



Employment and Multiple Sclerosis

A guide to vocational
exploration for Occupational Therapists



MS Information Line



The MS Information Line is there to provide professional and confidential support when it's needed. You are not alone - please get in touch if you need to talk about your MS.

CONTACT

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Why call the MS Information Line?

- Are you newly diagnosed with MS and feeling worried, frightened or simply looking for more information?
- Have you been living with MS for some time and are experiencing difficulty with aspects of it?
- Does a member of your family, a colleague, a neighbour or a friend have MS and you would like some support or information?
- Would you just like a friendly listening ear?

What can we do?

- We provide information on a wide range of topics related to MS including potential treatment options, symptom management and the different ways that MS can affect people's lives
- We help people source information about benefits and entitlements, statutory services, employment issues, insurance and many other areas
- We provide general and up-to-date information about MS to health professionals and students
- We make referrals to our nationwide team of Regional Community Workers and voluntary Branch network

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As our most popular community network this is where we post the latest news, ask our Tuesday Question which always gets people talking and encourage our supporters to share their achievements.

Twitter: [@MSIreland](https://twitter.com/MSIreland)



Sharing breaking news with our ever-growing number of MSers, talking to and sharing updates from our friends and colleagues in the international MS community.

YouTube: [MS Society of Ireland](https://www.youtube.com/MSocietyofIreland)



This is where you can watch over 70 videos ranging from conference presentations from leading international health professionals to living with MS personal stories and fundraising campaign clips.

Can't seem to find us? Don't worry! Simply open up a new web browser and either

1. Go to www.ms-society.ie and click the Facebook, Twitter and YouTube icons or
2. Go to www.google.ie and type in 'Multiple Sclerosis Ireland' followed by either 'Facebook', 'Twitter' or 'YouTube' and we will appear as the first search result. Click and you're there!

Acknowledgments

Handbook Authors

This handbook has been adapted from 'Vocational Rehabilitation for Clients With Chronic Pain and Musculoskeletal Disorders in Ireland – a Handbook for Occupational Therapists', with kind permission from the publishers, the Association of Occupational Therapists of Ireland and the original handbook authors.

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Worksheets 2 and 3 have been adapted from the MS Society UK's Work Toolkit, with kind permission.

Report template on page 15 was developed by the National Rehabilitation Hospital and was adapted for the purpose of this resource with kind permission.

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Funding

Development of this resource was supported by unrestricted grants from Merck Serono Ireland and Novartis Ireland. The concept, design and development of the resource are independent of Merck Serono and Novartis. MS Ireland retained editorial control of this resource.

Disclaimer

This manual is designed for use by qualified, CORU-registered occupational therapists who work with people with multiple sclerosis. The manual can be used to guide vocational exploration services for people with multiple sclerosis, however it is not a substitute for the clinical reasoning of a qualified OT. All information in this handbook is correct as of September 2018. Information in the handbook is liable to change and the identified sources should be referred to check the accuracy of information.

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Section 1 - Introduction and background

Approximately 9,000 people in Ireland live with multiple sclerosis (MS). MS is the most common disabling disease of the central nervous system in younger adults, with most people being diagnosed between the ages of 20 and 40 (MS Ireland, 2015).

There are several different types of MS. The most common form is relapsing remitting MS (RRMS) which affects approximately 80-85% of all people with MS. With RRMS, new symptoms appear or existing symptoms suddenly worsen. A relapse may last for a matter of hours or for months, and they vary in severity. Sometimes people require hospital treatment as a result of a relapse. Recovery from a relapse may be complete or partial.

Around 85% of those initially diagnosed with RRMS may develop secondary progressive MS (SPMS), when the person's condition starts to steadily worsen and disability starts to build up over time. A small percentage of people with MS are diagnosed with primary progressive MS (PPMS) in which the condition gradually worsens from the outset without relapses.

Whatever type of MS a person has, it is a highly variable and unpredictable condition. Symptoms vary from person to person and can vary from day to day for each individual. Common symptoms include fatigue, visual problems, mobility difficulties, tremors, memory problems and depression.

A person's condition would generally be considered stable if they are not experiencing relapses, their disability is not progressing, and MRI scans do not show the presence of new lesions. However, even in a stable condition the person may experience problematic and variable symptoms.

