

MS *in focus*

January 2014

Information, technology 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:

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

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Letter from the Editor



This edition of *MS in focus* is about information: where to find it, how to use it to be empowered, how it connects people and how it should be assessed.

Whether a person is newly-diagnosed or has had MS for a long time, information in today's multi-media world can be overwhelming, and many people with MS may be unsure of where even to begin looking for the information they need. While the Internet can offer a mass of information about MS, it can also be a source of inaccurate, biased, deceiving or confusing information. The key is having the resources to be able to filter trustworthy content from the rest. This *MS in focus* provides guidance to help people with MS and health care professionals use the Internet to its fullest potential.

We have also included a discussion on the role of social media and other new technology in the lives of people with MS. Today people with MS connect socially and supportively with others, as well as with health care professionals, to share personal experiences and expertise. Social media can be a link for people in remote areas or living in countries with limited health care resources. It can also be a resource for learning about MS and feeling connected to other people with the disease, even if the person has never physically met another person with MS. This can help people with MS who face isolation or discrimination in their daily lives to feel part of something bigger – the worldwide MS community.

Finally, we also discuss how information technology can be part of MS management. This relatively new approach to managing MS has already provided important tools for linking people with health care professionals, without having to meet in person.

Also read about the launch of MSIF's update of the *Atlas of MS* on page 18, and the information it provides about the epidemiology of MS and resources available for people with MS in 124 countries.

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 bladder and bowel control in MS. 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 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

Sherri Giger, National MS Society, USA

Information is commonly defined as ‘knowledge obtained by study, instruction or experience,’ and that knowledge shapes our perspective and affects our lives in many ways. Someone well informed feels much better about making a decision than someone who lacks the information they need. Information equips us for our journeys, and creates confidence to tackle whatever comes our way. It is no wonder, then, that when living with a disease like MS, many people want to acquire as much knowledge about it as possible.

Information and experts are everywhere

Over time, we have grown accustomed to relying on expert resources to deliver information – in print, on television, over the radio or in person. These sources of information are still important today, but we no longer rely only on these types of experts. The definition of ‘expert’ is evolving – and it includes each one of us in a unique way. Our individual experiences and perspectives are

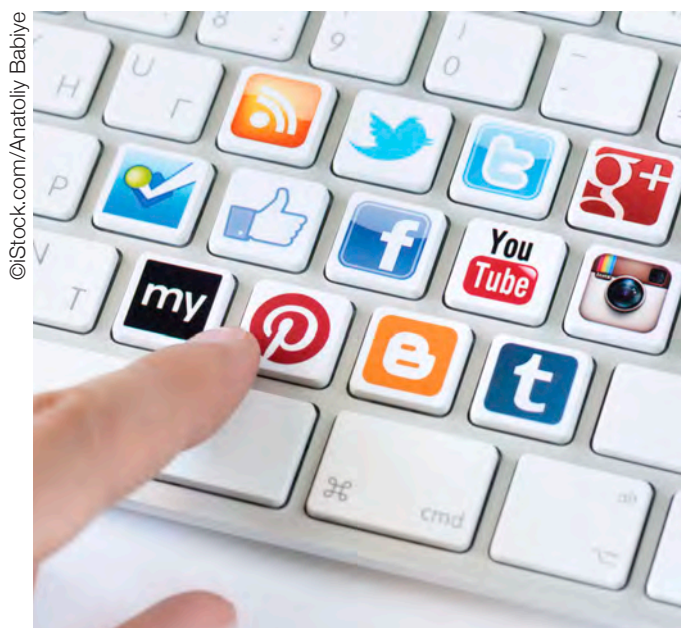
valuable to others; what we have learned can help someone else, and save them some time in the process. In reality, we have always been information providers, as well as information consumers, but the ways in which our experiences can now be shared have global reach as well as immediate impact.

Social media provides many of the platforms on which we share that information, connecting individuals and communities around the world in conversation. Facebook recently reported reaching 1.15 billion users, and it has millions of applications available. And more than one billion unique users visit YouTube monthly, viewing more than six billion hours of video each month – that would be equal to almost an hour for every person on the planet. Our individual experiences and perspectives are becoming mainstream media for the masses.

Trends indicate that many turn to online information about health, and when it comes to people living with MS, the numbers can be even higher. Data suggests that 93 percent of people with MS in the United States use the Internet – seeking online medical information at more than twice the rate of the average person with a chronic disease. Information is at the core of living the best life possible with MS, and people are increasingly looking online for answers.

Overcoming gaps

For the most part, information flows freely, making its way across geographic boundaries. Where individuals were once isolated because of geography, they now have access to information from experts around the world. Out of the 7.1 billion people on the planet, about 35 percent use the Internet. Just a dozen years ago, that figure



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was only 10 percent. Nearly 80 percent of people in North America and 65 percent of Europeans use the Internet, but in some areas such as Africa, usage is still well below 20 percent.

Although Internet usage in some regions is still sparse, many gaps are being filled. Mobile phone users worldwide recently reached 6.8 billion people. In developed nations, there is an average of at least one mobile subscription per person; in developing nations, penetration is, on average, 89 percent, with Africa having the lowest rate, at 63 percent. Smartphones are the only growing phone

category (basic and feature phones are declining), so even in areas where Internet usage may be lower, information is increasingly flowing on mobile devices via text messaging.

Access to professional care is not ubiquitous – in either developed or developing nations; sometimes MS experts are simply too far away. Several online health care communities are being tested around the world – many are patient-driven and others are facilitated by health care professionals. Some community forums enable individuals to have discussions with health professionals, in addition

to seeking online peer support. These forums are likely to become an important part of how we share and seek information, especially among disease-specific groups.

Additionally, community forums can provide a critical supplementary resource when professional care is physically distant – and a real-time resource and support system whenever it might be needed.

Active lifelong learning

With more sources of information available, finding what you are looking for amid the rising volume of data can feel arduous and overwhelming. Where do you look? What information is credible? Who can you trust? All of these questions, and more, cross our minds as we navigate the growing web of worldwide information.

Most of us have an instinct that can often be an accurate guide: if it sounds too good to be true, or too far-fetched to be real, it probably is. But even with that sixth sense, it sometimes can be difficult to determine the reliability of what you are reading

or hearing. Is it someone's opinion or individual experience? If so, then take it for what it is – we are all entitled to our opinions and are experts in our individual experiences. Is it a recommendation? This is probably the time to check out who is giving that advice and find out what type of “expert” he or she is. Equip yourself with the information you need.

With the evolving information landscape, we are taking an even more proactive stance in building our knowledge. We seek information and look for knowledge to better equip us for what lies ahead, wherever that information might be. We share lessons learned from what lies behind us, helping give knowledge to others about what we have experienced and learned along the way.

Active learning, both seeking and sharing information, helps us each live our best life – preparing for the things we can, and quickly responding to the things we cannot. Information gives us the strength and confidence to get through whatever comes our way, including the unpredictability of MS.

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Social media and its power to bring people with MS together

George Pepper, www.shift.ms founder, Leeds, UK

Social media has never been so prevalent. Whether it be catching up with friends, choosing a holiday destination, announcing the birth of your child or even expressing a political view, it is now completely acceptable – and expected – to do it publicly.

What is social media?

