

# MS Ireland AGM

The recent MS Ireland AGM reflected on the achievements of the past year

**MS IRELAND'S 2007/2008** AGM took place on 21 June, as a cross section of Branch volunteers and Board members turned out for the event. Held in the Tara Towers Hotel in Dublin, the AGM highlighted the many accomplishments of MS Ireland in 2007 and looked to the plans for the organisation in the year ahead.

Outgoing Chairman Louise Wardell reported on the many and successful activities of MS Ireland in her three-year tenure as MS Ireland Chairman. Louise noted in particular the opening of the Limerick Resource Centre, the many improvements and changes in governance and management, the streamlining of services and the useful international links made.

"I see our Society as a strong and vibrant organisation, which now has the necessary base from which to go forward," she said.

Chief Executive Anne Winslow also reported to the AGM and noted such 2007 achievements as the MSLiving convention, strides in advocacy work and improvements in service delivery. In addition, Anne presented a token of gratitude to Louise for her work and commitment to MS Ireland as Chairman.

The election of Board members was regarded as the most anticipated element of the AGM. Five Board members stood down — William Lonergan, Paul Hogan, Chris Fahy, Dr Stanley Hawkins, Jean Croucher and Vice-Chairman Oliver Durkin. Each of these people has played a vital and unique contribution to the Society and they will be missed in the current Board's make-up. However, their mantle is being passed onto some new, and not so new, faces. To read the full reports from the Chairman and the Chief Executive, visit [www.ms-society.ie](http://www.ms-society.ie).

## The 2008/2009 Board members are:

**Mr Allen O'Connor** (Chairman)\* is a past Chairman of MS Ireland and holds a number of positions on national and international MS/disability agencies.

**Mr Brain Farrell** FCA (Vice-Chairman) is a former Finance Director with Diageo, having previously held other management positions in his 33 years with the company.

**Mr Brian Barrett**\* is a community and voluntary-sector professional, having worked in the area for 12 years.

**Ms Margaret Burke**\* is a Nurse and past Chairman of the Carlow Branch. Margaret has lived with MS for 25 years.

**Mr Joe Cahill**# is a former Senior Manager in the Health Service Executive and, before retiring after 30 years of service, was Director for Physical and Sensory Disability Services.

**Dr Art Cosgrove** is a past President of University College Dublin, having worked in the university since 1963 in its history department.

**Dr Gemma Donnelly Cox** is a Lecturer in business studies and is the Academic Director for the Centre for Non-Profit Management, Trinity College Dublin.

**Ms Deirdre Dolly** is a past Nurse and Social Worker and has been involved with the Galway Branch for many years.

**Mr Kevin Doyle** is an active member of the North Wexford Branch and other disability and community agencies in Wexford. Kevin was diagnosed with MS in 1996.

**Ms Maureen Feeney** is an active member of the Castlebar Branch and has cared for her husband who had MS for 14 years.

**Dr Michael Hutchinson**\* is a noted Consultant Neurologist at St Vincent's Hospital and has published over 80 papers on MS.

**Ms Mary Keane** has worked with the Waterford Branch for over 25 years and is an active member on various disability and community organisations. Mary has MS.

**Ms Lorna Mitchell**\* is a former Fundraising Consultant with MS Ireland, having organised walks all over the world.

**Mr Gerry Murphy**\* has a long career in marketing, working in the food manufacturing and retail industries.

**Mr Sean Murphy** is an active fundraiser and organiser in the Cork Branch, where he has served for 25 years.

**Mr Paddy Power** has a long career in the petroleum industry. He is a past CEO of the state-owned Irish National Petroleum Company and is currently a partner in Shannon LNG.

**Ms Louise Wardell** is a solicitor and has been involved with MS Ireland for many years, both at Branch and Board level, where she served as Chairman for three years.

# Mr Joe Cahill has stepped down from the Board to act as Interim Chief Executive of MS Ireland

\* Those who were elected to the Board this year

# A lifelong voyage of discovery



**Linda Daly** speaks to an illustrious doctor, who has dedicated his working life to MS research. At the age of 89, his research remains as active as ever

**Pictured celebrating Dr Dean's honorary doctorate are, from left: Taragh Donohoe, Communications, MS Ireland; Art Cosgrove, Board member, MS Ireland; Dr Geoffrey Dean; Allen O'Connor, Chairman, MS Ireland; and Lorna Mitchell, Board member, MS Ireland**

**AN EXTRAORDINARY FIGURE** in the research world, Dr Geoffrey Dean has contributed hugely to MS research over the years, so it is fitting that he was awarded with an honorary doctorate from University College Dublin (UCD) in June.

Now 89 years of age, Dr Dean was the first scientist to find the causes of MS were both genetic and environmental. He looked at patterns of MS in South Africa and, in particular, compared rates in populations from northern Europe.

"MS is a disease of both inheritance and the environment," explains Dr Dean. "It's a combination of factors and the answer is always going to be complex. We've got to find out the environment involved and the genes involved."

Born in 1918 in Wales, Dr Dean qualified as a medical doctor in Liverpool in the early Forties and went on to serve in Bomber Command in World War Two in 1943. After the war, he moved to South Africa where he practised medicine for 20 years.

In 1967, Dr Dean chose Ireland as his home and was appointed the first Director of Ireland's Medico-Social Research Board (MSRB).

He was awarded a CBE in 2003 in recognition of his contribution to medical research, which has also promoted an improved understanding of lung cancer and motor neurone disease. MS Ireland encouraged UCD to award Dr Dean with the honorary doctorate. "I'm very pleased and surprised, but mostly very honoured," he says.