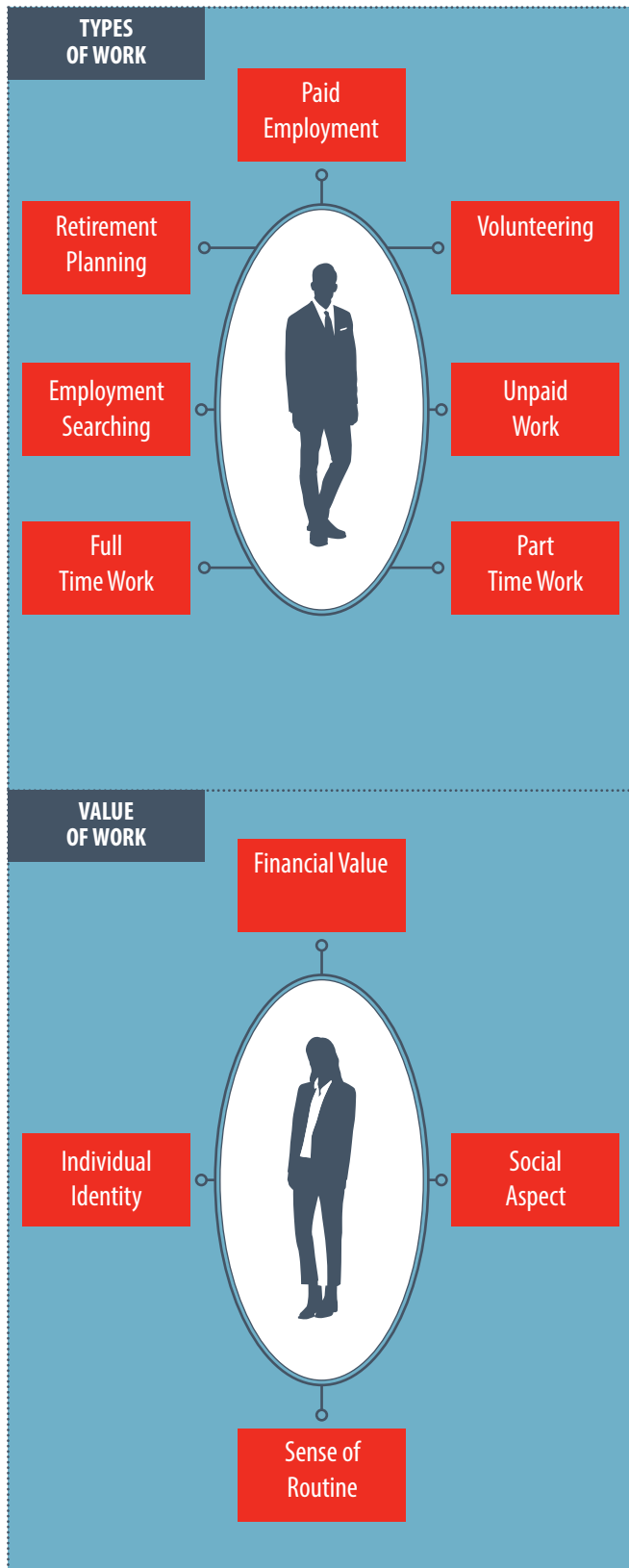
There is currently no cure for MS, but a range of treatments called disease modifying therapies (DMTs) exist for relapsing remitting MS which can reduce the number of relapses and slow down the progression of the disease. Treatment options for progressive forms of MS are currently much more limited, but there have been some very promising agents developed more recently. A number of treatments also exist to manage some of the symptoms of MS, such as mobility problems, fatigue, spasticity and pain. Oral or intravenous steroid treatment can reduce the duration and severity of relapses, but they do not have an effect on the degree of recovery from the relapse or the long-term progression of the condition.

It is estimated that approximately nine out of ten people with MS are of working age and that productivity losses associated with MS cost Irish society approximately €135.5 million per year (MS Ireland, 2016).

There is no formal structure in place to help people with MS maintain their work role and it is very important that questions around work and employability are addressed soon after diagnosis, in both acute and rehabilitation settings. This handbook was developed by the Multiple Sclerosis Society of Ireland (MS Ireland) as part of ongoing efforts to improve services and assist people with MS gain new employment or maintain their current work role. The handbook was developed in consultation with a group of occupational therapists with a specialist interest in MS. The purpose of this handbook is to support and guide occupational therapists who are working with people with MS to explore their vocational needs. We hope you find it useful.

Work – An occupational perspective

Strong evidence exists that good work is good for health and well-being.



Work is not just paid employment but includes employment interests and pursuits, employment seeking and acquisition, job performance, retirement preparation and adjustment, volunteer exploration and volunteer participation (American Occupational Therapy Association, 2008).

Work is a means of obtaining adequate economic resources (which are essential for material well-being and full participation in society), meeting important psychosocial needs, and is central to individual identity, social roles and social status (Waddell & Burton, 2006).

There is strong evidence that unemployment is generally harmful to physical and mental health and strong evidence that work is associated with indices of well-being and health (Waddell & Burton, 2006; Clark, Georgellis, Lucas & Diener, 2004; Winkelmann & Winkelmann, 1998).

Work has been shown to be positively associated with quality of life for people with MS, at every stage of the disease from mild to severe (MS Ireland, 2017a). The characteristics of a positive work experience include:

1. Employment security
2. Work that is not characterised by monotony and repetition
3. Autonomy, control and task discretion
4. A balance between the efforts workers make and the rewards they receive
5. Whether workers have the skills needed to cope with periods of intense pressure
6. Observance of the basic principles of procedural justice
7. Strong workplace relationships

(Coats and Lehki, 2008, p.6)

Multiple sclerosis and work capacity

Nine out of ten people with MS in Ireland are of working age (MS Ireland, 2016). Many studies have documented the impact of MS on employment across Europe, with high levels of withdrawal from the workforce commonly reported (Kobelt et al., 2006; Karampampa et al., 2012; Taylor et al., 2007). Data from Ireland suggests that less people with MS are working than the EU average – 43% in Ireland compared to an EU average of 60%. There are no known disease demographic differences between Ireland and the rest of the EU that would account for these differences, suggesting that there are attitudinal and systemic problems in Ireland that create barriers to people with MS remaining in the workforce (MS Ireland, 2016).

