

Community Work Service

UPDATE

Issue 51 - Autumn 2018

The aim of The MS Society of Ireland's Regional Project

is that people with MS live their lives to their fullest potential.

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.



Editorial

Hello and welcome to your Community Work Service newsletter 'Update'.

We aim to give you useful information on regional developments and schedules planned for the Autumn. Programmes include physical activity, research carried out on the needs of people with disability, information on the Clonea Mobile Home and details on the National Conference in Athlone.

If you feel like getting involved, please contact your Community Worker (details on back page) to discuss options.

Notify us if you wish to update your contact details (telephone, postal or email address) or if you wish to unsubscribe from correspondence. Happy Reading!

**Katie on behalf of The MS Society of Ireland
Community Work Service in South East**

General Data Protection Regulations

The General Data Protection Regulation (GDPR) came into force on 25th May 2018, replacing the existing data protection framework under the EU Data Protection Directive. The GDPR gives greater control to individuals over their personal data by setting out additional and more clearly defined rights for individuals whose personal data is collected and processed by organisations and businesses.



To comply with the new General Data Protection Regulations, The MS Society of Ireland needs your consent in order to continue to send you information, newsletters, text updates and emails. Therefore we should be grateful if you would complete, sign and return the Consent Form enclosed with this newsletter to us for our records. If you have already completed a Consent Form already you don't need to do it again.

Text Reminders/Updates

Every month a computer generated text reminder goes out to everyone on our Database regarding upcoming programmes. If you are already participating in a programme or if it is not of interest, you can ignore the text. If you wish to opt out of text updates/reminders, reply STOP.

If you have any queries or concerns please contact Katie Hourigan, Regional Co-ordinator, Tel: 056 7777771, email: katieh@ms-society.ie.



I. Research: Planning Service and Supports for people with disabilities

Health Research Board report and the importance of capturing key needs of people with MS so that service can be planned appropriately in their community.

Background

It is critical that agencies funded by the public purse provide services, going forward, which are based on real need and evidence based research. It is time to move away from allocating resources to those with a strong voice approach towards a more democratic method of *Evidence Based - Health Service Needs*. It is often said that the 'squeaky wheel gets the oil.' This real need and evidence based research approach would address needs regardless of postal code and inclusive of rural and urban communities.

What is NASS?

The National Ability Supports System (NASS) was established in 2018. It replaces two previous systems – the National Intellectual Disability Database (NIDD) and the National Physical and Sensory Disability Database (NPSDD).



It is a computer database that captures information on the service use and needs of people with disability. This information helps those who provide services to plan, develop and organise services and supports such as community and health services, county councils, voluntary organisations, sports partnerships, etc. Information is also used for policy and research.

Participation by people who need a service is important to help capture the true need for services, e.g. physiotherapy, occupational therapy, neurology service, respite, personal assistant, supports for daily living, difficulties faced because of disability, getting dressed, joining in community activities, etc. It also helps to identify gaps in service provision by looking at unmet need. Having accurate information helps agencies to review, plan, develop, organise and source money for essential services. It is a useful measuring tool that is standardised, consistent and provides comparative data across all disabilities available on an ongoing basis. If your needs are not captured or you haven't informed your service provider of your need, how will the planners know that there is an identified need?

Your needs identified / reflected

The most recent HRB report (2017) shows people with neurological conditions as being one of the largest groups in need of service and supports. In particular, people require supports to help them live well in their community such as PA, home help and respite.

- The most frequently reported type of disability on the NPSDD was neurological (39%).
- More than half the people registered on the NPSDD (60.0%) had a primary carer. The majority of primary carers were aged between 19 and 49 years (69.9%) and 2.7% were aged over 70 years.

Current service use

- 88% received one or more therapeutic intervention and rehabilitation services. The most-frequently used services are physiotherapy, followed by community resource work and occupational therapy.
- 68% used at least one piece of assistive technology. The most frequently used aids were special furniture and other aids to personal care, followed by aids to mobility.
- 58% received one or more day services or activities. The most frequently used services are mainstream schools followed by open employment.
- 27% received one or more personal assistance and support services. The most-frequently used services are peer support, home help and personal assistant.