Dr Dean published his memoirs in 2005, aptly titled *The Turnstone: A Doctor's Story*, which you can purchase on [www.amazon.co.uk](http://www.amazon.co.uk). He says he chose the name because

he sees great similarity between researchers and the turnstone birds, who spend their time turning over stones to see what lies underneath.

His research has taken him all over the world. At the age of 89, he is as active in mind as ever and continues to carry out valuable research into MS. Dr Dean recently published a paper exploring the comparative prevalence of MS between Sicily and Malta, the findings of which appeared in the journal *Neurology*.

**'I'm very happy with what I've achieved, but I'd like to see in my lifetime the ability to stop MS'**

He believes Malta is the key to uncovering the exact causes of MS and is hoping to secure funding to send a Maltese researcher to the US for two years to study this theory in depth. The proposed study would involve both the Irish and British MS Societies.

Despite his already huge contribution to MS, Dr Dean says he will always feel it's not enough until the answer is found and perhaps this is why he continues to work so hard as he approaches his 90th birthday in December.

"I'm very happy with what I've achieved, but I'd like to see in my lifetime the ability to stop MS," he says.

As I leave Dr Dean, he cites the Hippocrates quote: "Life is short, the art is long, the occasion fleeting, experience delusive, judgement difficult."

He says while he'd like to see the real cause of MS discovered during his lifetime, the most important thing is that it is eventually unearthed.

# Heart and sole

When Bernard Dray realised how helpful reflexology had been in managing his own MS, he decided to bring the benefits to others, writes **Carmel Doyle**

**USED PRIMARILY ON** the feet and hands, reflexology is thought to restore balance to the body, mind and spirit and help ease numerous medical conditions. It can also alleviate many of the symptoms people with MS have to cope with on a daily basis.

Reflexology is based on the premise that reflexes on the feet and hands correspond to all the organs, glands and structures of the body. When these reflex points are gently manipulated, they assist the body in cleansing itself of toxins and impurities to regain its natural equilibrium.

Based in Tramore, Co Waterford, Bernard Dray runs a reflexology and massage practice from his home. Diagnosed with MS in 2004, he says his symptoms gradually worsened to the secondary-progressive stage over the following two years.

Due to a lifelong interest in complementary medicine, Bernard began some extensive research and started to go for weekly reflexology and massage treatments.

He explains that very favourable reports have been published on the healing link between reflexology and MS, which indicate that the practice is a worthwhile addition to the overall treatment of MS.

"I now have very few MS symptoms. I attribute this to the adjustment of my medication and having a sympathetic GP," says Bernard.

"In my opinion, reflexology and massage have greatly complemented my medication and have helped bring

on my current remission, which has lasted over two years."

Because of the personal benefits he gained from reflexology, Bernard returned to education and trained in the Crystal School of Complementary Medicine in Waterford. He has since undertaken postgraduate courses with the European Institute of Advanced Reflexology.

Now a fully accredited and insured registered practitioner with the National Register of Reflexologists (Ireland) and the Irish Massage Therapist Association, Bernard treats every type of client, including those with MS.

Reflexology can be beneficial in treating common MS symptoms such as kidney and bladder problems, according to Bernard. "It also assists with muscular discomfort, circulation and lymph flow. It can act as a wonderful detox without interfering with medication."

Other symptoms that reflexology can alleviate include migraine, vertigo, infertility, acne, arthritis, colitis and irritable bowel syndrome.

"There are, however, no guarantees and a lot depends on a client's outlook and lifestyle," he adds. Having a strong positive attitude is therefore essential.

Following a healthy diet, drinking lots of water and not consuming too much tea, coffee or alcohol will also help people's healing processes.

Bernard says weekly treatments are recommended until some of the symptoms abate and people experience the benefits of reflexology.



## How reflexology can help those with MS

While reflexology can be helpful in alleviating bladder and bowel problems, it can also improve motor and sensory symptoms. In addition to this, reflexology can help ease eye problems and aid lymphatic drainage and balance. It is believed that reflexology:

- Enhances the assimilation of nutrients to improve the provision of nourishment for healthy functioning of the body
- Improves the circulation of the blood, with enhanced cleansing of the cells and elimination of toxins
- Regulates the function of the immune system. Reflexology can calm it down and stop the immune system attacking the nervous system, as it does with MS
- Assists the body in healing itself.

Reflexology is now covered by Quinn Healthcare, Vhi Healthcare and Vivas Health. Check with your provider for entitlements.

To learn more about reflexology, visit the Irish Reflexologists' Institute at [www.reflexology.ie](http://www.reflexology.ie).

# Focus on rehabilitation

Complementing the role of pharmaceutical treatments of MS, rehabilitation is intrinsic in helping people live their lives more fully

**THE HOLY GRAIL** of living as successfully as possible with MS is the discovery of ways to manage the individual and unpredictable symptoms and challenges of the disease.

One of the primary tools for managing MS is the use of various pharmaceutical treatments. In tandem with this, however, is the need for people to maintain a certain quality of life that may not be addressed solely by drug treatments. This is where the role and benefits of rehabilitation are apparent.

In their 2003 publication *Recommendations on Rehabilitation Services for Persons with Multiple Sclerosis in Europe*, the group Rehabilitation in Multiple Sclerosis (RIMS) defines rehabilitation comprehensively.

