

# UPDATE

THE MULTIPLE SCLEROSIS SOCIETY OF IRELAND SOUTH EAST REGION

## The Aim of The MS Society of Ireland's Regional Project is

That people with MS live their life to the full.

## The Operating Process is

to provide opportunities for people with MS to explore their experience, to make choices in relation to aspects of their lives, to encourage independence, to discover options, make choices and participate in the realisation of these choices

Pictured here at the 50th Birthday celebration & seminar in the Brandon House Hotel on 19th April is Nicola Wall, Regional Community Worker & Ned Burke, Carlow Branch

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The Multiple Sclerosis Society of Ireland, South East Project, Walkin Street, Kilkenny

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**Editorial:** Hello, I hope this finds you well and happy and enjoying the summer season. You will notice we have changed the name to reflect our focus. The purpose of this report is to Update you the reader, service providers, service users and donors of outcomes of work to date, current work in progress and our regional plans in the pipeline.

For instance some changes have take place in our project since our last edition:

- Denis Twomey, Regional Community Worker (RCW) has commenced working with us and is taking a lead in working with people with MS in Carlow/Kilkenny Community Care area. Denis is based in Kilkenny. He works part-time - Tuesdays, Wednesdays and half day Thursday. You will find his contact details at the back of this **Update**.
- Ann Cahalane and Nicola Wall have relocated to Waterford and Wexford Community Care areas respectively. Contact details are at the back of **Update**.
- Both data collectors Paddy and Tiina have moved on to pastures new. We wish them well and thank them for their support and help during their time with us. Their successors, in taking on the data collection/data inputting work, are Paula Dowd and Sharon Kerwick. Their details are also at back of this **Update**.

This Update gives information on the MS Society's 50th Birthday celebration, neuro rehabilitation seminar and programmes we are involved in as part of our Service Plan over the next couple of months. Please feel free to pass this regional Community Work Services Update to others who may be interested.

**All the best.**

**Katie on behalf of MS Society of Ireland**

Speaker: Dr. Aine Carroll,  
Rehabilitation Consultant  
Brandon House Hotel, New Ross,  
Co. Wexford On 19th April 2011

## The MS Society of Irelands 50th Birthday Celebration & Regional Neuro rehabilitation Seminar

The keynote address at this commemorative event was given by Dr. Aine Carroll, Rehabilitation Consultant in the National Rehabilitation Hospital, Dun Laoghaire. Dr. Carroll pre-empted the National Neuro-rehabilitation Strategy due to be published in the coming weeks with 4 centres of excellence in around the country. In Ireland where pro rata service provision is well below international standards this Strategy announces a number of Comprehensive Clinical Care Programmes (CCCPs) due to be rolled out throughout the country. The aims of these programmes are to ensure people have access to acute services at a local level, ascertain quality in clinical care and deliver sustained services.

Dr. Carroll explained the thinking behind Neuro-rehabilitation Therapy (NRT) emphasizing that 'it is not about doing things to someone but with some.' The steering group, qualified in primary and secondary levels of care, is interdisciplinary rather than multidisciplinary in approach. To this effect this patient-centric team gives a voice to the patient all the while endeavouring to understand how best to work with and for the person served. Dr. Carroll pointed out that NRT and access to related services is understood as a basic human right the lack of which results in a serious form of discrimination. The CCCPs are about implementing comprehensive care plans which promote empowerment and enablement thus laying down the very basic criterion for providing the right services at the right time to the individual concerned. A partnership approach is envisaged, looking at the broad spectrum of neurological illnesses and tailoring services accordingly. One of the biggest criticisms in this area is the lack of psychological support in the form of counselling for patients and carers alike. Dr. Carroll foresees that the CCCPs will attempt to remedy such inadequacies. In the instance of MS Dr. Carroll explained that NRT will deal with issues such as 'how to manage fatigue,



moods and how to get the best out of the muscles that are working.' In compiling the Strategy a survey was carried out to examine the use of language and what terms people with disabilities are most comfortable with in referring to themselves and issues relating to their condition. It was found that the term 'patient' is acceptable to most while words such as 'impairment' and 'activity limitation' could replace more commonly used terms thereby bringing our language more inline with international usage.

