Egypt, El Salvador, France, Gabon, Germany, Guatemala, Guinea, Haiti, Honduras, Hungary, India, Iran, Italy, Jamaica, Jordan, Kenya, Laos, Latvia, Lesotho, Malawi, Maldives, Mali, Mauritius, Mexico, Mongolia, Montenegro, Morocco, Namibia, New Zealand, Nicaragua, Niger, Oman, Panama, Paraguay, Peru, Philippines, Portugal, Qatar, Republic of Korea, Rwanda, San Marino, Saudi Arabia, Serbia, Seychelles, Slovenia, South Africa, Spain, Sudan, Sweden, Syrian Arab Republic, Thailand, Tunisia, Turkmenistan, Turkey, Uganda, Ukraine, United Kingdom of Great Britain and Northern Ireland, United Republic of Tanzania, Uruguay, Vanuatu, Yemen and Zambia.

Has your country ratified the Convention? If not, what can you do?

- Cooperate with similar or like-minded organisations, such as other MS societies in your region or other non-governmental organisations.
- Contact your government and elected representatives by to discuss if and when the government intends to sign and ratify the Convention.
- Create a dedicated web page.
- Ask the general public and people affected by MS in your country to write to your government.
- Undertake media work.

For further information and useful campaigning resources, please contact us on info@msif.org

Other useful campaigning resources

MSIF's *Principles to Promote the Quality of Life of People with Multiple Sclerosis*

To enhance the lives of people with MS, MSIF published a report which presents the "principles" to improve the quality of life of people with MS. For this edition of *MS in focus*, Principle 7 Employment and Volunteer Activities, is the most relevant. It requires that support systems and services are available to enable people with MS to continue employment as long as they are productive and desire to work.

In practice...

This principle was one of the ten analysed in a comparative study "Multiple Sclerosis: reality, social needs and quality of life" undertaken by the Spanish MS Federation and Multiple Sclerosis Association of Argentina to find out the reality of quality of life for people with MS in their countries.

The data was gathered through interviews and meetings with different groups: MS association leaders, professionals in rehabilitation of people with MS, neurologists specialising in MS and people with MS and their families. Overall, the concerns for people with MS living in Argentina and Spain were similar, but it was

found that the size of the concerns and problems was greater in Argentina. They concluded that most of the issues around employment needed further compliance with the *Principles to Promote Quality of Life of People with MS* in their practical implementation.

The European Code of Good Practice

This document outlines the issues of fundamental importance to people affected by MS such as accessibility, job retention and discrimination challenges. It has been drawn up by the European Multiple Sclerosis Platform following a European Parliament Resolution on MS. It calls for information and awareness-raising programmes for people with MS, employers and co-workers and is available on www.ms-in-europe.org

In practice...

EMSP launched a series of national "roundtables", meetings between members of the MS community, national level stakeholders and decision-makers to discuss the application of the European Code of Good Practice. In March 2009, following a roundtable in Romania, the Romanian MS Society were invited to the Health Ministry to discuss a long-term strategy to establish specialised MS rehabilitation centres.

MS Society Projects and Programmes

A partnership for vocational rehabilitation

The All-Russian MS Society (RMSS) sees vocational rehabilitation as the only form of rehabilitation with an investment component in it, since an employed disabled person both invests in his or her personal welfare and contributes to society as a whole.

Between 2004 and 2008, the Samara MS Society (a branch of the All-Russian MS Society) conducted training seminars for people with MS enabling them to work with computers. The society found that among this group, 93% wished to retrain for a new trade.

Ideally, vocational rehabilitation must combine the efforts of a range of healthcare professionals such as psychologists, lawyers, rehabilitation consultants, occupational therapists, vocational physiologists and ergonomists. However, it is not always practical for a person with MS to seek a permanent job. In Russia, the Samara MS Society uses a government-

run employment service programme. Through this programme, the Samara MS Society employs between 40 and 85 people with MS each year.

The programme works as follows: the employment service has a contract with the employer (in this case, the MS society) in which the government partially covers the disabled person's wages for a suitable job. After the contract expires, the person can register again with the employment service, but by this time they have often acquired the skills to compete in the relevant job market and do not need the same support.

Voluntary organisations such as MS societies are important in this programme, since these activities meet their objective to retrain people with disabilities. In addition, these activities help the employment service to play an active role in integrating people with disabilities into society and enable them to create jobs and provide services.



Through this programme, the All-Russian MS Society has successfully developed a department of experts. These experts have been trained to supervise the delivery of disease-modifying drugs and social services in Russia's regions. The department is currently staffed by 112 people with MS, who are biannually retrained and receive a salary.

Creating a successful work centre

The Fundación Esclerosis Múltiple (FEM) is a non-profit organisation created in Barcelona, Spain, in 1989. At the beginning, the main objectives of the foundation were to raise funds for scientific research and to improve the quality of life of people with MS by creating multidisciplinary rehabilitation centres.