- 8% availed of one or more planned respite services and 1% used emergency respite services in the twelve-month period prior to their NPSDD interview. Holiday respite placements and planned residential respite were the most-frequently used services.
- 3% availed of residential services. The most frequently used services are nursing homes followed by independent units in a dedicated complex.

Future need

Future need for services is recorded as unmet need (those who require assessment, those who were assessed and are on a waiting list or those who are unable to avail of a service) and enhanced/alternative service (those who need more of that service or who need an assessment).



People's needs include:

- 30% required one or more therapeutic intervention and rehabilitation services. The most commonly required services are physiotherapy, followed by occupational therapy.
- 11% required at least one piece of assistive technology. The most frequently required aids were aids to hearing followed by special furniture and other aids to personal care.
- 9% required one or more day service or activity. The most commonly required services are mainstream primary and secondary schools.
- 6% required one or more personal assistance and support services. The most-commonly required services are home help and sign language interpreter.
- 3% required one or more planned respite service. Planned residential respite with high support and holiday respite placements were the most frequently reported required respite services.

Summary

Data is a key resource for planning future services and evaluating service use. The HRB system is the only national database on disabilities in Ireland. Its data is used to inform decisions such as budget allocations and policy considerations. Therefore it is essential that everyone who is eligible for inclusion on the NASS database is encouraged to participate so that their needs are reflected.

Understanding people's needs

The aim of the report is to capture information on the needs of people with disability needs using evidence based research. The results inform us how we can intervene and act to address the needs. Agencies can plan interventions 'to support and maintain people to live at home in their own community and to promote independence and lifestyle choice as far as possible' (purpose of social care). Therefore it makes sense that the report findings must be used by planners, managers and policy makers to realign finite resources to evidence based needs, e.g. neurological disability service. The better we know the needs of people with disability the better we can plan intervention to support people live well in their community.

More information

For more information you can contact the disability office in your local HSE area (or you can contact your Community Worker). If you wish to access the reports, check out the HRB website: <http://www.hrb.ie/publications/publication/annual-report-of-the-national-physical-and-sensory-disability-database-2017/>

2. Specialist Information on MS

The Multiple Sclerosis International Federation (MSIF) website is a reputable resource for up-to-date specialist information on MS research, management of MS & new treatments in MS. You can download the latest 'MS in Focus' or previous magazines on www.msif.org.

Also the MS Trust UK website holds very good information on MS - www.mstrust.org.uk

MS Information Line Lo-call 1850 233 233 – Monday to Friday, 10am to 2pm

The MS Society of Ireland Information Line is a useful source of specialist information and professional advice on MS, symptom management, neurorehabilitation, physical activity, fatigue, mindfulness, etc.

Books / Information Sheets on MS

The MS Society of Ireland website has information on MS and symptom management. Some books/information sheets can be downloaded via the MS Society website –

<http://www.ms-society.ie/pages/living-with-ms/information-centre/our-publications>

MS Research eZine

The bi-annual Research e-Zine sharing updates from scientific and social MS research from Ireland and internationally is available on our website www.ms-society.ie.

South East Directory of Services

People can access The *South East Directory of Services* via www.ms-society.ie The Directory of Services acts as a signpost to guide people to useful services and has contact details of numerous statutory, community & voluntary services in the South East.

Public Information

For up to date information, advice or advocacy and also information on public services, allowances and benefits, check out Citizens Information website www.citizensinformation.ie, phone 0761 07 4000 or visit your local citizens information centre.

3. Individual Case Work

Community Workers offer 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, advocacy work, etc. The Community Worker may refer the person to a GP, PHN, Physical and Sensory Liaison Nurse, Physiotherapist, OT or relevant health professional. If you have queries on living with MS and wish to contact your Community Worker, contact details are at back of this *Update Newsletter*.