The panel discussion which ensued was contributed to by professionals currently working in the area of MS service provision in the South East Region. Questions from the floor followed. Asked by an occupational therapist working with PwMS if new resources will be made available to facilitate the delivery of the new services Dr. Carroll replied that a process of reconfiguration is necessary in order to achieve a more 'joined up' approach to service provision. It has been found via a close analysis of existing service provision that certain

losses are incurred. Intervention to prevent such losses could allow for the reallocation of funding for the provision of new neuro-rehabilitative services. One major lack in service provision in Ireland is in the area of early supportive discharge services whereby any gains in rehabilitation to the person while in hospital are drastically lost due to the lack in follow-up care.

Enthusied by the content of the day one PwMS said 'it's the best seminar I have ever attended'

The MS Society would like to thank all those who helped organise the day, master of ceremonies, guest speakers, discussion panel, organisers of branch display stands, cakes, prizes and attended the discussions. Thank you for celebrating our 50th with us!

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Pictured above is Dr Aine Carroll, Rehabilitation Consultant with the National Rehabilitation Hospital Dublin.

## Physiotherapy & MS – A Personal Story

I am a person with MS, clinically diagnosed in 2004. Once the symptoms were highlighted it would appear that the effects were there since about 2000. At first when I was told my problem was identified as MS, I was shocked and disappointed, as I have known the effects of MS on the body. But my family rallied around me and promised to support me in every way possible and, very soon I was put in contact with the MS Society of Ireland. I had a visit from a Community Worker who briefed me on all the aspects of MS and all the activities that the Regional Project offers to people with MS. One of the services offered by the Regional Project is Physical Activity Programmes.

At present I am a member of a group attending sessions for physiotherapy in the Waterfront in Enniscorthy. We have an excellent physiotherapist, Aine Doyle, who is putting us through our exercises every week. I find the sessions very worthwhile and it has a big influence on muscle strength and balancing power. These are exercises which I would not be as committed to doing at home on my own as they are organised for a group. I feel more of a commitment to support a group arrangement. Aine is a very dedicated person to her work and is almost giving each member one to one attention. Sometimes MS can make me very emotional and sensitive towards work and interests that I had before being

affected by MS. By being a member of The MS Society of Ireland and meeting with other people who have MS can lift my willpower and approach life more positively. Michael Brennan

## Self Management & Skills for Life

We recently ran the Self Management & Skills for Life programme over five weeks in Waterford. Classes were for two hours each Tuesday morning at the HSE building on the Cork Road. Ten participants, along with Emma Gavin (Physiotherapist), Denis Twomey (Facilitator) and Ann Cahalane (The MS Society, course creator) explored the ways in which MS affects each person individually and the skills we can use to manage it more effectively. As always on training such as this, we began with a 'class programme' – an agenda for each day - the group however tends to take on a life of its own and a lot of the learning is from the other participants! None of us present will forget about the importance of Tiny Attainable Tickable Tasks!

On the course we explored:

- Getting to know your MS using tools such as a diary and goal setting. Knowledge is the key to empowerment!
- Problem solving in a structured way.

- The importance of exercise. Even tapping your feet while watching TV can be beneficial! Exercise brings enormous physical and psychological benefits.
- Looking after yourself by being organised and not attempting to accomplish too much at once.
- Using breathing and guided imagery as a means to relax.

The course was well received and enjoyed by all and we hope to roll it out across the region in the near future.

## Professional Advice & Information Programme

The MS Society of Ireland worked closely with the Health Service Executive to develop a Professional Advice and Information Programme specifically for people with MS in Co Wexford during February/March. The aim of these sessions was to give people with MS a focal point for appropriate information, advice and support in small groups. These sessions were facilitated by highly skilled staff from the Health Service Executive and other non government agencies. Topics explored included Food, Nutrition and Lifestyle Management, Understanding Cognition, Fatigue Management and Continence Advice. These information sessions are a great way of learning more about MS in a relaxed and comfortable environment.

## Physical Activity Programmes

Physical activity programmes happening around the South East are as follows:

County	Activity	Location
Carlow/Kilkenny		Being organised at present Contact Denis Twomey for more information
Tipperary South	Group Physiotherapy	Our Lady's Campus, Cashel
Waterford	Yoga	Alphazone Studio, Cleaboy, Waterford
Wexford	Yoga	Adult Learning Centre, Gorey
	Group Physiotherapy	The Waterfront Leisure Centre, Enniscorthy
	Group Physiotherapy	Wexford Town – contact local branch (Wexford South) for more details - 086 3008585

If you are interested in participating in a physical activity programme, please contact the Regional Office on 056 7777771



## Research News: The National Physical Sensory Disability Database

The National Physical & Sensory Disability Database is an established and proven means of collecting information in order to better plan for the needs of people with long term and chronic conditions. Much like the national census which was completed in April this year, the database is an accurate record of every person who has a chronic illness or disability, a list of the services they are now receiving and the services that person may need within the next five years. This being said, it is really a database of people's needs, not their disability.