In 1999 the foundation realised that it was very difficult for people with MS to find or maintain a job due to the unpredictable nature of the disease and fears of employing someone with a chronic and disabling disease. For this reason the first Spanish special employment centre for people with MS was created.

Its primary focus is to perform productive work, participate regularly in market operations, and to ensure gainful employment and the provision

of personal and social adjustment required by workers with disabilities.

The centre offers its services in three different areas: telemarketing, secretarial services and manual procedures for 150 clients. Currently they employ 80 disabled people. People with MS who work in the centre start by doing simple tasks and, as their training progresses, their job becomes more complex. Meanwhile, if the evolution of the disease requires it, they can do different jobs.

A programme of training has been designed by a team of psychologists from the centre to train the employees to develop working capabilities and to provide them with tools and experience to be able to find an adequate job in ordinary companies.

After ten years of existence FEM are definitely satisfied and the experience has been extremely positive, although not always easy. They can proudly state that their special employment centre is a reference in the marketplace and consequently many physically and sensorially disabled people show an interest in joining the team.

Visit FEM's website at **www.fem.es**



Interview: Héctor García, Cuernavaca, Mexico

Cuernavaca is a city located an hour south of Mexico City. I moved here in 2005 after my MS left me quadriplegic at the age of 46 in 2002. It was then that I had to retire from my profession as a veterinarian.

In everything I do, in realising my projects and dreams, I depend on my wife, Ana Silvia, almost 100 percent of the time. She is my caregiver and companion and together MS has become “our job”.

How did you feel giving up your job as a veterinarian?

Recalling the moment that I had to leave my veterinary work behind me still brings tears to my eyes. When I first started using a wheelchair it took me a long time to carry out the work but I operated on animals by sitting on a bench with the assistance of my colleagues. On one occasion, however, I was left alone and my hands, which had been gradually losing their strength, were unable to manage the surgical equipment. The dog on which I was operating began to bleed but the spasticity and tremor in my hands, combined with the lack of strength, meant that I had to fight to stop the bleeding, without success, for some time. Finally, with great focus and patience I managed to stop it.

That was the day that my colleagues and I realised that I was a risk to the animals' lives rather than a help. The most painful moment of my 46 years was when I had to put down the medical instruments, close the files on my patients, sell my equipment and leave the consulting room, to which I have not returned in eight years.

What did you do next?

After my veterinary career ended, the employment I found was unrelated to my profession. A friend gave me minimum wage work in telemarketing. Without leaving the house (the first floor apartment where I had always lived with my mother and siblings), I communicated with customers and suppliers but the income was low. It did give me the right to social

security and medical attention – albeit it only just maintained my symptoms – but I began to depend entirely on my family.

However, I continued to devise ways to earn money: selling ornamental fish, sandwiches and even jelly but all of the ideas failed. The immobility caused by MS led me to spend a lot of time on the internet – up to ten hours a day. Ana Silvia, who I met in 2005, thought a blog would be the ideal way to intellectually stimulate myself, find purpose and possibly generate new employment opportunities.

Three years ago, the testimony of my life with disability, without employment, without pension rights and without financial support from the state was presented at a public hearing of the Federal District Human Rights Commission, and from that moment on the doors have been opened for me as attention was drawn to the needs of people with disabilities in Mexico.

For several years, while my MS allowed me, I worked as an independent advisor on disability rights, but as my disease advanced I was no longer able to carry out my work.



What do you think the main work-related challenges are for people with MS in Mexico and what needs to be done?

In Mexico there are Augustus laws (highly moral laws), which are accurate and complete in terms of acknowledging the rights of people with disabilities and providing assistance; there are national and local level laws and regulations regarding their implementation; and there are councils and commissions that monitor compliance, and yet in reality, Mexico remains an inaccessible country. It was once said that Mexico was inaccessible for those with shoes, let alone for a person with a disability.

When I realised that my country does not offer employment opportunities for a person with MS, and, in general, to all those with disabilities, I wanted to share my story and claim my right to work.

I sought the legal basis that would support my argument and found the International Convention for the Rights of Persons with Disabilities (see page 21), which had not been signed or legally incorporated into national law in many parts of the world. I joined the struggle for ratification with the hope that someday it would be possible to have the equity in Mexico that people with disabilities demand, where we are able to work, to travel without limitations, to have adequate health services and live a full life with our families.

I believe that the primary challenge people with MS in Mexico currently face is the prejudice associated with chronic, incurable diseases, and it is because of these assumptions that people with MS lose their jobs. Given this situation, people hide the disease so that they do not lose their jobs, regardless of the degree of disability they may have.

Secondly, physical problems such as fatigue or other disabling symptoms are major challenges. Employers often don't understand fatigue and how it affects people, and having a disability means one can lose the opportunity to find a job in Mexico.