Productivity losses due to MS in Ireland are estimated to be €135.5 million annually. These losses comprise of retirement due to MS (61%), presenteeism (18%), reduced working weeks (12%) and extra hours missed per week (9%). In terms of the personal impact of MS on working life, 68.5% of people with MS in Ireland felt the disease had limited their career potential, 33.5% had reduced their working hours and 26.1% had had to change their career (MS Ireland, 2016). Furthermore as MS is usually diagnosed between the ages of 20 and 40, most people will have considerable financial commitments such as rent, mortgage and families at the time of diagnosis. MS Ireland's My MS My Needs study (2017b) found that nearly 30% of people with MS were struggling on their current income.

As might be expected, there is a significant relationship between disease severity and employment status, with those with mild MS being more than twice as likely to be in employment than those with moderate MS, with a similar relationship existing when comparing those with moderate and severe MS, with employment rates of 26% and 15% respectively (MS Ireland, 2016).

The Multiple Sclerosis International Federation (MSIF) produced a Global MS Employment Report (2016) which identified key factors that both helped people with MS to stay in employment and prevented them from staying in employment (pp. 12-15).

The most commonly reported work-related factors that helped people with MS to stay in work were as follows:

1. Stable MS
2. Seated work
3. Disease modifying treatments
4. Symptomatic medications
5. Flexible working hours
6. Rest time during breaks
7. Routine/predictable workload
8. Change in type of work
9. Elevator in the building
10. Accessible bathroom
11. Rehabilitation
12. Good access to transport
13. A place to rest
14. Assistance with work
15. Computer adjustments
16. Other adaptive aids

The most commonly reported support-related factors that helped people with MS to stay in work were as follows:

1. Family support
2. Supportive employers/colleagues
3. Good salary
4. Lack of discrimination
5. Good awareness of MS among colleagues
6. Financial support from government/ council etc
7. Childcare support
8. MS Society helpline/employee advice

The most commonly reported external factors that prevented people with MS from staying in work were as follows:

1. Unpredictable workload
2. Lack of time off when needed
3. Lack of support from employer/colleagues
4. Own attitude to work
5. Environment too warm/cold
6. Poor access to transport/parking
7. Discrimination by employer/colleagues
8. Inaccessible bathroom at work
9. Lack of elevator
10. Lack of family support

The most commonly reported symptom-related factors that prevented people with MS from staying in work were as follows:

1. Fatigue
2. Difficulty walking/standing/bending/moving around
3. Weakness
4. Cognitive impairments
5. General MS worsening
6. Difficulty with manual precision – writing/typing etc
7. Pain
8. Urinary or bowel problems
9. Vision problems
10. Depression
11. Stiffness
12. Tremors
13. Speech impairments

Fatigue has been identified as the most common barrier to work in MS in a number of other studies (Coyne et al, 2015; Cadden & Arnett, 2015; Simmons, Tribe & McDonald, 2010).

Vocational exploration – an introduction

Occupational therapists (OTs) are optimally placed to play a central role in vocational exploration. Occupational therapists have knowledge and expertise of occupation and the complex relationship between occupation and well-being (College of Occupational Therapists [COT], 2008, p.1).

Occupational Therapists can help the person with MS explore the impact of their MS symptoms on their work roles. Together they look at ways to address and manage these difficulties (Van Denend, 2006). Below are examples of some of the areas in which occupational therapists can support and advise people with MS in the area of work:

1. Exploring work readiness
2. Mapping out a gradual return to work
3. Work hardening and/or simulation
4. Access to transport
5. Access to the work environment
6. Provision of assistive technology
7. Ergonomics
8. Symptom management
9. Training for employers

The Vocational Exploration Process: Step By Step

- Step 1** Referral to Occupational Therapist
- Step 2** The initial interview and assessment
- Step 3** An optional pre-vocational phase
- Step 4** A return to work rehabilitation plan
- Step 5** Implementation of the agreed program
- Step 6** Evaluation of the outcome and discharge

(Ross 2008, p.208).