Social media brings people together – it is a way of communicating with others online. You can be at home, on holiday, on the way to work or walking around the supermarket, as long as you have Internet access you can continue to exchange thoughts, information and ideas with others. Social media removes boundaries – the isolation of having a rare illness or an unusual hobby is reduced by being able to connect with people from anywhere in the globe. As in real life, you can choose who you interact with and you can be introduced to new people, but importantly you can also meet people you might never have access to normally.

Social networks allow you, often through an online 'profile', to find people who are similar to you with shared interests and opinions, or who have had similar experiences. Communities of like-minded people or those in a similar circumstance, are springing up all over the Internet, regardless of geographical location. Whether it is supporting the same football team, working in the same profession or having the same hobby, having found a common interest, people are engaging with each other in a way that was never possible before the Internet.

Rise of niche social networks

Niche social networks seem to be cropping up for every interest and circumstance. Ravelry.com was

launched in 2007. It is a social network for those with an interest in knitting, crocheting, spinning and weaving. It has more than three million members worldwide. Incredible. Do you have a dog? Are they registered on dogster.com? Well, over 700,000 dogs are! This site, set up in 2004, has proven to be hugely successful. Dogster allows owners to create a profile for their dog, find advice, meet other dog owners, find a breeding partner or even adopt a new dog.

The success of these social networks is down to connecting people with the same interest, on a platform that is dedicated to sharing ideas, asking questions and connecting with others.

Why should discussing your health be any different?

Until relatively recently, talking about diagnosis, symptoms or treatment was limited to medical appointments or face-to-face meetings. Now, social media in health care has exploded and this allows you to seek advice and information any time of the day and to share what is happening with you, regardless of your location.

Online communities for people with MS are on the increase, allowing those diagnosed with the disease to interact with others who are going through similar experiences. Whether people want to seek advice, offer comments or simply have an outlet to talk about the things that matter to them, various networks are enabling this form of online conversation.

For most people, it is a relief to be able to talk candidly with a community of people who understand, and it is often a positive step to gain

and offer support, identify with others and be reassured that you are not alone. Many use advice garnered on social networks to influence their treatment choices and symptom management. Some communities also encourage face-to-face meet ups to take online relationships offline.

Dangers and protection

Of course there can be dangers with the information you find about MS online. How do you know the information you find is accurate? How can you trust the views and opinions of people who you have never met, do not understand what you are going through or simply have not read your post properly? With anything you find online, you need to take a balanced view – there are people with extreme views, but it is important you find a reputable source for information. If there is ever any doubt, it is important to check with your health care professional before taking any action.

There are some guidelines that we should consider when finding information online:

- Who runs the site? Are they reputable?
- What is the site saying? Are the claims too good to be true?

- When was the information posted? Is it still accurate?
- Why does the site exist? Are they selling a product or service?

When sharing information online avoid sharing personal details, such as your home address, on an open forum. Individuals can often protect themselves through privacy settings and many networks will have guidelines for users, outlining social etiquette and how content on the site is moderated.

Despite the fact that the majority of members have never met each other, many online communities are incredibly close and will reactively moderate. If a post is deemed as offensive or inappropriate, another member of the group will usually respond with an alternative view. This self-regulation demonstrates how much a community values the security of sharing in a public space. If someone tries to abuse this trust, they are immediately chastised, which, when most communities pride themselves on having free speech, is an interesting concept.

Users must also apply common sense. When making an important decision, it is sensible to seek

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George's favourite social media sites

Shift.ms, Patients Like Me and MS Connection.

There is the fabulous network at www.giovanioitrelasm.it – a community of young adults in Italy supporting each other, primarily through a blog.

There is an active community of people with MS on Twitter using various hashtags, including #notwothesame, #msresearch and #multiplesclerosis, as a way of communicating with each other.

If watching videos is your thing, there are plenty of MS vloggers on YouTube, including the brilliant *Awkward Bitch* by Marlo Donato.

The Multiple Sclerosis Research blog ms-res.org – written primarily by Professor Gavin Giovannoni and Professor David Baker from Barts and The London – is an incredible source of research news. The blog is frequently updated and users often benefit from a two-way discussion with the authors.

MS Reports – a project created by Shift.ms, in partnership with The Wellcome Trust and UCLP at shift.ms/resources/ms-reports – enables those with MS to interact directly with some of the leading health care professionals in the world about the issues that are important to them.

a few opinions. Likewise, online you may benefit from finding a counter argument to ensure you have all the relevant information available.

Role of MS experts in social media

Sourcing professional advice online is a growing area and one which opens up expert advice to those who may, through geography or financial restrictions, not have access to it in person.

There are blogs run by MS experts providing up-to-date MS research news and some allow bloggers to engage with the authors directly.

These resources not only empower people with MS – because they know they can seek expert advice and manage their own condition – but help develop a greater understanding between those working in the sector and the people they are trying to help.

Future

It may seem unbelievable now, but 10 years ago Facebook, YouTube and Twitter did not exist. They are now entrenched in the way many of us communicate online, with Facebook having 1.15 billion profiles, YouTube more than one billion

unique users per month, and Twitter approximately 500 million accounts created. How will social media develop in the next 10 years? It is impossible to predict what will be the next “big thing”, but the landscape will continue to change.

How will these changes impact on the MS community? Will some of our visits with our neurologist or nurse occur online via Skype from hundreds of miles away? Will we choose our treatment through a ratings website? Will we be monitored though a chip implanted in our body to ensure our intake of vitamins is at an optimal level? Who knows?

What is clear is that for a person facing a diagnosis of MS, there has never been a time where more information, advice and support has been available to us. Whether you want to speak to people your own age, with the same hobbies, same profession, same religion or even the same hair colour, you now have access to a wealth of people from around the world in just a few clicks.

MS is an isolating illness. It can change the way we view ourselves and how others view us, but we should no longer feel alone. We are a global community of more than two million people and together we can be a powerful force.

Evaluating information: knowing which information to trust

Sally Shaw, Eastern Health MS Service, Melbourne, Australia

Introduction

Prior to diagnosis, a reference to multiple sclerosis heard in a casual conversation, or in the background noise of a television or radio, may go without notice. However, once diagnosed with MS, many of us will prick up our ears at a whisper of the disease in any format, keen to learn a little more about the chronic condition with which we now live.

An abundance of information on any aspect of MS (cause, symptoms, treatment) is available 24 hours a day, seven days a week. It is at our fingertips via search engines, delivered to our in-boxes by MS-related organisations, mentioned on radio, talked about on television, or offered up (sometimes without invitation) by well intentioned relatives who want to share the 'cure' that they heard about while queuing at their local supermarket with you.

So how should we evaluate the information that we seek (or just happen across) in order to distinguish between attention-grabbing headlines with little substance, and snippets of information that we can reliably take to our health care professionals to discuss?

Mainstream media

Attention-grabbing headlines are often what it is all about if you hear something about MS in the mainstream media. An appealing term like 'cure' or 'cause' is often inserted into a 20-second news story to catch your interest, but does not often lead to a substantial story



on such. An article written on 'the cause of MS' may, with further investigation, turn out to be one small (possibly significant) step (down just one path), that may lead to (an indicator of) a solitary contributing factor to the cause of the disease.

While it is fantastic to hear about MS research in the media, we need to remain wary about the true content, rather than the headline alone. Always question who may be benefiting from this media attention, while remembering that the ethics in media reporting in health is not always as transparent as would be ideal.