Although the database includes a persons name, address and other personal information, when the HSE and the Department of Health draw on the database for planning purposes all they have access to are the numbers of people in each area, with each condition, the services they now receive and the services they may need in the next five years. The database is maintained by the Health Research Board entirely on computer in Dublin. It is a completely secure and safe storage of information, used only for healthcare planning purposes. Thus, the Revenue Commissioners has no access to the personal information on the database, nor does the Department of Social and Family Affairs. To safeguard your anonymity, the database may not record your PPS number as it is unique to you and could so easily identify you.

Instead a PIN number is assigned to each person to make it easier to manage the data. At any time you can ask to see the information that is being held about you. Data from the database is used to plan for present and future services. It assists healthcare providers in placing services where they are most needed and it assists organisations in lobbying for services where they are needed. Neuro-rehabilitation in the South East is an example of a service that the database assists us in lobbying for. The database points to a need and it is clear that that need is not being addressed locally.

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## So what is Community Work?

For those of us who have been working in the 'helping' professions for a long time, we would have come into it versed in what is called the medical model of helping. This model saw us 'professional' staff as 'experts' with a great deal of knowledge and expertise and using this we would 'fix' the clients who as people with an illness, disability or other problems couldn't help or fix themselves.

As well as being insulting to many people, it was also unhelpful and inefficient. Realistically, regardless of how much knowledge, expertise or experience we had, there was no way we could be experts in anyone else's life, and most of us were happy to acknowledge that. We also realised that this old model which saw people only as clients who needed help was denying that they also had a great deal of expertise and often had a good

sense of what was best for themselves. So we began to change.

As workers (community workers, therapists, social workers, and so on) we began to see 'clients' as the key person managing their own illness or disability. So instead of us as professionals telling them what they needed to do next, we would now help them to explore a range of options, and to choose what was best for them. We began to talk much more about advocating on others behalf, rather than speaking for them. The key idea here is that any illness or disability, regardless of how pervasive it is, is only a part of who you are as a person, and there is much more to all of us that any diagnosis that we may have. A disability cannot rob you of your identity – but other people are in danger of doing that if we only see you as deserving of pity, or as a recipient of a service, and nothing more.

The way we work as Community Workers here in The MS Society of Ireland reflects this thinking. This is why we run a 'Self Management & Skills for Life' course and it is also why we focus a lot on education and information giving. We can make better decisions and better advocate for ourselves if we have more accurate information. This thinking is also reflected in other aspects of our practice. For example we ask that as much as possible people contact us directly if they need a service – though if you want your Personal Assistant to do that on your behalf then that is your choice. We also adhere strictly to the principle that individual work with clients is confidential. In exactly the same way that your business with the bank or your GP is confidential, so also are your dealings with The MS Society of Ireland. If you want to share information about yourself then that is your right, but we cannot share information about you, unless we have your permission!

While the old way of working was well meaning, we know from research and from feedback from countless clients, that the way we work now is so much more beneficial. The old way of working tended to create a dependency on us, rather than enabling you. Ultimately dependency disables people. It characterises people as victims, rather than survivors. The way we work now is more respectful of the people we work with and we would hope that this comes across in how we interact with people on a day to day basis.

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Pictured above is Billy Powell who sang 'Happy Birthday' at The MS Society of Ireland's 50th Birthday Celebration on 19th April.

## Individual/ Family Community Work

The Community Work team offers a confidential case work service to people with MS and their family. This service provides an opportunity for people with MS to explore their experience, their options and make choices that encourage independence. This may involve professional information and advice, case work, advocacy work etc. The person with MS self refers by contacting the regional community worker (contacts at back of **Update**)

The community workers may refer the person to GP, PHN, Physical and Sensory Liaison Nurse, Physiotherapist, OT or relevant health professional in community Primary Care Teams and hospital health professionals.



Above: Mervyn Rothwell reflecting on the many events that the Kilkenny Branch was involved in over the years.