National Counselling Service by the Health Service Executive

The Health Service Executive counselling service provides a professional counselling service to people with medical cards. Referral is via your GP or a member of the Primary Care Team, e.g. Public Health Nurse, Physiotherapist or Occupational Therapist.

4. Physical Activity Programme

If you are already involved in physical activity in your everyday life such as gardening, walking for leisure, or swimming for good health continue these activities as they help you to stay active and enjoy the benefits of a healthier lifestyle. Participating in exercise increases mobility and combats fatigue, improves physical, mental health and cognitive abilities.

If you are interested in incorporating new physical activity in your everyday life contact the Sports Partnerships, Sports Clubs or Community Centres in your county. The important thing is to be active.



Pictured above. Some of the Wexford South group celebrating International Day of Yoga

Physical Activity Programme (cont'd)

If you have specific queries or need specific advice ask your GP to refer you to the Health Service Executive Chartered Physiotherapist. You are entitled to be assessed by a physiotherapist who may set an individualized home based programme for you.

Below are details of the Physiotherapist led Exercise classes and Yoga classes organised by The MS Society of Ireland. We hope you might consider taking part.

If you have any queries regarding participating in any of the classes contact your Community Worker.

Autumn 2018 Schedules

Carlow / Kilkenny

Programme	Physiotherapist led exercise classes	Physiotherapist led Exercise classes	Yoga Classes
Delivered by	Nicola Connolly, Physiotherapist	Grainne Gallagher, Physiotherapist	Mary Ellen Brennan, Yoga Instructor
Venue	Sacred Heart Hospital, Carlow	SOS, Callan Road, Kilkenny	St Mary's Day Care Centre, Kilkenny
Start Date	Saturdays, 1 Sept to 20 October and 3 Nov to 15 December	Saturdays, 1 Sept to 20 Oct (exc. 22 & 29 Sept); 3 Nov to 15 Dec	Tuesday, 4 Sept to 23 October; 6 Nov to 11 December
Time	11am to 12.00pm	11am to 1pm	12 to 1pm
Cost	€40 for 8 weeks €30 for 6 weeks	€30 for 6 weeks €35 for 7 weeks	€40 for 8 weeks €30 for 6 weeks
Part funded by	Carlow Branch KRSP Grant/Age & Opportunity Grant	Kilkenny Branch KRSP Grant/Age & Opportunity Grant	Kilkenny Branch
Referral/information	Una Goan, Community Worker, 053 9180091 / 087 7375298	Katie Hourigan, Regional Co-ordinator 056 7777771 / 087 2663564	Katie Hourigan, Regional Co-ordinator, 056 7777771 / 087 2663564
Payment	Post to MS Society of Ireland, Walkin Street, Kilkenny R95 NXK5		
Acknowledgement	We would like to acknowledge grants from Kilkenny Local Community Development Committee towards the purchase of physio equipment, promotional flyers and computer		

Tipperary South

Programme	Yoga classes	Physiotherapist led exercise classes
Delivered by	Brigid Power, Yoga Instructor	Clare Kelly, HSE Physiotherapist
Venue	St Joseph's Ferryhouse, Clonmel	Our Lady's Campus, Cashel
Start Date	Monday, 3 Sept to 22 October 5 November to 10 December	Varies according to physiotherapist schedule
Time	11am to 12.30pm	Varies
Cost	€40 per 8 week block	Free
Part Funded by	Lottery Grant	Health Service Executive
Referral/information	Katie Hourigan, Regional Co-ordinator, 056 7777771 / 087 2663564	PwMS who are <u>not</u> known to Clare that wish to attend will require a GP referral and to be screened by Clare prior to commencing the class. Any queries contact Katie Hourigan
Payment	MS Society of Ireland, Walkin Street, Kilkenny R95 NXK5, 056 7777771	