Websites

You do not have to wait for breaking news in mainstream media to find all sorts of information about MS. The World Wide Web has given us unprecedented access to everything we could ever want to know (or not want to know) about

well... anything. So before we plunge ourselves into the amazing world of information overload, how can we be sure that what we are reading online is worth reading?

Here are some questions to ask before you invest your time and confidence in a new website:

Who is responsible for developing the site and its content?

The 'About Us' tab is a great place to start. It should tell you who the authors of the site are, which organisations are involved, and the name of any sponsors that are investing in the site. Examples of sponsors include government agencies, educational institutions, professional organisations such as a scientific bodies or societies, or commercial companies, such as a pharmaceutical company. Assess whether a conflict of interest may exist between the integrity of the information provided to you, and the sponsor's motivations for wanting you to read the information. Are the author's qualifications detailed, and are they a medical professional, researcher or a person with MS? Content from each can be valuable, but for different reasons, or for different types of information.

Is the content reliable, complete and current?

The content of the website should be composed of verifiable information that is of a high standard, which means that it is based on scientific evidence and best practice knowledge. A good indicator of this is whether the authors cite source articles that you can access if you are interested. These articles should be from well-regarded and peer-reviewed journals, and should include recently published information. You should be questioning reliability if the only articles cited are from more than a decade ago, or if they are from only one journal, or from only one author.

The provision of up-to-date information online is important, so check to see whether the website indicates when its information was most recently updated. If it has not been updated since 2007,

for example, it may not be the best source to base your opinions on.

Does it present a broad and unbiased view in an easy-to-read format?

There are some really easy-to-read websites online now, where navigation makes sense and content is easily digested. Be wary of websites that are difficult to navigate, and try to convince you of a particular point of view. Similarly, watch out for websites that tell you about one treatment option only (when many are available), or speak of conspiracy theories, cures or options that are extremely expensive, dangerous or recommended for a variety of conditions. If it sounds too good to be true, it is definitely worthy of intensive investigation – be a 'cyberskeptic' because there is a lot of dodgy stuff online!

Are the website's privacy policy and disclaimers clear and accessible?

Websites that are trying to provide you with accurate health information have nothing to hide. And as such, their privacy policies and disclaimers should be transparent, accessible and easy to understand. Reasons behind asking you to provide your information – if there is a real advantage to you in doing so – should be clear and appropriate.

The screenshot shows the MSIF website with a navigation bar including Home, About MS, Global MS Research, Global MS News, About MSIF, Donate, and Contact. The 'Terms & Privacy' page is displayed, featuring sections for Privacy Policy, Cookies, and MS organisations. The Privacy Policy states that MSIF collects no personal information except where specifically and knowingly provided by users. The Cookies section explains that cookies are used to track users and provide information to the owners of the site. The MS organisations section includes a search bar and a map of the world.

MS research communications or announcements

Subscribing to global MS-related organisations will offer you the convenience of current research findings and communications dropped right into your email inbox. But how should you sort through the dot points or abstracts to figure out what is what? Just because a study's findings have made their way to your inbox via a reputable organisation, does not mean it was a well-designed study with a methodology that should not be examined.

A good place to start is by educating yourself broadly about the different types of research out there, and how best to evaluate it. You will soon identify different research terms such as quantitative, qualitative, randomised controlled trials, sample sizes, statistical significance, and p values, to name but a few. Knowledge of some research terms will assist you to evaluate a study on its merits. Issue 17 of *MS in focus – Research in MS* (2011), gives an easy-to-read overview of the important things to know when evaluating research for yourself.

Want to know more?

Ultimately, if you want to find out more about something you have discovered through any form of media, do some further investigation and ask rigorous questions about the source. Print off a few key points and take two copies (one for you, one for them) to your next appointment with your health care professional. Have an open-minded discussion about what you have found (and where you have found it) because an honest and informed partnership with your health care professional is most likely to lead to the best medical outcomes.

Summary of things to consider when assessing online content:

- Check who is responsible for developing the site and its content - what are their reasons for providing information?
- Does the content seem reliable, complete and current? Check against other information sources.
- Does it present a broad and unbiased view in an easy-to-read format?
- Are the website's privacy policy and disclaimers clear and accessible?
- Even if a website looks professional it does not mean it is. Check their credentials.
- Check the country where the website is from. Treatments or services may not be available in every country.
- Be aware of abusive email messages from "trolls" online. Although they are spam and not personal, they can be distressing.
- If you join a forum or chat room, use an alias rather than your name and do not add a photo that can identify you.
- Finally, there are many positives to using the Internet, social media, chat rooms and forums. Many people find support, useful information and friendship online.

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Information technology and MS management

Bernadette Porter, University College London Hospitals, London, UK

Across the world health care is being transformed as technology is used to support remote delivery of care. There is growing evidence that use of technology in this way can result in services that are more focused around the patient or service user and services that are more effective and efficient.

The tele-technologies used in health care include the following:

- the remote capture or relay of physiological measurements from the home for clinical review and early intervention;
- a range of alarms and sensors in the home to enable independent living, linked to a call centre;
- video consultations and routine surveillance appointments between clinicians and patients.

These technologies have been around a long time and are often used in everyday life such as live web chat online when booking a hotel, checking a bank statement via a call centre or using a teleconference to see and talk to a loved one far away.

Telecare use in health care

In health the principle is the same. Telecare, or telemedicine, means using these technologies to provide care in ways that do not rely on a face-to-face appointment. Spain, Italy, France, Norway, Switzerland, Scotland, Japan, USA and Australia are world leaders in the adoption of telecare. These countries have employed radical approaches to ensure that telecare is an essential part of health services redesign, or is

incorporated into plans for preventive and self-care services.

Other countries are now beginning to realise that if they embrace telecare it may radically improve health outcomes. This is supported by the European Parliament, which concluded that “Telemedicine will only realise its full potential if Member States engage actively in integrating it into their health care systems.”

The health care professionals leading the way include radiologists, psychiatrists and dermatologists. To date neurologists have been a bit slow on the uptake, however there is evidence that this has improved in the last few years. There is evidence that the provision of an acute neurology service by video link to a rural district general hospital reduced the length of stay in hospital, and that the use of video link to a stroke neurologist means that people who have an acute stroke in a rural area can receive life-saving treatments within the necessary three-hour time window. Evidence of improved service efficiency has also been shown in epilepsy care and in rehabilitation, where people recovering from a stroke followed exercises delivered over a video link and were found to have improved balance and physical functioning.

Telecare for MS

It is easy to see how telecare could potentially benefit people living with MS. When a person with MS develops new symptoms it would be great if they could get an assessment quickly and easily, ideally without leaving home. However, this is rarely the case as most MS care is based in MS clinics or hospitals and most of the services are

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A doctor using telecare in India to assess a patient in another part of the country.

set up in a way that the person with MS has to travel to see an expert.

This model is changing and a number of centres are now using telecare to help deliver better services. In the MS community the USA Department of Veterans Affairs' (VA) Centre of Excellence leads the use of telecare. Their services are delivered in three strands: real-time telehealth, home telehealth, and store and forward telehealth. They have produced a wealth of evidence covering both the clinical and cost effectiveness of telecare interventions in long-term conditions.