Section 2 - Assessment

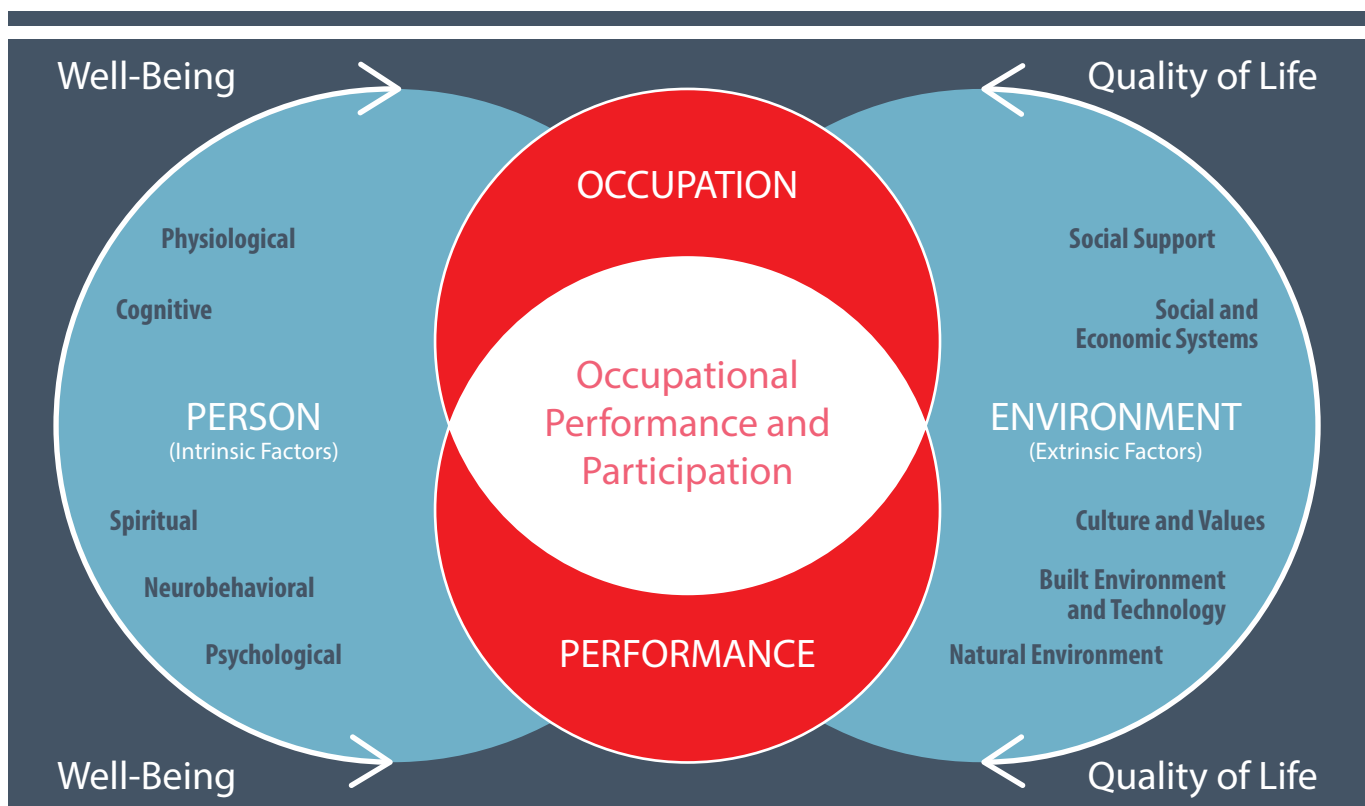
Vocational exploration key principles

- Different assessments are required depending on what stage on the work journey an individual is at. There is no one single assessment that will guide a vocational exploration process
- Assessment is not 'done to' a client but involves therapist and client collaboration and active participation (Kaskutas & Snodgrass, 2009). Assessors should support clients in both exploring their options and managing their expectations and aspirations regarding work
- Assessment must be multidimensional addressing client factors, performance skills, performance patterns, areas of occupation, context and environment and activity demands (Kaskutas & Snodgrass, 2009)

- A variety of assessment methods and a range of assessments including standardised and non- standardised assessments are required, and assessment should include both interview and observation(Kaskutas & Snodgrass, 2009; Holmes, 2007)

The Person Occupation Environment Performance model (POEP) (Law et al, 1996: Christiansen, Baum & Bass - Haugen, 2005) is a useful framework to assess an individuals function. Assessment will involve assessing dimensions of the person, their job, their worksite and their performance. The following diagrams illustrate how this works in practice.

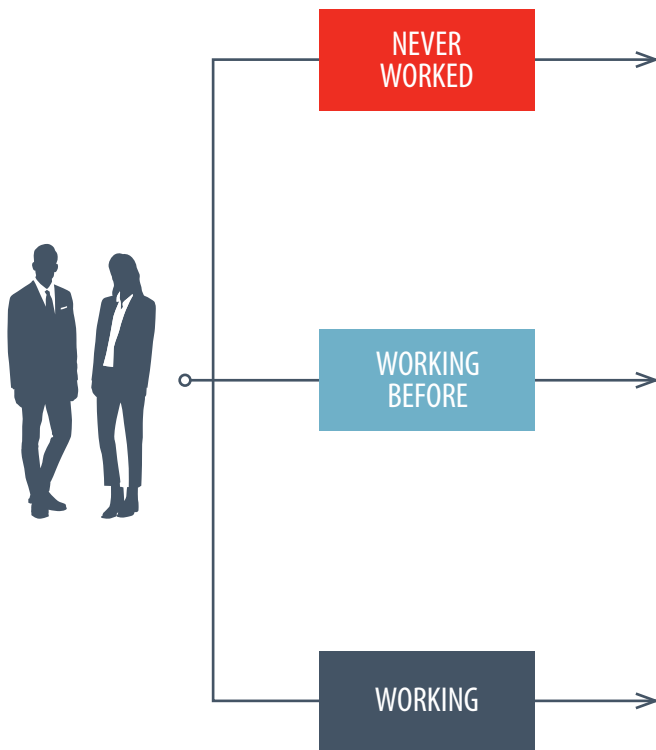
The assessment should begin by asking the work question and determining the client's starting point and aspirations, then assess relevant dimensions of the person, their occupation and their environment.