“MS has physical and psychosocial consequences, which may have an enormous long-term impact on almost every aspect of the everyday lives of persons with MS and their families. Rehabilitation is commonly thought of in terms of restoration of physical ability. The disease, however, can also affect cognition, memory and emotions.”

Rehabilitation is a way for people with MS to reduce the negative effects brought on by their condition. It is not a cure or a preventative tool, but is a way to assist people to adapt their lives and work with the changes brought on by MS.

Rehabilitation is vital for people with MS, according to Aidan Larkin, National Co-ordinator of the Getting The Balance Right programme with MS Ireland. “It improves the quality of people’s lives. Rehabilitation also prevents secondary complications, thus reducing the necessity for hospital stays,” he says.

“It is vital that people have access to it. Individuals will need different parts of a rehabilitation plan at different stages of the disease process. Rehabilitation needs to be very much person-centric.”

## ELEMENTS OF REHABILITATION

A wide selection of health professionals have a role to play in providing rehabilitative services to people with MS.

Physiotherapists, occupational therapists, neurologists,



**Dr Áine Carroll**

**‘Individuals will need different parts of a rehabilitation plan at different stages of the disease process’**

MS nurses, speech and language therapists and other professionals form what’s called the multidisciplinary team. This group of people aim to provide an holistic approach to the management of MS.

Dr Áine Carroll is a Consultant in rehabilitation medicine at the National Rehabilitation Hospital (NRH) in Dún Laoghaire and is Chair of its medical board. Dr Carroll and the team at the NRH provide a range of rehabilitative services to people with all types of difficulties and challenges.

“The physical side of things looks at the body’s ability to function, with particular emphasis on walking. Fatigue management, pain management, spasticity and things to do with balance and posture are important.

“Occupational therapists give advice. People have to be

taught how to do things properly and how to pace themselves,” she continues.

“We use speech and language colleagues to look at both swallowing and problems with speech. Speech and language therapists also look at the reading and writing abilities of the person with MS.”

MS can also affect emotions, memory and cognition. Therefore, rehabilitation must also encompass the improvement of quality of life and emotional well-being. Vocational rehabilitation is now being considered just as important as physical restoration, says Dr Carroll.

A high proportion of people with MS leave work shortly after being diagnosed and before they can no longer physically work. Vocational rehabilitation looks at ways in which people can remain at work and also advance by making changes in their career.

The work of a neuropsychologist can benefit areas such as attention, memory and cognitive impairment. The role of counsellors, psychologists and other professionals in the mental health field can offer much support for people coming to terms with changes in their body and lifestyle.

It may seem that people with MS require a whole team of people to help them adjust. However, this may not necessarily be the case. Aside from the actual provision of services in your area, the need for rehabilitation depends on the physical, cognitive and emotional affects of MS.

### WHEN TO START REHABILITATION?

The need for rehabilitation depends hugely on the progression of the disease and the effects this has on the person. As MS can be very individual and unpredictable, there are no hard and fast rules about when rehabilitation should occur. However, research has found that early, appropriate intervention can delay the onset of disability and help maintain independence for longer.

The report *Recommendations on Rehabilitation Services for Persons with Multiple Sclerosis in Europe*, compiled by the group Rehabilitation in Multiple Sclerosis, outlines some key considerations at varying stages of MS.

### EARLY STAGE OF MS

When someone is first diagnosed with MS, their rehabilitation will look at areas such as dealing with fatigue and eating healthily, as well as the various aids that can help make life easier. Vocational rehabilitation should start shortly after a person is diagnosed with MS to ensure job retention.

Major changes may not need to happen right away, but recognising where small changes can be introduced may help a person stay in their job longer. Career counselling and job placement services come under the process.

## Meet the rehabilitation team

Neurologist

Rehabilitation Physician

Psychologist

Neuropsychologist

Physiotherapist

Occupational Therapist

Speech and Language Therapist

Rehabilitation Nurse

Social Worker

Introducing flexible and mobile-working practices has proved very effective when it comes to job retention. Other workplace accommodations include memory aids, motorised scooters, climate control at the workstation or low-vision aids.

### LATER STAGE OF MS

In the later stage, disability can lead to loss of self-sufficiency. The European MS Platform [EMSP] and RIMS have called for long-term care programmes to help with spasticity, bladder dysfunction and reduced vision. They say neurorehabilitation can “provide a bridge between the acute hospital and community care”.

At this stage of MS, inpatient rehabilitation programmes should be provided. An alternative is the establishment of outpatient day units that have close links with the community.

### ADVANCED STAGE OF MS

As the person becomes dependent in both mobility and daily-living activities, the aim of rehabilitation at this stage is to maintain independence for as long as possible. Rehabilitation will look at installing equipment in the home, teaching carers how best to cope with physical tasks and to reduce the number of hospital admissions.

In the following pages of this feature, we look at the three most-commonly used therapies or interventions in the rehabilitative process: physiotherapy, occupational therapy and speech and language therapy. We also look at rehabilitative services in Ireland and how MS Ireland is responding to the gap in services.

# The role of occupational therapy

Occupational therapists assist people with MS to continue living their lives as independently as possible

**THE AREA OF** occupational therapy can often be confusing for those outside of the health profession. Occupational therapy deals with the daily occupations of people, whether it is your home life, your social life, your work, self-care and anything that keeps you productive.

People with MS often find there are limits to what they can do in their daily lives and occupational therapy will work to ensure that those individuals can achieve maximum independence and a good quality of life.

The occupational therapist will meet the person with MS and assess how they are performing. He will assess the physical and cognitive abilities of the patient and discuss their needs.