Other countries are following this path including the UK where the National Hospital for Neurology and Neurosurgery offers expert MS assessment and triage by phone and video conferencing clinics to manage complex symptoms such as spasticity, which has improved clinical outcomes and patient satisfaction. In Israel, the addition of telecare at home showed that people with

the added support of telecare experienced improvements in their symptoms and high levels of satisfaction with care when compared to people receiving standard care.

Rehabilitation via teleconference

There is recent evidence that rehabilitation via teleconference may be useful in MS. In a Spanish study, people with MS with balance or postural control problems were randomised to receive rehabilitation sessions in the clinic setting or at home. People attending the clinic received physiotherapy treatment twice per week for 40 minutes per session. In the experimental group, people with MS received telerehabilitation treatment using an Xbox™ console four times per week for 20 minute sessions, which were monitored by video conference. Both groups received treatment for 10 weeks and the results showed improvements in both groups. However the Xbox™ group showed more improvement in postural control than those who had conventional treatment.

Electronic health records

In addition to consultations by video, email and telephone, there is an increasing awareness that access to electronic health records may help people manage their health more independently. There is increasing evidence that good information, well used, is a vital component of improving health, well-being and quality of care. The provision of electronic patient held records is one of the strategies suggested to improve patient decision-making. This approach is echoed in the International College for Person Centred Medicine Geneva declaration on chronic care which recommends that: "Person- and people-centred care should be supported by a close collaboration between clinical care and public health. Each person with a chronic disease should be fully engaged in partnership to achieve joint understanding and joint decision-making to prevent and treat such diseases."

Although the demand for access to health records is currently low, it is growing. In principle this seems like a very good idea, however switching to patient access alone is not enough and appropriate support structures need to be put in place to help patients understand how to use the information. If they are to be useful, patient records need to be easily understood by lay readers in order to allow optimal decision support.

Health records are complex documents created by health professionals using medical terminology, codes and abbreviations that are likely to be unfamiliar to most people. A study by a Harvard group showed that even for actively involved, highly educated individuals, understanding their record is not always easy. The group suggest that, in order to develop patient-friendly electronic records, clinicians need to 1) know what kind of questions patients hope to answer when they access their records and 2) how information content and presentation affect record comprehension.

There is evidence that people with MS use the Internet more than the general population. A

study of portal usage identified these users as young professionals with minimal disability. The most frequent portal use was the secure patient-physician messaging system. It is suggested that usage could be higher if technological adaptations such as voice-activated commands and easy font size adjustments were used to maximise access for those with advancing physical disability.

As MS is a long-term neurological condition, people could potentially benefit from personalised care planning and access to electronic records. For example, the Cleveland Clinic in the US is currently giving patients access to parts of their medical records, and an opportunity to communicate electronically with their health care professional's office via a secured portal ("MyChart").

Researchers at the Cleveland Clinic tested to see if people with MS who had access to their own self-management programme on an electronic held record reported better care. The researchers concluded that there was no evidence that the addition of the self-management electronic record improved self-management of multidisciplinary MS care. However, the researchers point out that there might not have been enough difference between the two systems to demonstrate superiority and suggest that more research is needed in this area.

Conclusion

This is an era of rapid technological growth and health care services need to make transformational changes in order to deliver care for the 21st century.

As a community we want to enhance care, not entirely replace human contact or remove opportunities to meet each other. What we need to do is to dream and think smart. We need to look at how technology helps us in every other aspect of our daily lives and ask if we could use it in health or not. In this way, we may find ways for technology to help us connect better than we ever thought possible.

Using information to be empowered

Lauren E Hansen, MPH, East Lansing, Michigan, United States

MS is an unpredictable disease, with symptoms that vary in manifestation and severity over time, and from person to person. Each individual's experience with MS is unique. Faced with this reality, individuals can be left feeling alienated, betrayed by their bodies and helpless in the face of the disease.

The good news is that this unique and unpredictable body is also the source of vital information that is key to raising self-awareness and capacity, and empowers the individual and health care team to effectively manage the disease.

This article highlights ways to gather and manage this information, using it to better self-manage symptoms, identify and communicate needs, and to alter one's life with MS for the better.

Symptom diary

A symptom diary can be an invaluable tool for the self-management of MS. The diary is a place to record, on a daily basis, one's symptoms and symptom severity, as well as activities (level and type), emotions, environment (heat, humidity), stress, sleep and diet.

With regular use of a symptom diary, an individual can start to notice symptom triggers and patterns that might otherwise be missed. For instance, are symptoms cyclical in nature, steady, or are they progressing? Are symptoms worse during menstruation or certain weather patterns? Did symptoms abate after certain activities?

Individuals can also learn their peak functioning times of day and try to arrange their schedules and lifestyle to conserve energy and maximise productivity.

A person may even start to learn the typical "recovery times" needed following particularly stressful or intensive activities. By listening to and noticing body and health patterns, a person with MS may be able to better manage and predict symptoms and make small changes to improve daily function.

A symptom diary is also helpful when talking with health care professionals. A quick review of the diary



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before an appointment can help someone decide on priority talking points and allow them to give a more accurate account of their condition and needs than purely by memory recall. Review of a symptom diary with a doctor can also help to determine efficacy and potential side effects of current medications.

The information captured in a symptom diary allows an individual to determine the most salient needs unique to his or her MS and can provide insight into small changes that could be made to live the best life possible with MS.

A simple notebook to record symptoms will certainly suffice; however, more tech-savvy individuals may wish to utilise one of many smartphone apps (many at no cost) that allow for entry and analysis from any location. The best form of symptom diary is the one that an individual finds easy to access and that will be used on a regular basis.

Personal health record

Similar in content to the electronic health record (EHR) kept by a physician, a personal health record (PHR) is a record that patients themselves keep and use to organise and manage their health care.

The contents of a PHR are up to each individual, but most include the following:

- Important contacts
- Personal and emergency contact information
- Insurance policy number and contact information (where relevant)
- Contact information for all health care providers
- Current medical information
- Medications and dosages
- A list of any allergies (including to medications and food)
- Any current or chronic health conditions
- Past medical information
- Family medical history
- Major surgeries or procedures (with dates)
- Immunisation record
- Lab reports and imaging results
- Consent and authorisation forms
- Advanced directives

A PHR can be as simple as a notebook and file system at home. However online options, with added benefits and features, are also available. Electronic PHR can increase the communication between a person with MS and their doctor and may also be used to schedule appointments, view test results and refill prescriptions. Some electronic PHR also have applications to track and manage symptoms. Additionally, having a single location for health-related data from all doctors a person sees can help coordinate and avoid a duplication of care.

Currently, many doctors offer PHR hosting and there exist many third-party options as well. There are benefits and drawbacks to each of these platforms that should be taken into account. As with anything online, be sure to read the privacy policy and understand what each entity does with the information you provide. For more comprehensive information on PHRs and practical tools on getting started, www.myphr.com is a useful site, run by the American Health Information Management Association.

A personal health record is a great complement to a symptom diary. Together, they provide valuable information to aid the self-management of MS.

Self-advocacy

In addition to helping with the self-management of symptoms, the information gathered in a symptom diary and personal health record can enable a person to effectively advocate for their current and future health.

Education is one example of self-advocacy. The experience of sharing one's story is extremely powerful. Educating others about life with MS raises awareness, inspires others to help, and is often personally validating.

