

December 2008

East Coast Area News

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Hello and welcome to the Winter Edition of your newsletter from the East Coast Area. We have had a lot of changes here in the office over the past couple of months. Jennifer Reilly has taken leave for a year—she has a new arrival and will be spending time at home with her little son. Barbara Western has also had exciting baby news - her little boy was born in October and she will also be on leave until next September. Congratulations to both families!

Cathy O'Brien joined us in September and will be filling Jennifer's shoes as Community worker, and Geraldine Dunne, from our South Western Area, joined us in October to fill Barbara's position as Case worker, and also as the Regional Co-ordinator. A big welcome to both ladies. They have been fortunate to have met some of you already, and look forward to meeting and working with many more of you over the next while.

Please feel free to call us here at the office at any stage. Aoife Gallivan, our Resource Worker, is here from Mon-Fri 9:00 to 12:30. If Geraldine and Cathy are out working in the community in the afternoons, we will have our voicemail on in the office and someone will get back to you as soon as possible. As always, our helpline, MS Contact, is available on 1850 233 233 Monday to Friday from 10am to 5pm and on Tuesday and Thursday evenings from 6:30pm to 9:30pm.

We would love to hear from you with comments about any article you read in this Newsletter. Also don't forget to update us with news, events, etc, that might be of interest.

Finally, we would like to wish you all a Happy Christmas and a peaceful, healthy and prosperous New Year.

The ECA Team

Getting the Balance Right

We are nearing the end of the first round of the Getting the Balance Right project and are delighted with the response we have had. Approximately 55 people were linked to interventions between September and December. Second Assessments are taking place at the moment and are due to finish early in December, with the 3rd and final assessments commencing in January and due to finish up in February. We have also commenced working on the Getting the Balance Right programme for 2009, if we have not been in contact with you as yet, and you have registered with us, we will be in touch shortly.

If you would like to take part in the next round, and have not registered with us, please give us a call at the office, it's not too late!

Yoga for Everyone

The word yoga comes from the ancient Indian language of Sanskrit. In Sanskrit "yuj" means to join or unite. The ultimate aim of yoga is to unite the physical body, mind and spirit. Yoga has been practiced in India for thousands of years and is the oldest system of personal development in the world encompassing the entire body, mind and spirit.

Yoga is a way of life. It is not just an exercise program for stretching and increasing flexibility in your body. Regular yoga practice creates a healthier body, calms the mind and increases your sense of inner peace and well being. A typical Hatha yoga class includes breathing techniques, movement through all the major joints in the body, practice of a variety of yoga postures, meditation and relaxation. It is advisable to attend a specialist MS yoga class or to inform the instructor about your condition. Doing so enables you to fully participate in the class and reap the rewards of yoga practice.

There are many benefits to be gained from the practice of Hatha yoga. Regular yoga practice can be particularly invaluable to people with MS for a number of reasons. The focus on breath work and deep diaphragmatic breathing helps to increase lung capacity, improves circulation, helps reduce feelings of fatigue, aids in maintaining good respiratory health and preventing lung infections. The yoga postures (asanas) can help to combat fatigue, reduce spasticity, relieve stress, increase flexibility, strengthen the muscles and improve co-ordination and balance.

Regardless of whether there is a loss of energy, reduced range of motion, spasticity, weakness, imbalance or numbness in different parts of the body, yoga can serve to minimise involuntary muscle contraction, maximise range of flexibility, and improve strength, co-ordination and balance. Yoga effectively diminishes the impact of sensory changes by raising functional abilities to a higher level, improving overall concentration, calm and a sense of well being.

From practicing yoga regularly, you can learn how to manage your symptoms, raise your functional abilities to their highest level and foster independence and confidence.

Audrey Williams & Sandra Murphy

Alternative Therapies

Audrey is a fully qualified holistic therapist. She offers treatments in several alternative therapies; reflexology, holistic massage, aromatherapy, Indian head, sports and hot stone massage. She enjoys incorporating a varied approach to treat each client's individual needs. Audrey can be contacted at **086 8168441** for further details.

Getting the Balance Right Reviews

Yoga:

I have to admit to feeling a little disappointed when I heard I had been allocated to a Yoga group as part of the GTBR programme. Thinking how can I possibly do yoga from a wheelchair? How wrong I was!

There are 4 of us in the class and with the help of Sandra and Audrey (the teachers) we are being enabled to accomplish various movements all adapted for those sitting down. If it all seems too difficult when first demonstrated then help is always at hand. Emphasis is paced on breathing and the importance of controlling the breath whilst exercising. As the weeks have progressed movements which initially were just impossible are becoming less daunting and at times achievable!