An occupational therapist will focus on different issues, including physical abilities for daily living and mobility; cognitive dysfunction such as memory and organisational skills; what assistive technology or devices are used; and how these devices can be adapted.

Joyce Henderson is an Occupational Therapist with the MS Care Centre in Rathgar, Dublin. While her role is different to that of the occupational therapist in the hospital or community, Joyce follows the same principles.

Upon arriving at the MS Care Centre, residents usually request an appointment with the occupational therapist.

"I would then assess their needs in a variety of areas," explains Joyce. "These include personal care, for example, dressing and toileting."

A major role of the occupational therapist is to maintain mobility. "Some people have stopped doing things without proper assessment. They stop making the dinner, but if they had their kitchen designed properly and had the proper aids they could continue doing things," she explains.



Joyce always encourages people to get a driving assessment before they cease driving, as they may be able to get adaptations to allow them continue to drive.

Mobility is, understandably, a thorny issue for some individuals. "People are often very reluctant to make the change from walking mobility to wheeled mobility, so they spend a lot of time sitting at home. If powered mobility is suitable, it opens up a whole area of lifestyle for the individual and gives them a new lease of life," she says.

If the occupational therapist is community-based, he will examine the physical environment in which the patient lives, taking into consideration the set-up of the person's house, workplace or community. He will then make recommendations to make life easier for the patient.

"Environmental controls are very important as the disability progresses. They include things such as answering the door and opening and closing curtains at the switch of a button etc," says Joyce.

## THE AIM OF THE OCCUPATIONAL THERAPIST IS TO:

- Maintain and restore physical, cognitive and social capacities
- Provide alternative methods and techniques to maintain independence and compensate for limitations
- Provide advice regarding suitable adaptive equipment and modifications to assist in independent living.

Source: EMSP

## OTs take into consideration everyday activities

Personal care - Washing and dressing

Everyday tasks - Cooking meals, gardening and shopping, working and education

Leisure - Social activities and sport

Communication - Writing, talking and using the computer

Mobility - Getting from one place to the other

# The role of speech and language therapy

Fiona Hill, Senior Speech and Language Therapist, Neurology at the Adelaide, Meath and National Children's Hospital, explains the function of speech and language therapy for people with MS

**MS IS ONE** of the common neurological conditions where speech and language therapists are involved. It is the role of the speech and language therapist to assess, diagnose and manage problems relating to speech, language, communication, voice and swallowing the person with MS may present.

It has been reported that 50% or more of people with MS exhibit speech difficulties (dysarthria), which can relate to factors such as increased tone, weakness, tremor and reduced co-ordination in muscles used for speech and can be complicated by medications and fatigue. When speech and voice disturbances do occur, they usually present as problems in loudness of the voice, voice quality, breath support, speaking rate and clarity of speech.

Intervention from a speech and language therapist aims to maximise the individual's ability to communicate within his or her everyday setting. This may focus on improving the speech itself and/or modifying the person's environment and those in it. The Lee Silverman Voice Treatment (LSVT), which aims to improve vocal loudness by increasing effort of voicing, can help improve intelligibility of speech in individuals with MS. Full assessment by a speech and language therapist is required to determine candidacy.

Ideas to help if your speech is difficult to understand:

- Speak loudly and slowly
- Take regular breaths
- Pause before important words to make them stand out
- Exaggerate your speech
- Face your listener
- Avoid important/long conversations or phone calls when fatigued
- Try to monitor your speech and self-correct
- Ask others to let you know when they do not understand.

Where natural speech is no longer a functional means of communication in all settings, another means of communication may be appropriate to support or replace speech. This can take the form of low-tech aids such as written words/pictures, alphabet charts, high-tech devices such as computers or voice output devices. A voice amplifier can magnify the volume of an individual's voice through a discrete microphone placed near the mouth.

While language disturbances are less common in MS,



**'Intervention from a speech and language therapist aims to maximise the individual's ability to communicate within his or her everyday setting'**

individuals may experience difficulties in understanding and producing spoken and/or written words.

Additional cognitive changes, which may include deficits in attention, memory and speed of processing, can often give rise to difficulties such as accessing the name of something or processing information in a noisy environment.

MS may affect a person's ability to swallow food and drink safely, placing them at risk of developing chest infections linked to the entry of food/drink into the lungs (aspiration). Swallowing difficulties (dysphagia) may include difficulty chewing, pocketing of food inside the cheeks and leakage of drink from the mouth. Further signs of a swallowing problem include weight loss, malnutrition and dehydration.

Individuals with MS with suspected dysphagia should be referred to a speech and language therapist for a clinical examination of swallowing. Management of swallowing problems vary depending on the severity of the difficulties or the stage of the MS, but the primary aim is to maximise safety and efficiency of swallowing.

# The role of physiotherapy

Maria Garrett, Neasa Hogan and Dr Susan Coote of the Physiotherapy Department at University of Limerick outline physiotherapy techniques and exercises for individuals with MS

**PEOPLE WITH MS** have varying physiotherapy needs. Based on the latest research, this article will describe the importance of physiotherapy for those with MS who have different types of ability.

For people who are independently mobile or who use a stick, it is important to participate in aerobic and strengthening exercise regularly. Aerobic exercise means getting your heart rate up to about 65% of your maximum heart rate and includes activities such as cycling, swimming, walking and running. Benefits can be seen in strength and fitness activities such as walking, resulting in increased ability to participate in activities you enjoy.