In my opinion, long-term solutions are needed to overcome the challenges. This requires a process of educating, raising awareness and informing people about MS, which, for many in Mexico, is still considered an 'exotic' disease.

What advice would you give others with MS?

Knowing the problems facing those with MS, I felt it necessary to seek out those who were newly diagnosed to try and help them to adjust more quickly to living with MS, without thinking that their life is over; and, on the contrary, to look for ways to find happiness in spite of the disease.

In terms of employment, my advice is to talk about MS with all of those around you, your relatives, friends, colleagues and employer. Only then will people know that we, with maybe a few changes made, can continue to be active, productive and useful.

Have you enjoyed the work you have done since leaving paid employment?

Together with my wife, Ana Silvia, I lead the association "ZOE", supporting people with MS in our community, connecting with people via our online network and by telephone. I do not get paid for my current work; the focus is on helping association members through conferences, meetings and providing advice on learning to live with MS.

We also publicise the disease on the radio, informing the public of its existence. It is a rewarding job that I enjoy even though it is sometimes stressful and I often find myself in highly emotional situations. It is also a full-time job and Ana has to be with me all the time as I cannot be without assistance for long. Ana, who also cares for her son Mariano, gave up her role as a university lecturer in journalism to care for me. She is also responsible for communications for the national MS society – Esclerosis Múltiple México.

I continue to write my blog, recounting anecdotes from my life and reflecting on the changes MS has made to my life and sharing my views on issues relating to the disease. This is my new job.

Reviews

<http://www.whatcanyoudocampaign.org/>

This website focuses on employment and disability. For someone with MS, once the diagnosis is made and the fear and anger has calmed down, the links that appear on the homepage of this website look like they will help a reader remain at work. So far, so good. Expectations are made. The message – and no doubt it is true – is that you have to do it by trying.

A headline on the site for employers leads you to a pep talk about equality for all at the workplace, using and respecting the skills of people with disability or dysfunctional behaviour. Unfortunately though, there is, in my opinion, no employer who will act upon reading this page. The few case stories are not convincing. For a deeper analysis about the reality of employing disabled people, there is very little.

A link for employees leads you to some terrific sentences and expressions about the importance of work in life and in combination with disability. But an ambitious person with MS who is keen to work will realise, after a few interviews, that more needs to be done to get success in the labour scene. Other pages and links discuss the need to educate professionals and society in general, but again the text is stimulating but no practical answers are given.

This is a USA site and is not particularly useful worldwide. Many countries in western Europe have a caring, super-regulated society where disabled or chronically ill people get benefits, and adaptations can be made to their workplace or way of working. The website also discusses the need to have a change of attitude in society about employment and disability. It says that this change and a “you can do it” attitude are likely to lead to employment.

However, for many people I believe that this website does not give a realistic view.
Reviewed by Guy De Vos, Belgium MS Society

Women, Work, and Autoimmune Disease – Keep Working Girlfriend!

Authors: Rosaline Joffe and Joan Friedlander.
Publisher: Demos, 2008,
ISBN-10: 1932603689,
ISBN-13: 978-1932603682



Women, Work, and Autoimmune Disease is a book about how we have to keep our hope and our struggle for life, and how to enjoy living with an unwanted and incurable disease.

If your doctor tells you that you have an autoimmune disease (AD) which is incurable and may sometimes stop you from taking part in several life activities, such as your working life, how will you feel? Maybe sad, angry, frustrated and like “that’s it, it is the end of my career!” These are normal reactions upon hearing this news but sometimes these reactions are exaggerated.

Throughout the book Rosalind Joffe and Joan Friedlander use simple but convincing words to tell us that a person with an AD such as MS, can also have a good job and be a successful career woman. The authors are themselves people with ADs, and along with inspiring stories from other women with ADs, they give us ideas and advice about what you can do to enjoy life and your career while managing an incurable disease. Topics include developing appropriate strategies and tactics, evaluating communication skills, building a support team and considerations for self-employment.

So, if you or one of your family members has an AD, before thinking of quitting your job and feeling sad about it, read this book and find out how living with an AD can be enjoyable and manageable, and how particular strategies and tactics can help you to be a successful career woman. Keep working, girlfriend!
Reviewed by Kanya Puspokusumo, President of Indonesia Multiple Sclerosis Group and MSIF Board Member

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MS and employment

MS often strikes when a person is entering the workforce, or is considering their next career move. If this edition of *MS in focus* has been helpful for you, please make a donation towards the costs of its production and the valuable work that MSIF does providing support and services to the MS community around the world.

- ✓ Your **\$16/€10/£10** donation could keep a person affected by MS informed about key issues through *MS in focus*.
- ✓ **\$50/€35/£30** could help us to translate, print and distribute copies of *MS in focus* in countries where access to information is limited.
- ✓ **\$200/€140/£125** could help us to raise awareness of employment issues and MS amongst governments, employers and policymakers.



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MS *in focus*



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