Waterford

Programme	Physiotherapist led Exercise Classes
Delivered by	Yoga Classes
Venue	Carrickphierish Library, Gracedieu, Waterford
Start date	Tuesday, 4 th September 2018
Time	11.30am to 12.30pm
Cost	€30 for each 6 week block
Part funded by	Waterford Branch & participants contributions
Referral/information	Una Goan, Community Worker, 087 7375298, 053 9180091
Payment	Payable to Physical Activity Link Person on first day of class

Wexford

Programme	Yoga classes	Physiotherapist led exercise classes
Delivered by	Barbara Rocks, Yoga Instructor	Aine Doyle, Physiotherapist
Venue	Gorey Adult Learning Centre	Astro Active Centre, Enniscorthy
Start date	Monday, 3 Sept to 22 October 5 November to 10 December	Wednesdays ongoing
Time	11am to 12pm	10am to 11am
Cost	€40 for 8 weeks, €30 for 6 weeks	
Sponsored by	ETB Wexford Grant	
Referral/information	Una Goan, Community Worker, 053 9180091, 087 7375298	
Payment	MS Society of Ireland, Walkin Street, Kilkenny, R95 NXK5, 056 7777771	

Programme	Yoga classes	Physiotherapist led exercise classes	Physiotherapist led exercise classes
Delivered by	Helen Dunlea, Yoga Instructor	Mairead McDaid, Marie Codd & Tricia Murphy, Physiotherapists	Marie Codd, Physiotherapist
Venue	Davitt House, Wygram Nursing Home, Davitt Road, Wexford	Murrintown Community Hall, Wexford Town	St Louis Day Care Centre, Ramsgrange, New Ross
Start date	Thursdays ongoing	Tuesdays ongoing	Fridays ongoing
Time	10am to 11.15am	10am and 12pm	11am to 12pm
Cost	Contact Wexford South Branch for details of cost		
Sponsored by	Wexford South Branch		
Referral /info.	Una Goan, Community Worker, 053 9180091 / 087 7375298		
Payment	Payment to Wexford South Branch		

Note regarding classes:

- Payment to be made on the first class of a new block of classes to a designated MS Ireland representative. If sending a cheque please make it payable to The MS Society of Ireland and post to: The MS Society of Ireland, Walkin Street, Kilkenny. Do not post cash.
- Wear loose comfortable clothing and bring your own mat, a towel/blanket and water.
- Remember to allow sufficient time for parking and arrive at the class on time so that class can begin promptly with no disturbances. If you are going to be unavoidably late please advise the physiotherapist/yoga instructor in advance.
- For security reasons only class members and staff of the centre have access to the venue during class.
- Once class is over, please leave the building promptly so the premises can be locked up.
- If you have any queries regarding classes contact your Community Worker.

5. In-service for Health Professionals & Service Providers – Fri, 21 Sept 2018

An Information Day for **Health Professionals** will take place at the Radisson Blu Hotel Athlone on Friday, 21 September with the following speakers;

- Dr Jens Bansi, Exercise Scientist; PhD. Valens, Switzerland – *Neurorehabilitation & Exercise*
- Dr Sabina Brennan, Trinity Brain Health & ADAPT, TCD – *Brain Health Matters*
- UL Physiotherapy MS Research Team – *Current Research & Outcomes*
- Edina O'Driscoll, Programme Manager, Rehabilitation Medicine– *Neurorehabilitation in Ireland*
- Irish Hospice Foundation – *Planning for the future with neurological conditions*
- Gavin Giovanonni, Professor of Neurology– *MS Treatment, Management in improving quality of life.*

Five CPD points available on request. The cost is €60 which includes lunch.

To book and for more information on venue/accommodation etc, contact The MS Society of Ireland on 091 768630, or email western@ms-society.ie, website: <http://www.ms-society.ie/pages/what-we-do/national-conferences>

6. National Conference for People with MS/families – Sat,22 Sept 2018

Living Well with MS Conference for **People with MS/ Families** is a well worthwhile conference for people with MS, families and Branches to attend.