Continued...

As a form of exercise yoga is gentle and pain free and has the advantage of waking up some muscles which we thought had gone to sleep for ever! If like me you are sceptical about what yoga can do for you, thinking it was for people with no mobility issues, you should give it a try!

One added advantage of the class is to get out and meet others with MS to chat, share ideas and thoughts - and that can't be bad.

Teresa Harty

Fitness:

The programme in Arklow got underway on 6th September with an assessment carried out by Chartered Physiotherapist, John Nwobo. There are four volunteers from this area, two from Arklow, one from Carnew and myself from Aghrim, all women. The programme will last about 10 weeks.

The activity sessions take place in the Leisure Centre at the Arklow Bay Hotel. We began on the 16th September, by being measured for strength, height, weight and BMI (Body Mass Index). Our trainers, Ronan Robinson and William, using these details and the assessment report, designed an exercise programme for each of us. As we all have different symptoms and disabilities we each have a different programme. I have to work on my legs, the left side in particular. We use a variety of machines, including the shoulder press, chest press, leg extension and curl machines, rowing machines and the bikes. I also do some aerobic exercises.

After a few weeks we were given another, harder programme, and on 6th November we were weighed again and given a further programme, very difficult and strenuous this time. We are expected to spend an hour working out on Tuesdays, and we are encouraged to do the same on Thursdays. We are also allowed to use the swimming pool, which three of us have done at least once a week.

I feel that I have benefited from these exercises. My weight and BMI have reduced. Although I feel exhausted when I get home, after food and a rest I feel more energetic than usual and my walking has improved.

There will be another assessment later on after our last session at the gym. I shall be very interested to learn the results of this exciting and stimulating programme.

Julia Hart

An Inspirational Journey

My name is Iwona, I am 28 years old originally from Poland. I've been living in Ireland for 3 years. I first got involved with MS Ireland when I joined a yoga class in Stillorgan Park Hotel with Audrey Williams. Barbara Western of the East Coast Area then inspired me to study yoga on a teacher training course (Many thanks to the Bray Branch who kindly gave me some financial assistance with the fees). Then my healing journey really began! For the first time I proved to myself that I could do something that I didn't think a PWMS could do. Now I am on my second year of teacher training and I feel like my whole life has changed. I discovered my true self and how much power we all have within us. Every morning at 6.17am I get up and meditate for half an hour, then I practice some yoga asanas for half an hour before I go to work. I have found meditation to have a very positive effect on my life. When I was in Poland I met Pope John Paul II and I vividly remember the white light which appeared to surround him, it was a bright sunny day. When I meditate I visualise this white light and I imagine him resting his hand on my head, sending me healing energy. Another reinforcement on my journey has been watching the DVD "The Secret" which I have found really inspirational. This teaches techniques in how to positively change your life. You can watch a clip of this on www.youtube.com. I am lucky to have some great friends who give me fantastic support – especially Ewa Borowiec – thank you! I also believe that each of us has an angel with us all the time – remembering this has given me so much strength and confidence, and I never feel lonely anymore, even on the not-so-wonderful days. I hope other PWMS will find some inspiration from my journey.



Pictured: Iwona Kaczor

Yoga Teacher

Jean McDonald is a yoga teacher who has worked with MS Ireland for the past few years at our Friday morning class in Shankill, Co. Dublin. If you would like to contact Jean her details are :
www.jeanmcdonald.ie, 01-2722317 / 086-3637314

Department of Social and Family Affairs

In recent years the Department has been making a particular effort to make its services as accessible as possible to all customers including those with disabilities. These services include:

- A fully accessible website (www.welfare.ie) that meets required standards
- An online request facility for forms and leaflets
- Information available in alternative formats such as large print, Braille and audio tape on request
- Sign Language Interpreter available on request
- A building and refurbishment programme
- Disability Consultative Forum providing stakeholder organisations with an opportunity to express their views and suggestions on services provided
- Disability awareness training for staff
- Supporting Advocacy services provided through Citizens Information Centres (CICs).

To enhance compliance with the requirements made of the Disability Act 2005, the department:

- developed its existing Comments and Complaints System to accommodate the recording of comments and complaints regarding access to our services.
- appointed 23 Access Officers on a nationwide basis, who, with other responsibilities have specific roles in the comment and complaint handling process including: overseeing/monitoring all complaints made under the Disability Act 2005 and ensuring that the necessary action is taken to address them.
- appointed an Inquiry Officer who will investigate and report on the complaint where the complaint has not been resolved to the customer's satisfaction.
- initiated a review of the comment and complaints process itself to ensure that all customers including people with disabilities are provided with every support in making their comment or complaint.
- issued circulars reminding staff of the various facilities available to make services more accessible, for example, internet site, loop system, minicom, or formats such as Braille, large print or sign language.