Christiansen Baum & Bass-Haugen (2005)

Assessment Starting Point

Assess

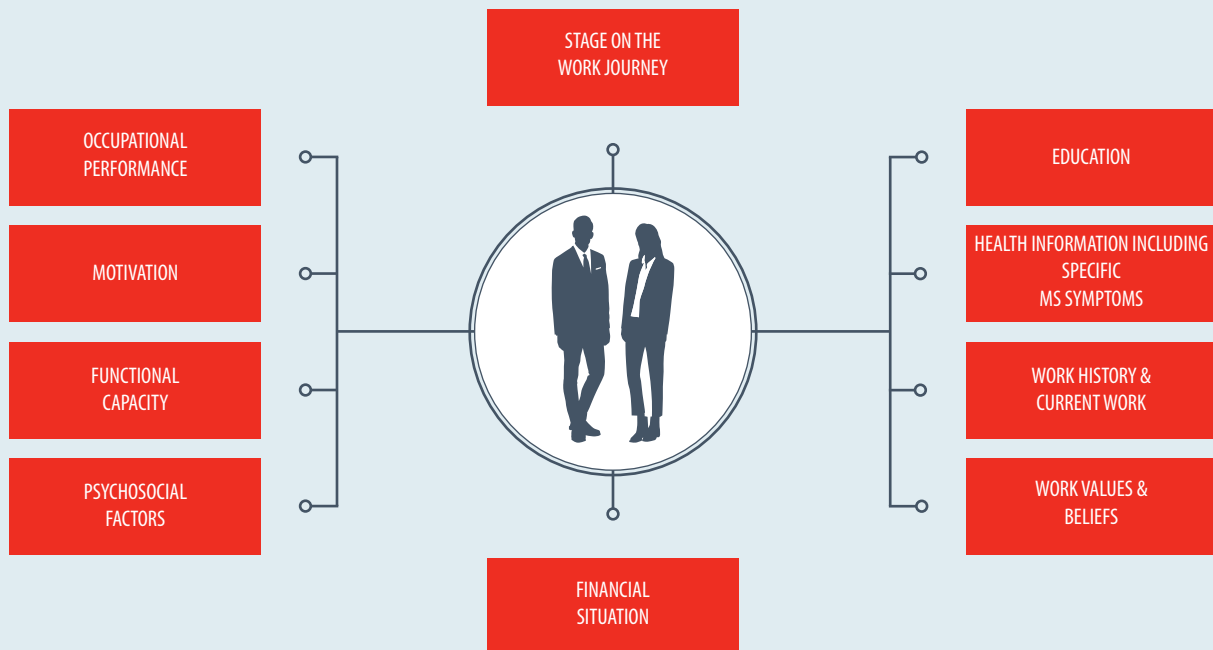


SKILLS
VALUES & INTERESTS
CAREER ASPIRATIONS
EDUCATION & TRAINING COMPLETED
PHYSICAL CAPACITY
PSYCHOSOCIAL FACTORS
FINANCIAL SITUATION

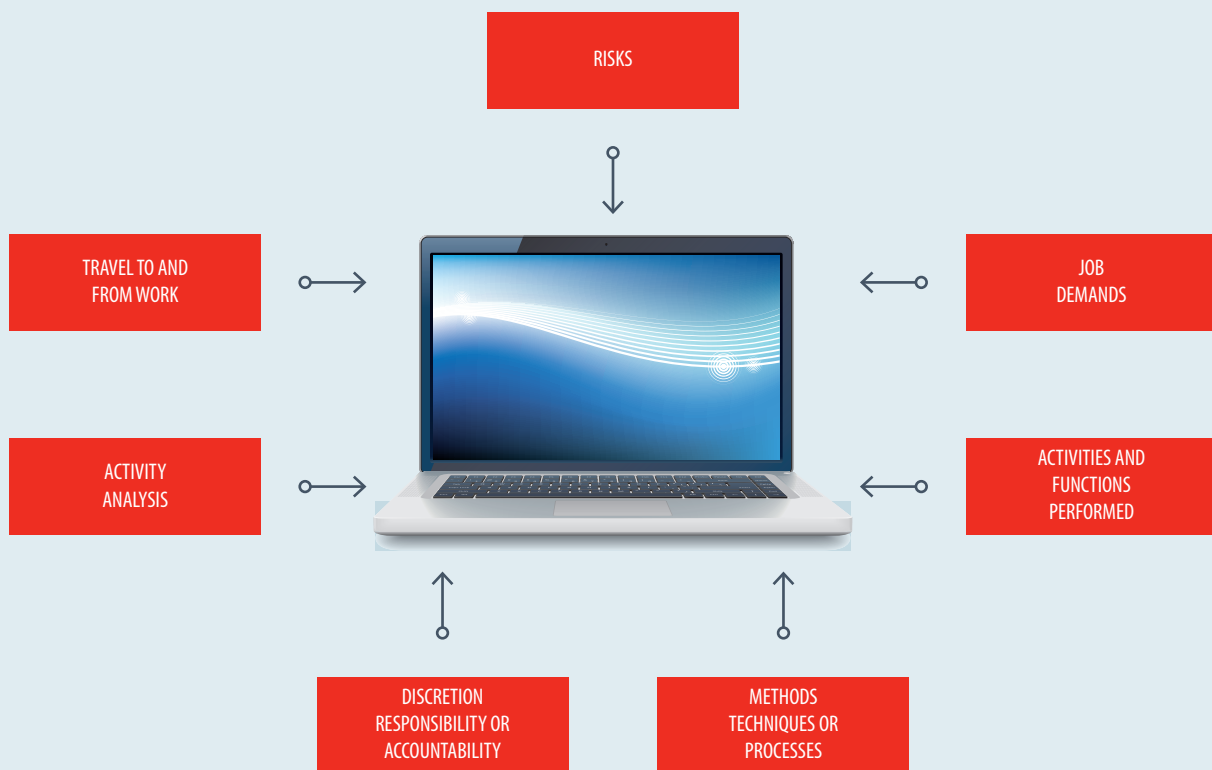
WORK HISTORY
VALUES & INTERESTS
CAREER ASPIRATIONS/MOTIVATION
PHYSICAL CAPACITY
PSYCHOSOCIAL FACTORS
TRANSFERABLE SKILLS
WORKPLACE ASSESSMENT
FINANCIAL SITUATION