Communicating specific needs is another example of self-advocacy. People are more likely to offer assistance if they are given specific ways they can help. Individuals should be able to communicate specific needs, what someone can do to help and how it would be of benefit. It is helpful to try to tailor

a request to fit the potential helper's abilities, unique skills and interests. This strategy works with friends, family, community members and people in local and national government.

Another example of self-advocacy is to communicate with non-MS doctors. With new therapies available at an increasingly rapid rate, it is unrealistic to expect a doctor who is not a MS specialist to be familiar with them all. People with MS should come to appointments prepared with basic information on his or her specific type of MS (for example, relapsing-remitting or primary progressive) and current medications, including what they do, possible side effects and interactions. This basic knowledge, supplemented with information on their unique MS experience, will enable individuals to help their non-MS doctors to provide the best care possible.

For an individual with MS, the information provided by his or her own body is of utmost importance. This information holds the key to effective self-

management of symptoms, efficient communication with others, improved interactions with physicians and increased feelings of ability and confidence.

Using technology for empowerment

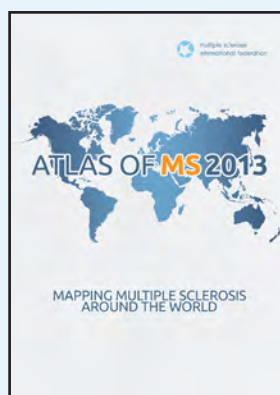
Technology can also help to track activities, such as the number of steps walked per day, exercise data, and even movement during sleep. This can be useful for a person with MS and their health care providers to assess an individual's current status, to help implement interventions such as an exercise routine, and to monitor change over time.

Technology can also help someone continue in their daily activities, for example by storing information and setting reminders to help individuals with memory problems.

It should be noted that these applications and devices have not all been tested specifically for people with MS, and may not work for everybody.

Atlas of MS 2013

MS is one of the world's most common neurological disorders. Despite this, global information on the epidemiology of MS, and the availability of resources and services for people with MS is scarce in many regions. The first *Atlas of MS*, published in 2008 as a joint project of MSIF and the World Health Organization, endeavoured to fill this knowledge gap with information from 112 countries. MSIF has now launched the update, titled *Atlas of MS 2013: Mapping Multiple Sclerosis around the World* at www.atlasofms.org with information from 124 countries.



The key findings from the 2013 update include:

- The estimated number of people with MS had increased from 2.1 million in 2008 to 2.3 million in 2013
- Improved health care and support services compared to 2008 (increased numbers of

neurologists and MRI machines)

- Continuing inequity in availability of these services with a widening gap between high and low-income countries
- Increased number of MS groups and organisations worldwide since 2008

MSIF calls on policy makers, health professionals and MS organisations to make use of the data in the *Atlas of MS* to:

- Ensure improved diagnosis, treatment, information and resources are available to all that need them, regardless of where they live
- Call for more research into effective treatments and practical ways to improve quality of life of people with MS and related disorders
- Raise awareness and general understanding of MS and related disorders among the general public, employers and health care professionals
- Support MS-related organisations and patient groups, by investing in them and developing their capacity
- Work together to make treatments more affordable, either directly or through wider reimbursement by insurance or government.

Your questions answered

Q. People I know with MS blog or pose questions on the Internet but I am always concerned about the validity of the responses, ulterior motives and have privacy concerns. Is it safe to tell my story or ask advice using social media?

A. You may find some security in using a nickname and an unidentifiable email address to message and receive replies without giving out personal or demographic information. It is also advisable to turn off any location devices when posting on sites such as Facebook.

There are many excellent and trustworthy websites providing information about MS, particularly non-profit MS organisations who are there primarily to support people with MS and their families.

For medical information there is no substitute for advice from a health care professional who knows you as an individual, knows MS and is trusted by you, whether this is in person or online.

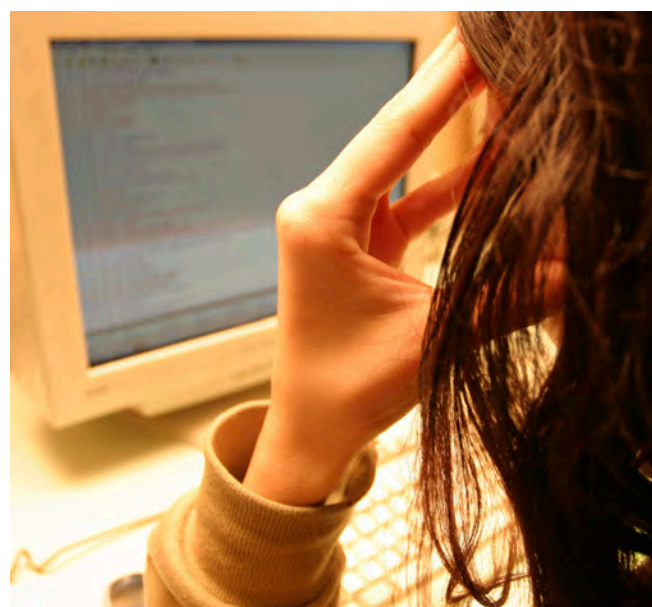
As in many areas of communication, it pays to know your source, rely on credentials, and be an alert and savvy consumer of goods, services and information.

Q. My 14-year-old daughter has MS and spends a lot of time looking online at MS websites and blogs. I worry that she might read too much about it and from unreliable sources. What can I do to support her in her quest for knowledge but also protect her?

A. This is a difficult issue for any family, and is even more difficult when a young person has MS. You

appear to be supportive of your daughter seeking information about MS which is good - trying to prevent her from looking at Internet sites or blogs (or scolding her for doing so) is likely to cause problems and may even be detrimental for the family relationship.

Try to encourage her to read information from reliable, unbiased and well-informed sources, such as from your national MS organisation, and explain that these are good websites to trust. Encourage your daughter to share her experiences online with you. Look at websites together and talk about what you find so you can support her learning.



Your daughter should also take note of any questions or concerns she has after looking at MS websites or blogs and discuss these at her next appointment with her neurologist, MS nurse or the psychologist from her MS Centre if she has one.

Many thanks to Professor Maria Pia Amato from the International Pediatric MS Study Group (www.ipmssg.org) for her advice answering this question.

Living with MS in Argentina – three views about MS information

My name is Silvina Milanesi and I am 48 years old. I was diagnosed four years ago with relapsing-remitting MS.

I've never explored the Internet – I rely on my doctors (specialists and health care professionals), my family and my close friends.

I am very confident with the information my doctor and other health professionals give me. I only follow them and fully trust them. The results are visible. I have a group in Facebook which I interact with once in a while.

For people living in Argentina, I would recommend visiting websites of the FLENI (a neurological diseases institute in Argentina) and Multiple Sclerosis Argentina (www.ema.org.ar) for information about MS.

It is difficult to say if there is information lacking about MS because it is such an unpredictable disease. I rely on my instincts. I'm truly convinced that MS is like the fingerprint, different in each person and the attitude you put on it.



My name is Andrea and I am 46. I live in Buenos Aires and was diagnosed with MS in November 2012.