Evidence shows people with MS participate in exercise less than the general population and those with other chronic conditions. Furthermore, long-term steroids can lead to bone thinning. Thus, as well as the benefits for mobility, quality of life, strength and fatigue, participating in regular exercise can protect you from co-morbidities such as heart disease, diabetes and osteoporosis.

Sometimes heat can temporarily exacerbate sensory symptoms such as fatigue or visual disturbances. It is important to remember that these symptoms usually resolve within 40 minutes of exercise.

There can be many barriers to exercise such as access to facilities, concern about safety, time, temperature, cost, fatigue and incontinence. Discuss these barriers with your physiotherapist or wherever it is that you do your activity, as there are many ways to facilitate exercise.

Other types of exercise such as aqua aerobics, pilates and yoga may also be just as beneficial. The important thing is to be as active as you can and to choose an activity you enjoy. However, if any problems arise, it is important to get assessed by a chartered physiotherapist or your GP.

For people who use a rollator or two sticks and may occasionally use a wheelchair, physiotherapy can help improve balance and mobility.

Studies show that different types of physiotherapy and exercise can be effective for people with MS who have mobility problems, as they have a risk of falling. Taking part in a balance programme can reduce this risk. This type of programme consists of different exercises aimed



at improving balance and strength such as stepping, standing with your eyes closed and practising sitting to standing in a safe environment. Other benefits of different types of physiotherapy include reduced fatigue, improved confidence, increased strength and increased quality of life and mood.

Physiotherapists also play a role in prescribing various types of walking aids or splints.

For people who are confined to a wheelchair and cannot walk, or people who spend most of their time in bed, there is no simple recipe. Physiotherapists aim to promote comfort, reduce stiffness, prevent contractures and educate family and carers about the easiest way to help you to transfer at home.

A physiotherapist can also help with respiratory problems such as chest infections and pain management.

## TAKE-HOME MESSAGE:

Chartered physiotherapists can provide assessments and treatments for every level of ability in people with MS. They can help to implement the programme that is right for you. The important message is to be active, regardless of the activity that you choose to do.

A list of chartered physiotherapists is available on [www.iscp.ie](http://www.iscp.ie). In addition, the Getting The Balance Right Project — a physiotherapy and exercise programme for all people with MS — is now up and running nationwide. Contact your local regional office for further details.

# A positive vista

Finding services for MS in Ireland more constrained, one individual details how his visits to a rehabilitation centre in Tenerife have helped him stay on track

**IT WAS ON** a hike in the Wicklow mountains in the early Nineties that Alexis Donnelly first noticed the symptoms of MS. Hiking had never been a problem, but on this occasion he simply couldn't keep up.

In 1991, Alexis was diagnosed with primary-progressive MS. His condition progressed quickly — soon he had to walk with a walking stick and eventually he had to use an electric scooter. Today, his mode of transport is an electric wheelchair.

While Alexis still has feeling in his left leg, the sensation is reduced somewhat and he finds it almost impossible to walk. His left arm is also weak.

Despite his disability, Alexis continues to work as a Lecturer in computer science at Trinity College Dublin. He says one of the biggest factors in his continued working is his visits to a rehabilitation centre in Tenerife.

Six or seven years ago, Alexis began travelling to Vintersol, a renowned clinic that was set up by two Swedish visionaries in the Fifties. The centre provides an intensive rehabilitation programme.

"There are a lot of Irish people with a similar degree of disability [to me] who are living in institutions, unable to work and deteriorating much faster," says Alexis. "We started looking at the literature and knew intensive physiotherapy was standard procedure in many countries, but sadly not in Ireland. I credit my visits to Vintersol as being a very significant element in my continuing to work."

Located in Los Cristianos in Tenerife, Vintersol has residential accommodation for over 90 patients. The facilities are completely accessible to those with disabilities. Vintersol has two gyms, with various kinds of equipment, and two swimming pools. Upon guests' arrival, a rigorous assessment is carried out and then a physiotherapy and occupational therapy programme is established. Patients are assigned dieticians and speech therapists if they need them. They also see a team of neurologists and can have an assistant assigned to them.

While Vintersol sounds exotic, Alexis says a visit involves hard work. He now travels to Tenerife once a year for five weeks. A programme such as this is expensive, however, and depending on the facilities you need, you could spend between €1,000 and €1,500 per week.

But why doesn't he spend less money and use services



Alexis Donnelly

**'I credit my visits to Vintersol for being a very significant element in my continuing to work'**

closer to home? The simple answer is there aren't the services in Ireland. While Alexis has been lucky to stay at the National Rehabilitation Hospital in Dún Laoghaire, he couldn't go regularly. The Swedish government pays for MS patients to travel to Vintersol.

"I have no doubt the physiotherapists and occupational therapists there are the equal of or better in technical or clinical ability than the ones in Tenerife, but they're constrained. The amount of time I was given was relatively short and it was then reduced because of severe budget constraints," he says. Also, because of the limited number of beds in Dún Laoghaire, car accident cases naturally take priority.

"I cannot understand why, given the clear financial benefits to the State, we don't have something like Vintersol in Ireland. Long term we're building up a big health bill, which could be easily avoided." Back in the Fifties the Swedish state decided that the cost of the rehabilitation programme was easily outweighed by prolonged working life, significantly reduced downstream medical complications and increased quality of life.

Alexis remains optimistic about his health, however. "I don't surrender. One way I retain a positive mental attitude is through regular physiotherapy and rehabilitation."