How to Complain?

A customer with a disability or a person on their behalf can make a complaint by any of the following methods:

log on to www.welfare.ie to download a comment and complaint form.

telephone or call in to the Social Welfare Local Office

write to Customer Services, Social Welfare Services, College Road, Sligo.

email QCS@welfare.ie

The Department's staff will try to resolve all complaints as soon as possible. If the customer is unhappy with the response, the complaint can be reviewed by the local office manager/supervisor.

Our Information Service phone number is LoCall 1890 66 22 44.

Note that the rates charged for the use of 1890 (LoCall) numbers may vary among different service providers.

Finding a Lifeline and a Friend

DALLAS — In 2000, after 31 years of robust health, James Chippendale, a wealthy Dallas business executive who had travelled much of the world, was found to be suffering from a lethal form of leukaemia. Mr. Chippendale's doctors told him that his only chance of survival was a bone marrow transplant, and that the likelihood of finding a matching donor seemed bleak. "I was a hard match," Mr. Chippendale said, "and there was nothing for me in the United States. So we had to go on the international registry."

More than 5,000 miles and a world away, Klaus Kaiser, who repairs bicycles in the German village where he was born, had unsuccessfully tried to be a marrow donor for a friend with a blood disorder. Each year Mr. Kaiser received a form asking if he wanted to continue being listed on the donor registry, and each year he checked the box marked "yes."

On paper, Mr. Kaiser's marrow seemed a perfect match for Mr. Chippendale. In November 2000, doctors extracted marrow from Mr. Kaiser's hip bone, packed it in 10 pounds of dry ice and flew it 5,214 miles to Dallas, where Mr. Chippendale and his medical team waited anxiously at Baylor University Medical Centre

They need not have worried. The bone marrow transplant was a success, and today, Mr. Chippendale said, his doctors tell him he is cancer free. Two years after the transplant, Mr. Kaiser received a telephone call from the donor organization that had found him. "They asked if I wanted to get to know the person who received my bone marrow," he said. "It made me so happy, because I knew then that it had helped. I didn't know before."

A short time later, a letter appeared in Mr. Kaiser's mailbox in Gutter, a town of 150 people west of Berlin. Mr. Kaiser did not speak or read English; he did not have to. Mr. Chippendale had had a friend translate into German the words he had written to the man who had saved his life. He sent the letter to the tiled-roof cottage where Mr. Kaiser grew up and where he lives with his wife, Regina.

When the letter arrived, Mr. Kaiser said, "it felt like a close family member emerged from somewhere."

But Mr. Chippendale knew that a letter could not begin to express his gratitude. He enrolled in night classes to learn as much German as he could and bought a plane ticket. His arrival in Gutter in early 2003 was cause for a village-wide celebration, with songs and beer lifted high in steins.

"You would think we would be so different," Mr. Chippendale said, "but down to the core, we are not. Klaus would do anything for the ones he loves, and he has taught me to do the same."

On his first visit to Gutter, Mr. Chippendale brought presents, a laptop computer with translation software and a digital camera for swapping photos. He has returned three times — once to surprise Mr. Kaiser on his 50th birthday — and he sends e-mail messages twice a week to him and Regina and their children — Steffi, a dental technician, and Jens, a metalworker like his father.

On his most recent visit to Gutter, Mr. Chippendale took note of the house across the road from Mr. Kaiser's, a storybook stone bungalow left abandoned and overgrown. "I thought Klaus would like to have his first grandchild close," he said, "so my family bought it for them without their knowing."

Now, a village effort is under way to renovate the home. "Everybody is something," Mr. Chippendale marvels, "a carpenter, an electrician, a bricklayer."

Mr. Chippendale had some other ideas about what he wanted to do with Mr. Kaiser's gift of life. He wanted to climb. In 2007, he and a fellow cancer survivor, Mike Peters, a rock musician, thought they could raise money for hospitals that lacked the resources to provide modern cancer screening and treatment.

They started the Love Hope Strength Foundation, which puts on concerts in unexpected elevations worldwide: the Empire State building, the base camp of Mount Everest and, last month, at Machu Picchu in Peru. So far they have raised \$1.5 million.

Their settings are places Mr. Kaiser will probably never visit. He has never been on an airplane and seems content not to travel far from his home. But he certainly does not feel deprived.