When I was first diagnosed with MS, I didn't look too much on websites – my doctor told me not to. A friend in the US sent me some books but I still don't really think I have enough information about MS. It seems that nobody knows much, or they don't know how (or don't want to) explain it. What I have found out has made me feel very worried about the future.

I think health care professionals don't tell me all the information they have. It is true that each case is different, but I have heard that in other places they may know how MS is going to affect you, based on scans. I don't have any idea what is going to happen to me, and it looks like nobody can help me.

Sometimes I read articles from the *New York Times*, but not often. People in the US send me some information by mail which I always find helpful.



My name is Dauquén. I am 33 years old. I live in Buenos Aires. I work as a Chief Creative Director in an advertising agency. I have had MS for almost one year.

When I was diagnosed I browsed through the Internet to learn about the disease, plus I read through all the information my doctor gave me.

Truly, I went through many feelings, particularly fear and impotency, and I couldn't imagine my future because of everything I learnt and read about MS. It was hard and difficult to assimilate to the idea of having the disease. But now, as time passes by, I realise that what I'm facing with my MS is not very severe and that I am going to be able to develop my life quite normally.

Until I was diagnosed, I didn't know that MS existed. But once I got the results and diagnosis, of course I trusted my doctor. But I also felt that many

aspects of traditional medicine weren't taken into consideration or recognised as possible treatments for MS.

I think that there is still not yet a place of easy access for everyone to learn and inform themselves about MS, particularly about treatments. Today the Internet is a constant source of information for everyone but I think it is not used as well as it could be as a source of information about MS. The general public needs to know more about what MS is without necessarily having it. I use the Internet to inform myself, but do not use it to interact with other people, or to provide help to anyone. Today on the Internet there are a thousand versions of MS and that confuses me a lot.

I think that clear information about drugs and treatments is lacking. It is important that people with MS know that in the future there may be alternatives that improve their quality of life.

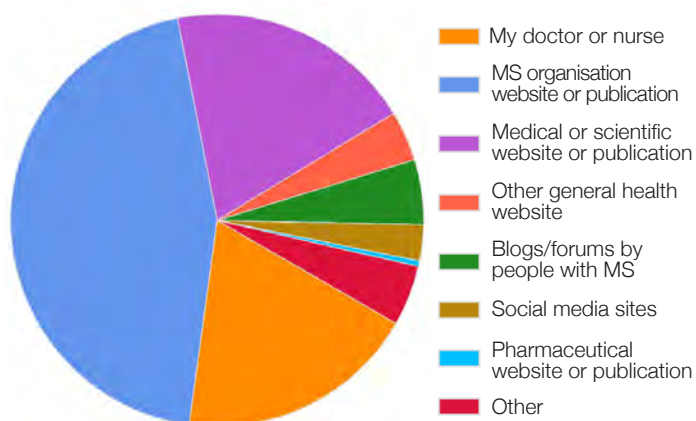
Results of the online survey about information, technology and MS

A total of 879 people took the survey, from 65 countries around the world.

The largest age group were people 51-60 (31%) followed by people 41-50 years (26.3%). More than three quarters of respondents were female, with 23% being male. More than half (56.5%) had relapsing-remitting MS, while 18.4% had secondary progressive MS, 11% had primary progressive and 4.5% had progressive-relapsing MS. 10% were unsure.

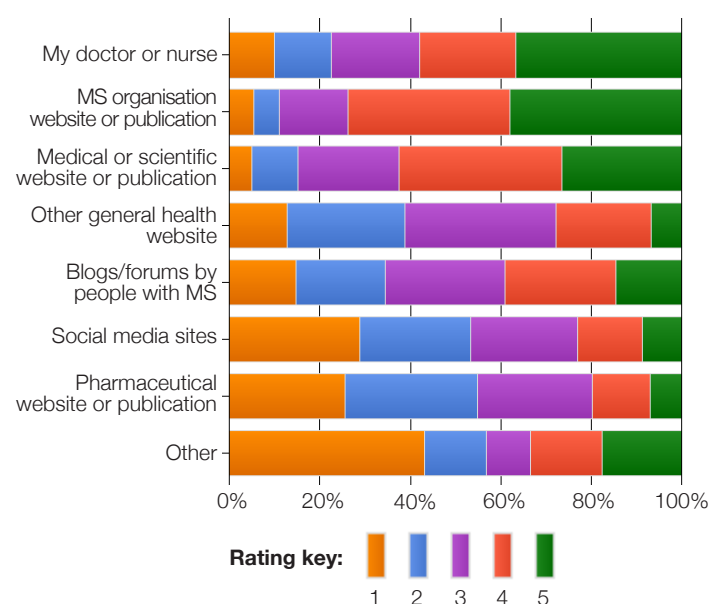
When asked where respondents mainly looked for information about MS, the majority said they looked at an MS organisation website or publication. The second most popular source was a medical or scientific website or publication, followed by a doctor or nurse.

Where do you mainly go for information about MS? (please choose one)



When asked how useful the sources of information were, “MS organisation website or publication” and “My doctor or nurse” both had a majority ranking of 5, where 5 was most useful and 1 was least useful. 73.7% of respondents ranked MS organisation website or publication as a 4 or 5, indicating the importance of this source – the other sources received a lower rating on usefulness.

Please say how useful the following sources of MS information are to you, from 5 (most useful) to 1 (least useful).

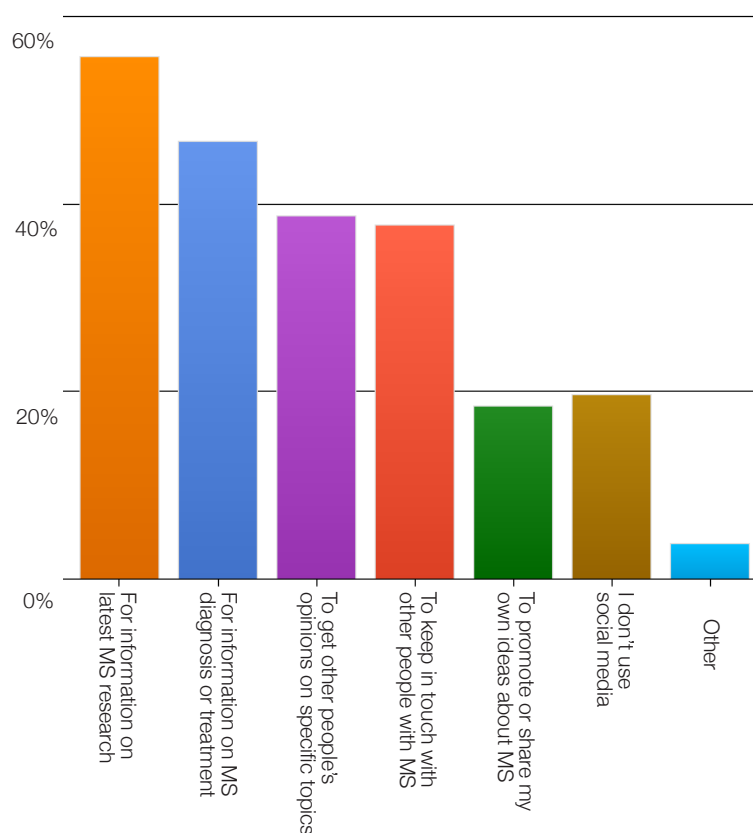


Respondents were asked which information source was the most useful then they were first diagnosed with MS. 42.3% of respondents said their doctor or nurse, followed by 32.7% who answered that an MS organisation website or publication was the most useful.