# Current rehabilitation services

With rehabilitation services currently lagging in Ireland, experts in the field believe that more co-ordinated and community-based services need to happen across all regions

**DESPITE HUGE STRIDES** in rehabilitation services over the past decade, Ireland still lags behind in its provision of such services. Aidan Larkin, National Co-ordinator of the Getting The Balance Right programme, believes there is a lack of rehabilitation services in Ireland because of physical, personnel and financial issues.

Dr Áine Carroll from the National Rehabilitation Hospital (NRH) agrees. “What people should have access to and what they have in reality are two poles apart,” she says.

“In the NRH, our main scope of services mainly relate to spinal injuries. We don’t have a remit for managing progressive neurological conditions. We do, however, try to have some of our beds available.”

At present, the NRH has capacity for 119 beds. However, a new €200m hospital is due to be built and will double capacity to 235 beds.

Dr Carroll stresses that inpatient treatment is only one part of the process, however, and that rehabilitation should become more community-based.

“People with MS need access to rehabilitation and there needs to be a development of community services. People with MS need to have access to multidisciplinary rehabilitation, so they can maximise their potential and maintain their independence. There is very good evidence to show that multidisciplinary rehabilitation has a far better outcome.”

Aidan points out that despite a number of local rehabilitation services, there is a lack of harmony in the way these are delivered. “There are many rehabilitation-type services around the country, but they are provided in a very uncoordinated way.”

## MS IRELAND SERVICES

MS Ireland provides programmes and workshops that help address some of the effects of MS. Organised by the Regional Offices, such sessions include fatigue management, newly diagnosed programmes, symptom management and personal development. Added to this is the provision of core services such as one-on-one home



visits, provision of counselling and a comprehensive referral process to other local and national services. All these services and activities help people and families living with MS to address concerns, manage the effects of MS and improve quality of life.

The Getting The Balance Right programme is the latest initiative by the Society and it is hoped that this will shine a light on the importance of physiotherapy among people with MS.

“Getting The Balance Right is going to be very important for two reasons: It is an opportunity for people with MS to participate in exercise-related activity, plus it is a chance for us to profile the physical needs of people with MS in Ireland and to objectively compare the benefits for the first time,” says Aidan.

“Research will be very important as it will objectively measure service delivery in the area of physiotherapy and exercise. Secondly, it will provide us with the evidence to influence government policy,” he explains.

## LOCAL SERVICES

Katie Hourigan, Regional Co-ordinator with the South East Regional Office, provides some insight into the provision of rehabilitation services locally. She says neurorehabilitation is in dire need of investment.

“Rehabilitation services are very poor in the south east. There’s only one national rehabilitation hospital in Ireland and that’s in Dublin. Only recently have we got a

neurologist in the south east and he's not full time. People with MS don't really get a fair share of the resources," says Katie.

Nonetheless, certain individuals and groups are doing their best to improve rehabilitation services in Ireland, she adds.

"There are local people who have taken the initiative with MS themselves. In Carlow, for example, Bernie Kent and Margaret Burke are running exercise programmes. They are very passionate about it. Ceart is another organisation that is helping people to access adequate therapy and rehabilitation in the south east."

### REHABILITATION: THINKING STRATEGICALLY

The Health Service Executive (HSE) is currently working on a Rehabilitation Strategy that aims to address and co-ordinate the rehabilitation services throughout the country. Two national working groups have been set up: the National Working Group on Rehabilitation and the NAI National Rehabilitation Strategy Working Group. NAI is the Neurological Alliance of Ireland. MS Ireland is represented on both groups, although work is still in the early stages. In addition, the HSE has completed, but not published, a Review of Neurology and Clinical Neurophysiology Services.

This document takes a comprehensive view of neurology services in MS Ireland and will make a number of key recommendations. Included in the review is the provision of neurorehabilitation and the recommendations associated with it. It is hoped that both documents will prove useful in adequately meeting needs.

Under its five-year strategic plan, *Making It Happen*, MS Ireland is committed to increasing its service impact by researching and developing community-based therapeutic and rehabilitative resource centres in four regions in Ireland. The objective is to provide accessible and suitable rehabilitative and therapeutic options for people with MS.

Work on this has begun via the establishment of a rehabilitation working group. Consisting of a number of key staff members, the group will investigate current services, look at international models to provide a comparative analysis and establish a best practice model for Ireland. The group is working with the Board of MS Ireland through the Strategy, Policy and Development sub-committee.

"We need to look at the possibilities and cost-benefit analysis of rehabilitation and how much it will save in the sense that it will keep people in employment and out of hospital," says Katie.

"Certain gaps exist in service provision to people with MS and carers, which include inappropriate models of accommodation and inadequate community rehabilitation and therapies. MS Ireland's specific services to people

with MS need to be more equitable across the country."

The Society hopes to collaborate with other agencies and a variety of service providers to make these rehabilitation centres a reality. Ultimately, it would like to see integrated community-based rehabilitation services supported by the HSE.

"The best delivery model would be where the key stakeholders have a stake in how it's delivered and measured," says Katie.

There are certainly moves forward in addressing rehabilitation, but this will not happen quickly. However, Dr Carroll is optimistic for the future of rehabilitation services in Ireland. "I don't think I'd be doing my line of work if I wasn't optimistic. I keep plugging away and hope that, with the passage of time, the services that are required are developed."