WORK HISTORY
CURRENT WORK
VALUES & INTERESTS
CAREER ASPIRATIONS/MOTIVATION
PHYSICAL CAPACITY
PSYCHOSOCIAL FACTORS
LEVEL OF WORK
INSTABILITY
WORKPLACE ASSESSMENT
FINANCIAL SITUATION

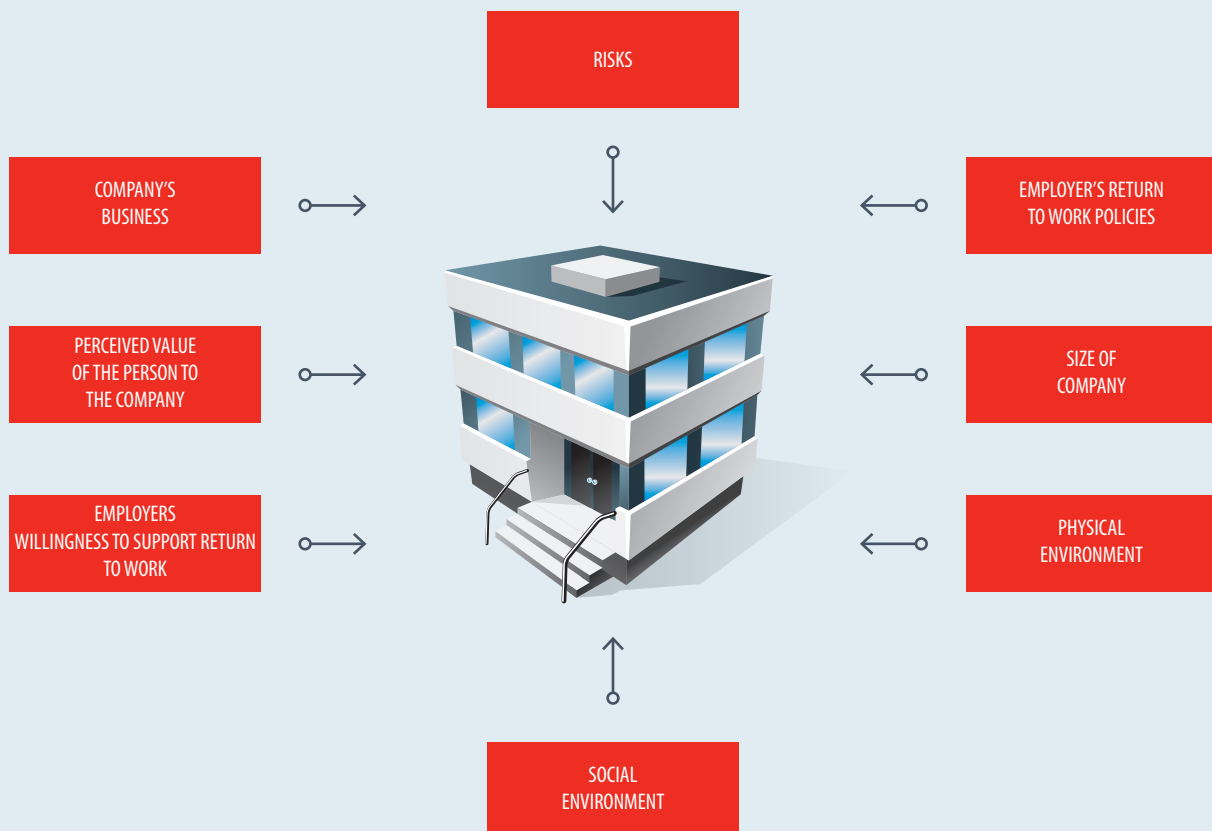
Person - Assessment Dimensions



Occupation - Assessment Dimensions



Environment - Assessment Dimensions



Initial interview - Work Sheet 1

Client self-assessment

Prior to the initial interview, the client should be asked to complete a self-assessment of their vocational needs. A suggested template for this is below:

Worksheet 1 Checklist for readiness for work

What best describes your current work situation:

- Currently working:
- Employed - on sick leave:
- Currently unemployed:
- Engaged in education or training:

What are your aspirations and ambitions regarding work?

- I wish to stay in/return to my current work role:
- I wish to explore alternative employment options:
- I wish to seek education and/or training opportunities:
- I am not currently considering work and/or educational options but may wish to do so in the future:

- None of the above:

Of the following list of common MS symptoms, can you indicate which, if any, may cause or are currently causing difficulties for you in work:

- Fatigue:
- Difficulty walking/standing/bending/moving around:
- Weakness:
- Difficulties with memory, everyday thinking and concentration:
- General MS worsening:
- Difficulty with using your hands:
- Pain:
- Urinary or bowel problems:
- Difficulties with vision:
- Depression/anxiety or other mood problems:
- Stiffness, tremors or difficulty controlling movement:
- Speech difficulties:

What do you see as your main challenges in returning to or maintaining work?