People were asked about which factor most increased the reliability of MS information for them. A third said that the most important factor was a scientific or statistical basis. A medical or professional basis was chosen by 28% of respondents, and personal experience was chosen by 24.5%.

When asked about what they used social media for, more than half (55.8%) said they used it for information on the latest MS research. 46.7% said

Do you use social media regularly for:



they used it for information on MS diagnosis and treatment. More than a third used it to get other people's opinions on specific topics (38.8%) or to keep in touch with other people with MS (37.8%), showing the peer support and MS community aspect of social media use.

Most people taking the survey did not use any apps for managing their MS (75.5%) or any assistive technology software when accessing the Internet (77%). When asked if they had difficulty accessing websites with MS information because they were not suitable for people with disabilities, most answered never (58.7%), 21.5% said rarely and 15.9% said occasionally.

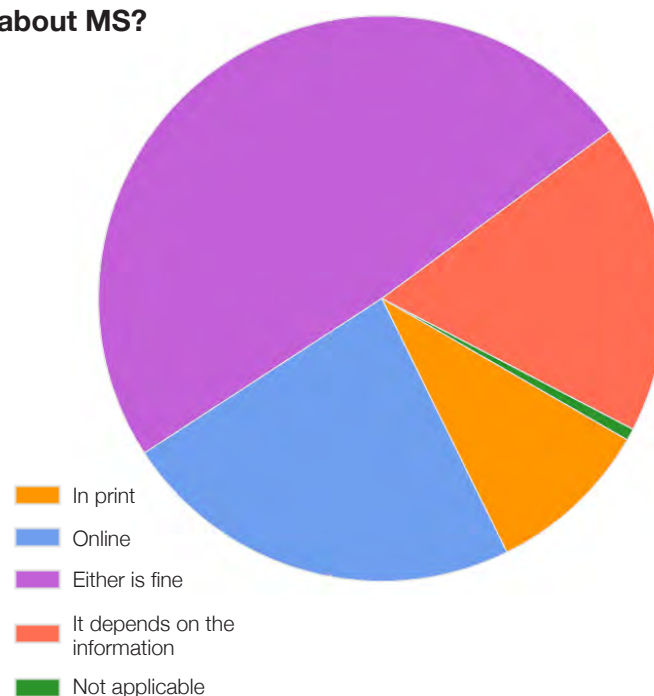
When asked how they preferred to read information about MS, the majority of respondents said either in print or online was fine. Most respondents also said that when they read information about MS online they typically read it on screen (76.7%). Some people (18.3%) said it depended on the information and 4.4% said they printed it.

More than 232 people left comments. Some of the common themes covered included that people trusted their MS organisation to only present reliable information on their websites. Other people noted that they used the Internet to find information but checked its reliability on databases such as Pubmed, a database of scientific research (www.ncbi.nlm.nih.gov/pubmed). Some people noted their frustration with only being able to get a scientific summary of the latest research for free, and having to pay for the full paper or study report. Some said they did not trust people or organisations that are making money from the information they provide.

"All info is helpful; professional people try but we are all learning and teaching ourselves, it can be overwhelming."

"I feel a lot of stories are relevant to older people who haven't had the new treatment when they were diagnosed. Less information for people who are on new treatment and have no idea what to expect down the line."

How do you prefer to read information about MS?



Knowledge is Power Educational Series

Wenda Carlson, National MS Society, United States



Rationale and objective

When a person receives the unwelcome news that they are diagnosed with MS, they may know very little about the disease and feel overwhelmed and frightened by this new development their life. The Knowledge is Power (KIP) series was developed by the National MS Society, USA, to help individuals better understand and navigate through their recent diagnosis. KIP provides information about dealing with one of the greatest challenges presented by MS – the unpredictability and uncertainty of the future.

Background and structure

KIP is a free, at-home, 6-week educational series for people newly diagnosed with MS and their families to help educate them about the various aspects of MS. It was developed in 1998 by Dr Rosalind Kalb, a highly regarded author and psychologist, who knows about MS and the effect it can have on people's lives and those who care about them, and it remains the National MS Society's premier programme for newly diagnosed people with MS.

The programme consists of six core volumes, and one supplemental volume for family members, which are delivered weekly to people's homes via mail or e-mail.

Topics include:

Vol 1: What is MS? Dealing with your diagnosis and disclosure. A supplemental booklet is included for family members.

Vol 2: Disease-modifying treatments for MS. Discusses the treatments that are available that have been shown to alter the rate and/or extent of disease-progression.

Vol 3: Maximising your employment opportunities and financial security. Outlines important steps to plan effectively for the future.

Vol 4: Treating yourself well. Includes information on how to manage various symptoms, prevent unnecessary complications and minimise disability.

Vol 5: Maintaining healthy relationships. Talks about the ways in which MS can impact family members, and then provides some ideas for how to maintain healthy relationships with people both personally and professionally.

Vol 6: Working with your doctor. Talks about ways to build or improve this relationship and make visits to the doctor as comfortable and productive as possible.

Appendix: Glossary of MS terms

Additional volumes upon request include:

Vol 7: Building and maintaining intimate relationships. Talks about meeting new people, maintaining long-term relationships and sexual feelings.

Vol 8: Parenting with MS.

Addresses concerns about ability to have children, being a good parent and the impact of MS on children.

KIP is currently available in English and Spanish.

Outcomes and results

KIP has been delivered to more than 100,000 individuals (more than 7,000 annually). Readers have said that they like the weekly format, learned more about the disease, will be more proactive in their medical care, are able to make more informed decisions about disclosure, feel more confident and capable of managing the impact of MS on their lives (job, family, friends) and say their communication has improved with others. People are less afraid and more capable of dealing with their feelings about MS.

Ninety-nine percent of readers would recommend KIP to other people who are newly diagnosed and their families.

Marketing the programme

KIP is offered to people living with MS, their family, friends or anyone who calls the National MS Society, USA and wants information about being newly diagnosed with MS (1-800-344-4867).

Registrations are also accepted online at www.nationalMSSociety.org/knowledge. Mail or email subscriptions are available in US or Canada.



Email subscriptions are available to all other countries. Mailings start at the beginning of each month.

Expenses to consider

The National MS Society, USA receives approximately 650 registrations per month (about 450 requesting hard copies). Costs to administer the programme include printing the programme brochure and all volumes (including a folder/container for storing articles), labour for assembling mailings, envelopes and postage, and the subscription cost for a mass e-mail delivery service, if applicable.

Limitations

The National MS Society, USA does not offer the mail option to subscribers overseas to keep the costs manageable, but the e-mail option is available to all subscribers.

For more details on the programme or other questions, contact Wenda Carlson (wenda.carlson@nmss.org) or Kimberly Koch (kimberly.koch@nmss.org).

Review

**The Cochrane Collaboration
Reviewed by Linda Edgerton, a
person with MS from Australia.
Visit her blog at:
www.lollypopbeach.com**

In a digital world where Googling “MS” or “multiple sclerosis” brings up hundreds of millions of results, searching for reliable information can feel a bit like navigating a maze. It can be totally bewildering — until you find sites such as the MS International Federation (www.msif.org), your local MS Society and the Cochrane Collaboration (www.cochrane.org).