#### Vital web links:

- For information about MS Ireland services and programmes, go to [www.ms-society.ie](http://www.ms-society.ie)
- For information about rehabilitation in the south east, visit [www.ceart.ie](http://www.ceart.ie)
- The National Rehabilitation Hospital website is found at [www.nrh.ie](http://www.nrh.ie)
- The Multiple Sclerosis International Federation based its seventh issue of the *MS in Focus* magazine on rehabilitation in 2006. Visit [www.msif.org](http://www.msif.org)
- RIMS (Rehabilitation in MS) is the European network of MS care centres. For further details, go to [www.rims.be](http://www.rims.be)
- For services in your local area, contact your local HSE unit or go to [www.hse.ie](http://www.hse.ie).

# An *inspiration* to all

Having lost his wife to MS earlier this year, Sean O'Brien recalls the initial event that brought them together and encourages people to make the most of everything



**DUBLINER AND FORMER** North Dublin Branch Chairman Sean O'Brien talks about his wedding day in October 2007 in the same excited tones you would expect from anyone who has been married less than a year. The difference, however, is that Sean lost his new bride to MS just six months after the couple made their vows.

Deirdre O'Brien (née O'Keeffe), a long-time member of the North Dublin Branch passed away on 4 April at the age of 43. Both Deirdre and Sean had MS for many years; in fact, their story is irretrievably linked to the illness because it was on an MS outing that they first met back in 1984.

"I had heard about this weekend event that was happening down in Trabolgan, so I drove down with a pal who had just found out he had MS. I had known that I had it for some time at that stage," explains Sean.

"We were all brought into this big room and each of us was given a number. The idea was that you found your matching number and talked to that person about yourself, how long you had MS, how it was affecting you and so on.

"I picked out the number of an elderly lady, who wasn't able to speak much because of problems with her throat. I started talking to her anyway, but then her helper approached and said I'd be better off picking someone else in the room, as the lady wouldn't be able to talk to me.

"So I looked around; everyone was paired off by then except this one girl in the middle of the room. I went up to her and asked would she mind if I sat with her. She was a bit standoffish at first, but we got talking. I offered to buy her a drink and she asked if she could have a pint of Smithwicks. I said 'not from me you can't; I don't buy girls pints!' But she convinced me."

Sean says he knew immediately there was something

special between him and Deirdre and, much later, she admitted that she had felt the same way.

He says that when they first met all those years ago Deirdre hadn't known about her MS for long. "I'd had time to get used to it at that stage, but she was still a bit stunned by the whole thing. There were people there [in Trabolgan] who were wheelchair-bound and some who had MS for quite a few years and were in a bad way. It all just took her aback a bit."

Sean's own MS story stretches back to when he was eight years of age. A district nurse was doing a routine visit to his school and when she examined Sean she asked for his mother to come and see her. "She said I would be blind by the time I was 20. My mother didn't tell me that at the time though."

Thankfully, the nurse's prediction didn't come true. Although Sean's sight has deteriorated significantly, he retains some sight but is unable to drive.

It was 1982 before Sean was diagnosed with MS. He will be familiar to many MS Society members around the country, as he was chairman of the North Dublin Branch for about 15 years and only left his post when Deirdre became very ill.

After meeting in Trabolgan, Sean and Deirdre kept in touch, but they didn't start going out together for some time after that.

"Deirdre ended up getting a flat in Drumcondra, which was much closer to me than where she had been living in Malahide," says Sean. "We weren't seeing each other at that stage, but I was always asking for her. By then I knew she was the one for me."

By 1990, Sean, who is from Whitehall, and Deirdre, who hails from Artane, had become a couple, even though Deirdre was in supported accommodation



because her health had disimproved.

Sean, whose father passed away two years ago, says it was his mother's goal to have Deirdre move into the O'Brien family home. Unfortunately, it wasn't to be.

"It didn't work out because Deirdre got quite unwell in her later years."

**'She was fabulous — so soft and mild mannered. She was easy-going and everything she did was for the both of us'**

In fact, Deirdre saw off several seemingly insurmountable challenges over the past few years of her life, fighting off five bouts of MRSA before finally succumbing to yet another bout earlier this year.

"Four years ago, she had a kidney taken out and I thought that was it for her. But she was such a fighter and she just started eating and drinking again and got herself going," he says.

Before her death, Deirdre stopped eating completely and her consultant told Sean on a Friday that it would be a miracle if Deirdre lasted until the following Monday. True to form, however, she fought on for an entire week after that.

"All that week, we were sitting at her bedside and Deirdre didn't open her eyes at all. But when I talked

to her, she would move her brow, so I knew she could hear me."

In spite of their circumstances, Sean and Deirdre had a fantastic time on their wedding day on 10 October — an event that wouldn't have happened, says Sean, if it hadn't been for the dedication of Deirdre's mother and sister Marianne. "Once she knew we wanted to get married, Marianne took over and arranged the whole thing." He says the support of all of his and Deirdre's family and friends at that time was crucial.

The ceremony took place in St John Vianney Church in Artane, very close to where Deirdre lived, and it is clear that everything about the day — and about Deirdre — is as fresh as ever in Sean's mind. "You wouldn't believe how well she looked that day." When asked what kind of person Deirdre was, he is not stuck for words. "She was angel like; she was fabulous — so soft and mild mannered. She was easy-going and everything she did was for the both of us. We were so much of a couple. Deirdre was my life. I loved her so much."

Despite their short time as husband and wife, Sean says he is thrilled they finally went ahead with their big day. "If we had left it to the following year — this year — it wouldn't have happened; she'd be gone."

Sean's advice to anyone in a similar situation to his and Deirdre's is simply to make the most of everything. "Without a doubt, we did that."

Deirdre is survived by her husband Sean, her mother Margaret, her sisters Marianne and Carmel and her brothers Anthony and Austin.