"After the transplant," Mr. Kaiser said, "the physician thanked me for the donation in the name of mankind. I am very proud of James. He tries to give back to the world what he got from me. I am very happy that we have become such great friends."

Holidays in France

We have been notified of a property available in France. It is run by an English couple, who have been living there for 5 years and have spent that time renovating/converting an old cotton mill on the banks of the River Jaudy in La Roche Derrien.

They also offer equipment hire, adapted transport, support workers and more. The proprietors are on hand at all times to ensure that peoples needs are met as far as possible.

The Cotton Mill has been transformed into six light and airy apartments, all with level access showers, raised toilets, grab rails, etc . The garden itself is also accessible with large seating areas, bbq and children's play area too. With off road parking the owners state that it is an ideal location to explore the region.

There is more information on their website - www.ineedaholidaytoo.com which has photos of each apartment, the area, the equipment, measurements of apartments, doors, heights of beds, etc. All the important things that any traveller would want to know in advance!

Scooter for Sale

Shop Rider Mobility Scooter for Sale. 3 Years old. €800. Contact Corina Duyn - corinad@eircom.net

Primary Care Teams

The aim of the Primary Care team is to bring first class primary care to local communities by pooling talent and resources. Services will include GP's, HSE professionals, Community Nursing (Public Health Nurse and Community RGN) , Physiotherapists, Occupational Therapists, Social Worker and Home Support Services. A wider network of services will include Psychologists, Speech & Language Therapists, Mental Health, Dental & Environmental Health Services and Community Welfare Services.

Primary Care Teams at different stages of development in Wicklow are located in Arklow, Carnew, Shillelagh & Tinahely, Wicklow Town, Rathnew, Ashford stretching up to Roundwood, and Newtownmountkennedy / Kilcoole. The latter will be offering services from both Kilcoole Health Centre and Newtownmountkennedy Primary Care Centre when completed in 2009.

In Arklow, a service aimed at speeding up diagnosis from x-rays and ultrasound scans has been operating since February of this year. The Community Radiology Service is located in the newly extended primary care centre in Arklow. It is the first local x-ray and ultrasound service of it's kind in Ireland, servicing patients throughout South Wicklow and as far as Wicklow Town and it's environs.

There are also 30 Primary Care Teams in Dublin Mid- Leinster including locations in: Irishtown, Churchtown, Ballogan, Ranelagh, and Dundrum/ Milltown.

For more information on the above, please contact your local HSE Office:

HSE Dun Laoghaire: Tivoli Road, Dun Laoghaire 01 2843579

HSE Clonskeagh: Vergemount Hall, Clonskeagh 01-2680300

HSE Wicklow: Glenside Road, Wicklow Town 0404-68400

Living Well with MS Refresher Day

Refresher Day for 2006 /2007 Living Well With MS courses

On Saturday 4 October 2008, eight people gathered in a lovely room at the Respite Centre to experience a day filled with calmness and clarity, honesty, and warmth and friendliness. This was the Refresher Day for people who had taken a Living Well With MS course, two of which have been run by MS Ireland in the last two years. There were several aims to the day: to provide a reminder of Mindfulness, the main skill that people learnt on the course; to give people an opportunity to practice Mindfulness together, as a group; and last, but not least, to provide the opportunity for people on the courses to meet each other again and catch up.

So what is Mindfulness, and why does it help with MS? Mindfulness is learning to inhabit the present more fully, rather than harking back to the past or worrying about the future; it develops self-knowledge and self-acceptance; and it cultivates kindness towards ourselves (most of us are very hard on ourselves!), as well as towards others. All of these qualities are extremely useful in achieving, or enhancing, your quality of life while living with a long-term illness such as MS. Like anything of lasting value, learning and practising Mindfulness is not always easy, but the results are so beneficial to mental, emotional and physical well-being that it is well worth the time and effort.

Mindfulness is developed mainly through meditation. During the day, we did three meditation practices. The Body Scan helped us to relax physically and develop awareness of the body; Mindfulness of Breathing, where you focus on the breath, helped our minds to become calmer and quieter; and Kindly Awareness helped us develop more positive emotions and a more positive outlook on life. We also did some gentle movements from Qi Kung (a type of Tai Chi), led by my colleague, Aksobhin Tracy. Even though the day was generally quiet and calm, there was plenty of discussion about aspects of the course, not to mention plenty of chat at lunchtime over the slap-up meal provided by the Respite Centre! By the end of the day, we were all feeling calm and refreshed, ready to go back to our lives with renewed optimism and faith in ourselves.