Do you think any of the following will be a barrier to engaging in work?	YES	NO	Please give further details	If yes, do you have any proposed solutions or supports already in place?
Performing independent activities of daily living such as: <ul style="list-style-type: none"> • Showering • Getting dressed • Preparing and eating food • Cleaning • Shopping • Anything else 				
Having consistent energy levels and a sleep routine				
Accessing work e.g. driving, using public transport				
Access within work e.g. being able to access the following: <ul style="list-style-type: none"> • The workplace building • Your workspace within the building • Accessing and using workplace equipment e.g. computers • Toilets • Communal areas e.g. staff room, canteen • Anything else 				

Do you think any of the following will be a barrier to engaging in work?	YES	NO	Please give further details	If yes, do you have any proposed solutions or supports already in place?
Maintaining activities outside of work – e.g. socialising, hobbies, family life, household skills				

What is my work and education experience?

What skills (if any) require to be updated? Is there any further education or training that you would benefit from or be interested in undertaking?

Financial considerations e.g. current financial commitments, social welfare payments and entitlements currently receiving

Initial interview Suggested Prompts/Questions

1. Current work status- do they plan to return?

- a. Are they currently working? Have they talked to their employer about returning?
- b. Do they have a date in mind for return to work?
- c. Have they discussed a return to work with their employer? Is a gradual return to work possible? What would this consist of?
- d. What do they identify as the main barriers to return to work? (Is this in line with what you identify?)
- e. Does the patient know what needs to happen before they return to work?
- f. Other factors:
 - i. How do they travel to and from work?
 - ii. If doing shift work, how will fatigue impact on this?
 - iii. Are they going to be getting further rehab?

2. If person with MS is planning a change in work/ further training:

- a. Do they have a plan regarding this?
- b. Have they identified areas of interest?
- c. Are they ready to pursue training or finding other work yet? If not, what are the barriers to this?
- d. Are there options available locally? How would they travel?
- e. Are they getting Illness Benefit/Disability Allowance? If so, are they happy to discontinue this?
- f. Will they be able to follow through on recommendations from vocational assessment (such as linking in with SOLAS, job searching online etc)?
- g. How will vocational assessment help them?

Assessment

Some assessments commonly used by occupational therapists when working with people with MS are listed below. It is important to note that this is not an exhaustive list:

- **Functioning/independence** - Functional Independence Measure/Functional Assessment Measure (FIM/FAM); Activities of Daily Living assessment; Occupational Self-Assessment – Daily Living Scales (OSA-DLS)
- **MS symptoms/impact** – Multiple Sclerosis Impact Scale (MSIS29); MS Quality of Life (MSQoL-54)
- **Fatigue** - Fatigue Severity Scale; Modified Fatigue Impact Scale
- **Cognition** - Addenbrook's Cognitive Examination (ACE-111); Addenbrook's Cognitive Examination Revised (ACER); Behavioral Assessment of the Dysexecutive Syndrome (BADS); Trail Making Test; Everyday Memory Questionnaire; Symbol Digit Modality Test; Montreal Cognitive Assessment (MOCA); Test of Everyday Attention
- **Dexterity** - 9 hole peg test; Box and Blocks; WOLF Motor Function Test; timed typing WPM; Range of Motion (ROM)
- **Seating** – HSE Seating and Postural Care Assessment
- **Assistive technology** - SETT Model to assess AT Needs
- **Mood** - Beck's Depression Inventory; Perceived Stress Scale and Spielberger Trait Anxiety Inventory

Report - Suggested template for report from initial interview

and assessment:

Name:

Address:

Telephone/email:

Date of birth:

Occupation:

Date of assessment:

Date of report:

Medical history: E.g. type of MS, time since diagnosis, medications currently and previously taken, other diagnoses.

Previous medical history: Anything of note in previous medical history.

Present complaints/present status: Including analysis of MS symptoms.

Education: Age at which left school – if left early, why? Type of school attended. Examinations taken and their results. Any further /higher education or professional qualifications undertaken.

Work history: Detailed and chronological. Give reasons for leaving jobs, periods of unemployment and how they were filled. Any courses, e.g. SOLAS or night courses, undertaken. Any work from home.

Include a description of the requirements of current or most recent job. Physical requirements such as lifting, standing, awkward positions, manual dexterity e.g. typing. Cognitive requirements such as information processing, written and analytical skills. Any work conditions that may impact on or be impacted by MS symptoms such as shift length and timings, hot or cold environment, travelling, driving, operating machinery.

Financial: How much earned including overtime. Prospects for promotion. What monies and allowances the person is in receipt of at the present time, e.g. Disability Allowance, Illness Benefit, Medical Card

Hobbies and interests/leisure pursuits: Have these changed as a result of MS?

Ambition: Self-assessment of job prospects. Does the person wish to stay in/return to/find work? If currently working, do they think the job could be adapted to suit their present circumstances?

Assessment: Then follows the assessment. List the tests used with the results and what they indicate.

Observations: How she/he presented.

Vocational implications: List the implications of the interview and assessment results for work – e.g. fitness for manual work, work speeds, accuracy levels, manual dexterity, grip strength, educational levels, alternative work skills, possibilities for retraining.

If the person cannot return to their previous job, suggest possible alternatives and indicate rates of pay for these alternatives.