Sean would like to thank everyone who sent mass cards or passed on words of condolences during this

difficult time. He would especially like to thank his sister Stephanie who has always been at his side, helping him live his life. If you would like to get in touch with Sean, write to Sean O'Brien, c/o *MSnews*, MS Ireland, 80 Northumberland Road, Dublin 4.



## Agenda

### Friday 17 October

Registration begins from 2pm

Delegates can purchase a buffet-style dinner in the main restaurant

Light entertainment will be provided in the Enclosure Bar from 9pm

### Saturday 18 October

All-day Activities from 10am to 5pm

Therapies (Massage, Bowen Therapy, Beauty Therapy)

Book at the registration desk

Price list available on the day

#### 10.30am Welcome and Official Opening

Joe Cahill, Interim Chief Executive, MS Ireland

#### 10.45am 'The Rehabilitation Approach:

Treatment of People with MS' talk by Dr Belinda Weller, Consultant Neurologist, Western General Hospital, Edinburgh

#### 11.45am Getting the Balance Right: A National

Exercise Programme for People with MS Pilot Study Results from the Research Team, Physiotherapy Department, University of Limerick

#### 12.45pm Lunch

#### 2pm 'Memory and Thinking Problems — Combating the

Challenges of Cognitive Decline in MS' talk by Professor Kurt L Johnson, Department of Rehabilitative Medicine, University of Washington

3.15pm One-Hour Workshops (as per choice on booking form)

5pm Ecumenical Service

7pm Drinks Reception in lobby foyer

#### 8pm Gala Dinner and Awards Ceremony

MS Ireland will present awards for MS Person of the Year, MS Volunteer of the Year and MS Carer of the Year

# National Conference 2008

17 to 19 October 2008,  
Clayton Hotel, Old Monivea Road,  
Ballybrit, Galway

**MS IRELAND'S NATIONAL** Conference 2008 is taking place in Galway in October and this year's event will be a mixture of education, information and enjoyment.

The theme of the 2008 conference is rehabilitation, which is a very worthy subject for people with MS.

One of the most anticipated presentations of the event will be by Dr Belinda Weller, Consultant Neurologist with Western General Hospital, Edinburgh, who is set to talk about 'The Rehabilitation Approach: Treatment of People with MS'.

The 'Getting The Balance Right' programme will also be on the agenda and the results of the pilot study will be discussed by the research team in the Physiotherapy Department at University of Limerick.

People with MS may face challenges of cognitive decline, so the talk on memory and thinking problems by Professor Kurt L Johnson of the Department of Rehabilitative Medicine in University of Washington will certainly arouse interest.

In addition, there will be plenty of workshops to choose from and delegates will be able to book various therapies throughout the day.

The gala dinner and awards ceremony, where the awards for MS Person of the Year, MS Volunteer of the Year and MS Carer of the Year will be presented, should also not be missed.

To learn more about the conference, call the Western Regional Office on 091 862478 or visit [www.ms-society.ie](http://www.ms-society.ie).

### Sunday 19 October

Products Fair on Rehabilitative Devices and Adaptations in main lobby — continues all morning

#### 11.30am Plenary Q&A

Chaired by Consultant Neurologists

#### 12.45pm Closing Address

Joe Cahill, Interim Chief Executive, MS Ireland

1pm Lunch and Departure

## National Conference Booking Form

€195 per person sharing (room-sharing basis only)  
2 nights B&B, 2 lunches, 1 Gala dinner

Name: \_\_\_\_\_

Address: \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

Tel No: \_\_\_\_\_

Double  Twin \_\_\_\_\_

If twin room, other occupant: \_\_\_\_\_

Are you a wheelchair user?

Yes  No

(If yes, tick appropriate) Motorised  Manual

Wide-based

Do you require access to a hoist\*?

Yes  No

Do you require a bath board/lift\*?

Yes  No

(\*Please note that these are a shared resource and available on request)

Do you have any special dietary needs

Yes  No

If yes, please specify \_\_\_\_\_  
\_\_\_\_\_

Please pick one of the workshops you would like to attend:

Hydrotherapy  Yoga  Tai chi

Laughter  Voice therapy

I will be paying for my own costs Yes  No

My Branch will be paying for my costs Yes  No

Branch name: \_\_\_\_\_  
\_\_\_\_\_

Please note that every effort will be made to match your needs to available rooms, but due to the limited availability of accessible rooms, these will be allocated on a first-come first-served basis.

A non-refundable deposit of €50 secures your place.

Please make cheques payable to MS Ireland and send to: Tina Lally, MS Western Regional Office  
Roxboro House, Raleigh Row, Galway  
on or before Friday 19 September 2008.



## Health Professionals Day

**ON FRIDAY 17** October, a Neurological Information Day will be hosted in the same Hotel as the main conference.

Titled 'Neurorehabilitation in Progressive Neurological Conditions', the conference is open to all health professionals who wish to learn more about the topic.

Speakers include Dr Belinda Weller, Consultant Neurologist, Western General Hospital, Edinburgh, and Professor Kurt L Johnson, Department of Rehabilitative Medicine, University of Washington.

A variety of presentations and workshops will cover many areas such as treatments for people with progressive neurological conditions, cognitive dysfunction, rehabilitation from a nursing perspective and meeting the demands of the multidisciplinary team.

To learn more about the Health Professionals Day, or to book a space, call the Western Regional Office on 091 862478 or visit [www.ms-society.ie](http://www.ms-society.ie).