Speakers Include:

- Gavin Giovanonni, Professor of Neurology, *MS Treatment, Management in improving quality of life*
- Dr. Jens Bansi, Exercise Scientist; PhD., Switzerland. *Neurorehabilitation & Exercise*
- Dr. Sabina Brennan, Trinity - *Brain Health and ADAPT, TCD. Brain Health Matters*
- Irish Hospice Foundation - *Planning for the future with neurological conditions*
- Genomics Ireland, Dr. Kate O'Brien identifying specific *patterns in genes* in people with MS so as to develop new diagnosis tools, treatments, and better our understanding of disease progression.

Date	Saturday, 22 September 2018 – 9am to 3.30pm
Venue	Radisson Blu Hotel, Athlone
Cost	€20 (includes refreshments and light lunch)
To book	Contact The MS Society of Ireland on 091 768630, or email western@ms-society.ie
More info.	http://www.ms-society.ie/pages/what-we-do/2018-national-conference

7. Voluntary Branches

Regional Integrated Meeting

Programme	Regional Integrated Meeting DATE FOR DIARY
Delivered by	Voluntary Branch Committee and Regional Community Work Team
For	Branch Committee
Venue	Hotel Kilkenny, College Road, Kilkenny
Date	Wednesday, 10 th October 2018
Time	10am to 2pm followed by lunch (included)
Referral / booking	Katie/Una The MS Society of Ireland, Regional Office, 056 7777771
Sponsored by	The MS Society of Ireland
Cost	Free of charge

The purpose of the Regional *Integrated Meeting* (RIM) is that both voluntary Branch committees and the Regional Community Work team plan and review South East service collectively.

Working collaboratively is important so that people get a joined up service.

It is helpful if as many participants attend RIMs as possible so that each Branch is actively involved in the planning process. RIMs are a wonderful space for committees with common interest to network, share ideas, expertise and learn from each other.

Please phone 056 7777771 to confirm your attendance. Hope to see you there!

Mobile Home at Clonea Strand

The MS Society of Ireland has an accessible mobile home at Clonea Strand, Dungarvan, Co Waterford available to rent for the months of June to September. The mobile home is very spacious and sleeps 6. The mobile home is booked out for 2018, however bookings can be made for 2019.

For more information and details of cost, please contact:
The MS Society of Ireland,
South East Regional Office
Tel: 056 7777771
Email southeast@ms-society.ie.



Voluntary Branch Contacts

Carlow Branch Catherine McDermott - 085 7249193	Kilkenny Branch Valerie O'Shea - 086 8494983	Tipperary South Branch Lorraine Fahey – 086 3181220
Dungarvan Branch Branch dormant	Waterford Branch Catherine Quinlan - 087 7804756	Wexford South Branch John Butler - 089 2114861

Voluntary branch committees generally meet once a month in a local community centre or parish hall from February to June and September to December. Contact your local Branch for more information.

8. Community Work Service email, post and phone contacts

Keep in touch with your local MS Ireland Regional Community Worker (RCW) to find out about services and programmes in your area:

Carlow/Kilkenny

* Una /Katie
The MS Society of Ireland
Walkin Street
Kilkenny R95 NXK5

* Una Goan – Carlow
* Katie Hourigan – Kilkenny

Tipperary South

Katie Hourigan RCW &
Regional Coordinator
The MS Society of Ireland
Walkin Street,
Kilkenny R95 NXK5
Monday to Friday
Tel: 056 7777771
Mobile: 087 2663564
Email: katieh@ms-society.ie

Waterford

* Una / Katie
The MS Society of Ireland
Waterford
Tues, Wed, & half day Thurs
*Katie – case work
*Una – physical activity
programme

Wexford

Una Goan RCW
The MS Society of Ireland
Block A 1st Floor Wexford
Local Development Offices
Spawell Rd, Wexford
Tues, Wed, & half day Thurs
Tel: 053 9180091
Mobile: 087 7375298
Email: unag@ms-society.ie

The MS Society of Ireland, South East Region, Walkin Street, Kilkenny, Landline: 056 7777771, Information Line: 1850 233233, Email: southeast@ms-society.ie, Website: www.ms-society.ie, Charity No. 5365

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