## Individual/Family Counselling

A time limited professional counselling service is available to provide opportunities for a person with MS to express emotions and feelings in a confidential/ safe environment. A counsellor can work with you to explore coping skills and solutions that work for you. Self referral is required. Referrals for counselling are made by the regional community worker (contacts at back of **Update**).

## Looking for Professional Advice/ Information?

The MS Information line – 1850 233 233 is a useful source of specialist information and professional advice on MS over the telephone on multiple sclerosis, symptom management, neuro rehabilitation, physical activity, fatigue, nutrition, mindfulness, stress management etc Open Monday to Friday, 10am to 2pm.

## Respite Care available

Do you feel you would benefit from respite care and therapy services? Respite Care is available free of charge at the MS Care Centre in Dublin to people with MS in Carlow, Kilkenny, Tipperary South and Waterford. These breaks are available due to a National Lottery grant received from the HSE.

The MS Care Centre provide short term respite care and therapy services for people with Multiple Sclerosis. Fully trained and experienced staff provide high quality personal and nursing care 24 hours a day. The centre has a holistic approach combining specialised services such as MS specialist nurse, physiotherapy, yoga, extend movement and occupational therapy. Social and therapeutic activities are also available e.g. art, in-house entertainment, massage, reflexology, chiropody, hairdressing, beautician.

If interested in availing of a respite Care please contact your Regional Community Worker (contacts at back of this **Update**).



Pictured above is Anne Nolan from the Wexford North Branch who attended the 50th Birthday celebration & seminar in New Ross.

## International Information on MS

The Multiple Sclerosis International Federation (MSIF) website [www.msif.org](http://www.msif.org) is a very useful and reputable resource for up to date specialist information on research, management of MS and new treatments in multiple sclerosis. You can download their latest 'MS in Focus' magazine or previous magazines on [www.msif.org](http://www.msif.org).

## Voluntary Branches New Committee Officers 2011 Update

If you wish to contact a voluntary branch eg. for social outings, fundraising, and informal support contact the branch committee secretaries:

- **CARLOW**  
Kieran Coughlan - 059 9151608

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- **KILKENNY**  
Josie Molloy - 086 814 1977

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- **DUNGARVAN/TIPPERARY SOUTH**  
Eleanor French – 058 46217

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- **WATERFORD**  
Eddie Sullivan – 051 877146

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- **WEXFORD NORTH**  
Clare Doyle - 053 9421024

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- **WEXFORD SOUTH**  
Tony Breen - 086 3008585

For information on volunteer activity you can keep informed by logging onto the website at [www.ms-society.ie](http://www.ms-society.ie) which provides up-to-date information on local activities and meetings.

## Date for your Diary

The MS Society of Ireland MS Living Convention will be held on 9th and 10th September 2011 in the Burlington Hotel, Dublin. Details will be posted on the website [www.ms-society.ie](http://www.ms-society.ie). International renowned speakers invited. Check the website for information nearer the date.

### Disclaimer

The views and opinions expressed here are those of individual contributors and may not reflect the views and policies of the MS Society of Ireland. Whilst every effort has been made to ensure the accuracy of the information provided, the editor is not responsible for any error or inaccuracy contained herein.



Physiotherapist Aine Doyle & OT Laura Hunt at the 50th Birthday celebration/seminar in New Ross.

## Keep in touch!

Keep in touch with the Regional Community Workers to find out about forthcoming programmes in your area, eg. PROFESSIONAL INFORMATION AND ADVICE WORKSHOPS, SELF MANAGEMENT PROGRAMMES/ SKILLS FOR LIFE, AND PHYSICAL ACTIVITY PROGRAMMES. Contact details below:

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Regional Community Worker  
The MS Society of Ireland  
c/o 75 St Catherines, John's Hill  
Grange, Waterford City  
Landline: 051- 844726  
Mobile: 087 249 8853  
Email: [annc@ms-society.ie](mailto:annc@ms-society.ie)  
Available:  
Tuesday, Wednesday, Thursday

Nicola Wall  
Regional Community Worker  
The MS Society of Ireland  
c/o St Bridgets Community Centre  
Roches Road  
Wexford Town  
Mobile: 087 9804205  
Email: [nicolaw@ms-society.ie](mailto:nicolaw@ms-society.ie)  
Available:  
Monday, Tuesday

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