While I’ve been a regular visitor to the MSIF, MS Australia and MS Research Australia sites since being diagnosed with MS in 2002, I’m new to the Cochrane Collaboration. The Collaboration is an international effort to improve health care by finding and promoting the best possible scientific evidence.

According to its website at www.cochrane.org, the Cochrane Collaboration believes that “effective health care is created through equal partnerships between researcher, provider, practitioner and patient”.

The independent, not-for-profit Collaboration involves a network of more than 31,000 people from over 120 countries working together to prepare, update and promote the accessibility of an online library of Cochrane Reviews. These reviews are the international benchmark for high-quality information about the effectiveness of health care. They combine the evidence of different trials that address the same or similar questions to work out whether or not treatments work.

The Cochrane Collaboration is an important website. Cochrane reviews can influence funding decisions about particular drugs, enable medical practitioners to select the right treatment when



various options exist, and assist patients to assess the potential risks and benefits of their treatment.

The website is regularly updated with new reviews, navigation is clear and pages load quickly. The reviews are written in plain language, which makes them accessible to non-medical people.

Although the site includes 5,000 reviews, those relating to MS are not the most useful first resource for people with MS making decisions about their health care. One reason for this is that MS affects people in different ways, with many possible symptoms and an ever-advancing range of treatment options, and these possibilities are not all covered by reviews. A personalised discussion with a neurologist who is aware of the latest MS research and treatments relevant to individual symptoms is likely to be more helpful.

In considering MS symptoms such as pain, fatigue and spasticity, the *MS in focus* editions on these topics provide a comprehensive and practical starting point to understand symptoms and treatment options. The freely accessible Cochrane Collaboration website is useful to medical practitioners and people with MS who then wish to search on particular treatments. Reviews cover

treatments ranging from individual drugs and supplements, to psychology and exercise.

The high quality of scientific evidence demanded for the reviews means that summaries are 'cautious' or inconclusive when not enough research has been done in the area. In the review "Dietary interventions as complementary therapies for multiple sclerosis" the reviewers wrote "available data are insufficient to assess any potential benefit or harm", yet they also noted "50% to 75% of people with MS do use dietary regimens and supplements". This is an example where MS organisations and other sites can provide more helpful guidance.

This website can be book-marked as a trusted and informative resource. Its 20th Anniversary series of 24 videos is fascinating for anyone interested in medical research. In the first video, Peter Gøtzsche, Director of the Nordic Cochrane Centre says, "I realised that being a doctor I could help one patient at a time, but by joining the Cochrane Collaboration I could help tens of thousands of patients at a time by doing a Cochrane review."

Makingsenseofmsresearch.org.au presents Cochrane reports on MS treatments in English in a user-friendly language and format specifically developed for people with MS and their families. It can also be a useful resource for health care professionals.

NARCOMS

The North American Research Committee On Multiple Sclerosis (NARCOMS) registry is a global database designed to expedite and promote MS research, treatment and patient education. The goal of the registry is to improve clinical care and quality of life for people with MS and their families through increased knowledge about MS. NARCOMS is a project of the non-profit organisation Consortium of Multiple Sclerosis Centers (CMSC).

All individuals diagnosed with MS can enroll with NARCOMS free of charge. More than 37,000 people with MS have joined since 1996, most of them from the US and Canada. Participants complete two or more surveys each year, either online or by mail, responding to questions on various aspects of their MS, such as symptoms, ability to carry out daily activities, quality of life and treatments.

All the data received by NARCOMS is kept confidential. NARCOMS researchers and collaborators use only de-identified data gathered on a large number of people to help answer important questions regarding MS. Each set of data can facilitate several studies over the years, allowing the registry to be very productive. Registry results have been published in more than 70 peer-reviewed articles in 26 different scientific journals and also shared with the MS community in the form of 140 posters and presentations. NARCOMS Now, a quarterly magazine published specifically for NARCOMS registry participants, features news on the latest MS research and updates on NARCOMS registry status and activities.

In summary, the NARCOMS Registry is an example of how people with MS can expedite several MS research projects simultaneously and greatly improve our general understanding of the disease and its consequences, simply by submitting information on how MS affects their own life.

You can access more information about NARCOMS and enroll as a participant on the NARCOMS website (www.narcoms.org/). For questions or to request an enrollment questionnaire to be mailed to you, please call 1-800-253-7884 or email MSregistry@narcoms.org

MSIF Member Organisation contact details

Argentina: Esclerosis Múltiple Argentina
info@ema.org.ar; www.ema.org.ar

Australia: MS Australia
info@msaustralia.org.au www.msaustralia.org.au

Austria: Multiple Sklerose Gesellschaft Österreich
msgoe@gmx.net www.msgoe.at

Belgium: Ligue Nationale Belge de la Sclérose en Plaques/Nationale Belgische Multiple Sclerose Liga
ms.sep@ms-sep.be www.ms-sep.be

Brazil: Associação Brasileira de Esclerose Múltipla
abem@abem.org.br www.abem.org.br

Canada: MS Society of Canada /Société canadienne de la sclérose en plaques
info@mssociety.ca www.mssociety.ca
www.scleroseenplaques.ca

Cyprus: Cyprus Multiple Sclerosis Association
multipscy@cytanet.com.cy www.mscyprus.org

Czech Republic: Unie Roska česká MS společnost
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Germany: Deutsche Multiple Sklerose Gesellschaft Bundesverband e.V.
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Japan: Japan Multiple Sclerosis Society
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MSIF Member Organisation contact details (cont.)

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Malta: Multiple Sclerosis Society of Malta
info@msmalta.org.mt www.msmalta.org.mt

Mexico: Esclerosis Múltiple México
emmex-org@hotmail.com http://emmex-ac.blogspot.com

Netherlands: Stichting MS Research
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New Zealand: MS Society of New Zealand Inc
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epost@ms.no www.ms.no

Poland: Polskie Towarzystwo Stwardnienia Rozsianego
biuro@ptsr.org.pl www.ptsr.org.pl

Portugal: Sociedade Portuguesa de Esclerose Múltipla
spem@spem.org www.spem.org

Romania: Societatea de Scleroza Multipla din România
office@smromania.ro www.smromania.ro

Russia: The All-Russian MS Society
pzlobin@yahoo.com www.ms2002.ru or http://ms2002.ru/

Slovakia: Slovenský Zväz Sclerosis Multiplex
szsm@szm.sk www.szsm.szm.sk

Slovenia: Združenje Multiple Skleroze Slovenije
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kmss2001@gmail.com www.kmss.or.kr

Sweden: Neuroförbundet
info@neuroforbundet.se www.neuroforbundet.se

Switzerland: Schweizerische Multiple Sklerose Gesellschaft
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Tunisia: Association Tunisienne des Malades de la Sclérose en Plaques
ATSEP@topnet.tn contact@atseptunisie.com
www.atseptunisie.com

Turkey: Türkiye Multipl Skleroz Derneği
bilgi@turkiyemsdernegi.org www.turkiyemsdernegi.org

UK: MS Society of Great Britain and Northern Ireland
info@mssociety.org.uk www.mssociety.org.uk

Uruguay: Esclerosis Múltiple Uruguay
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USA: National MS Society
www.nationalMSSociety.org

MS *in focus*



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international federation

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