Fidelma Farley, Mindfulness Trainer

Saturday 4th October a refresher course took place for some of us who had previously completed the 'Living well with MS'. As gale force autumnal winds lashed the care centre in Bushy Park Road we prepared for a 'Me' day. The six participants were welcomed by Aksobhin and Fidelma and we introduced, or in some cases re-introduced ourselves to the group. We briefly outlined what we hoped to get from the day and Aksobhin gave a synopsis of the refresher course. We started off with Fidelma leading us in the Body-scan which was a 20 minute led meditation. After this we had a short chat about difficulties that we experience with this exercise. Then it was time for coffee break....with really nice biscuits! Aksobhin then led us in Mindfulness of Breathing, a meditation again for about 20 minutes, during which we shut out the outside world and even when our minds wandered we brought them back with kindness to the task. Lunch followed and despite the restfulness of the morning I must admit I went for a snooze in the sunroom!

In the afternoon we went over the Three-Minute breathing space, a quick fix meditation! Then some gentle exercise followed by the Kindly Awareness Practice. The latter provoking some interesting discussion surrounding the choice of 'a person with whom you have a difficulty'. All was resolved with a bit of a laugh. What did we achieve by the end of the day? This method really does help, to quote Aksobhin...pain and illness are unpleasant sensations that we normally react to, causing a host of further problems and physical and emotional stress....but we can train ourselves to lessen and/or overcome this reactive cycle. We can learn to live in the present moment and breathe into our experience. We can learn to 'respond' rather than 'react' to our life's circumstances. This refresher course gave me the kick start I needed to make the practice part of my day...Thanks Aksobhin, Fidelma and my fellow participants for a lovely 'Me' day.....

Joan Sheridan– Participant

If you completed a Living Well With MS course with Aksobhin Tracy and Fidelma Farley, you may be interested in a Practice Day run by Fidelma. This is a day of quiet and stillness, practising mindfulness and meditation, and is a great opportunity to refresh your practice and meditate with each other and with other people. When? Saturday 13 December, 12 – 6pm.

Where? Dublin Buddhist Centre, James Joyce St (off Talbot St.), Dublin 1 (wheelchair accessible).

How much? €30 waged, €20 unwaged

For further information and to book, ring Fidelma at 087-6834717.

Contact us:

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www.ms-society.ie

Information Sessions East Cost Area

Commencing **January 20th - February 10th 2009** we will be running a series of "Information Sessions" in The Beacon Hotel, Sandyford. These sessions will include the following topics; Fatigue Management, Memory Aids, Emotional Support, Meditation, Diet & Nutrition & Exercise. Those who attend should find the presentations and discussions helpful and informative, and it is also an opportunity for you to share information with other participants. We will be sending out application forms in a couple of weeks time.

Festive Smiles

- *Why did the skeleton refuse to go to the party? Cos he had no body to go with!*
- *How does Jack Frost travel to work? By Icicle!*
- *Knock. Knock. Who's there? Hanna. Hanna who? Hanna partridge in a pear tree!*
- *What do you get when you cross a vampire and a snowman? Frostbite*

Calendar of Events January to April 2009

All events will be confirmed by post

January

- 20th** Information Sessions- Beacon Hotel Sandyford x 4 weeks Tues Eve for PwMS & Families/Carers
- 23rd** Yoga– Daytime Shankill x 8 weeks
Fri Morn, 11.00-12.30
- 26th** Yoga – Evening Stillorgan x 8 weeks
Mon Eve 7.30-09.00

February

Yoga Shankill continues
Yoga Stillorgan continues

March

- Newsletter
- 5th** Informal Coffee & Chat Carers
- 18th** Informal Coffee & Chat PwMS

April

- 3rd-5th** Spring Feast in the East (TBC)
- 22nd** Tai- Chi– Wed Evening Wicklow x 8 weeks

Wicklow County Tourism is launching its sparkling 2008 Christmas campaign, with an extensive festive section on our website www.visitwicklow.ie/xmas. Here you will find all the information you need about what is happening in the Garden County this season including Christmas parties, seasonal events, carol singing, festive markets, Santa visits, great accommodation packages etc. Come enjoy Wicklow this Christmas season. Wicklow County Tourism wishes you a Merry Christmas and a Happy New Year!



If you have any advice or information on MS and your own experience, and would like to share it with others through our next newsletter, please contact us at the office. We plan to send our Spring edition out in mid-March and would welcome any contribution before the end of February 09.

Disclaimer:

The views expressed here do not necessarily reflect the views and policies of MS Ireland. While every effort is made to ensure the accuracy of the information provided, the editor is not responsible for any error or inaccuracy that may occur.