Conclusion: This is basically a synopsis of the report: the impact of MS, the effects, the present status, the ability or not to continue with the job, the possible alternatives.

Section 3 - Next steps: interventions and recommendations

If the client is not currently working (never worked or worked before)

Below are some services that clients can be signposted to for support and advice if they are not currently working:

Finances

The client should be advised of the availability of services that can provide an assessment of their current financial situation to make sure they are in receipt of all allowances they are entitled to, and how this is likely to be impacted if they enter education and training or employment.

- Intreo Centres are a single point of contact for all Department of Social Protection income support enquiries. Contact details for the client's local Intreo Centre can be found on the Department of Social Protection website
- MS Ireland's Regional Community Workers and Information Line can provide information, advice and support on social welfare payments and other entitlements. Regional Community Workers can also provide practical assistance with completing application forms. Contact details for these services are available on MS Ireland's website
- The Citizens Information Service website has the most up-to-date information available on social welfare payments and other entitlements for people who are unemployed. The Citizens Information Service also have drop-in centres around the country and a telephone helpline that clients can be referred to for further advice and information
- The Money Advice and Budgeting Service (MABS) provide confidential information and advice for people dealing with debt problems. Further details of their services are available on their website

Education and training services

The National Council for Special Education (NCSE) and the **National Disability Authority (NDA)** have produced an information booklet on post-school education and training options for adults and school leavers with disabilities. The booklet covers a range of services and options including further education, vocational training, higher education, rehabilitative training and

services provided by the Department of Social Protection for people with disabilities. The booklet is available on the NCSE website.

Local Education Training Boards (ETBS) provide advice and guidance services for adults with disabilities who wish to explore their vocational options. Clients can also make an appointment at their local Intreo office to meet an employment services officer who will provide information and advice.

National Learning Network provides a range of flexible training programmes and support services for people who need specialist support (job seekers, unemployed, people with an illness or disability) in 50 centres around the country. Further information is available on their website.

Careers Portal is a very useful web-based guidance resource for all adults and young people provided by a public/private partnership. It includes information on the needs of people with disabilities.

National Adult Literacy Agency (NALA) provides confidential information, advice and support for adults looking to improve their literacy skills. Further information about their services is available on their website.

The Association of Higher Education Access and Disability (AHEAD) provides an information (phone and online) helpdesk for students, prospective students and graduates with disabilities. They can advise on access routes to higher education for people with disabilities, finance and the supports that universities and colleges provide to students with disabilities. AHEAD also run information events and a paid internship programme called Willing Able Mentoring (WAM) for graduates with disabilities – the person does not necessarily need to be a recent graduate to apply for this programme, they just need to hold a third level qualification. Further information is available on their website.

Currently working

Return to work and disclosure

Next are suggested template worksheets that can be completed with clients who have been off sick for a period of time and/or who are deciding whether or not to disclose their MS to their employer.

Return to work after time off sick - Work Sheet 2

If you've been off sick for a period of time, this form can help you to think about some of the issues around returning to work and how you can overcome them.

How long have you been off sick?

Have you spoken with your employer about returning to work?

If so, who?

Work relationship to this person:

Why do you want to return to work?

What expectations do you have about returning to work? Do you wish to return full-time or part-time? Have you considered redeployment to another position within the organisation?

Has your employer informed you of their expectations of you regarding your return to work?

When would you like to return to work? Is this practical/achievable?

Do you have any worries about returning to work? Is there anything you are unsure about? If so, list them below.

Are you aware of your workplace policies and procedures regarding returning to work after time off sick? Do you require an occupational health assessment? Do you require a Fit to Work certificate?

What support is available in your workplace to help you with your return to work? (for example, occupational health, human resources, line manager, colleagues).

Are there any parts of your job or the work environment that you may have difficulties with, or for which you need extra support?

Are there any adjustments that would help you?

Phased return to work plan

If you've been off work for a period of time, it's a good idea to return to work gradually, building up the number of hours you work over a number of weeks. Your workplace may have its own timeframes and policies in place, but if not you may find the tables below helpful to plan your return to work. The Department of Social Protection may also offer programs that assist with your return to work.

Example

Week	Mon	Tue	Wed	Thur	Fri	Total hours (excluding breaks)
1	10 - 2	10 - 2	Rest	10 - 2	10 - 2	16
2	10 - 4	10 - 4	10 - 4	10 - 4	10 - 4	25
3	10 - 4	9 - 5.30	10 - 4	9 - 5.30	10 - 4	28
4	9 - 5.30	9 - 5.30	9 - 5.30	9 - 5.30	9 - 5.30	32.5

For you to complete

Week	Mon	Tue	Wed	Thur	Fri	Total hours (excluding breaks)
1						
2						
3						
4						

Think about how you can adjust your workload and/or workplace to fit the plan. What do you need to do to make sure it happens? Who will you need to involve? The table with examples below may help you think about this.

--

Task or problem	Adjustment	Who can help?
Working at the till	Sitting not standing to manage fatigue	Occupational health, HR
Typing – numbness in hands	Use voice-activated software	Occupational health
Bladder control	Switch to desk nearer to the toilet	HR

Telling your employer decision sheet - Work Sheet 3

The decision of whether or not to disclose that you have MS to your employer or potential employer is a personal one. While legal protections are in place, discrimination still happens in the workplace and worry of discrimination is often the main reason people resolve to deal with their MS without seeking support from their employer.

MS Ireland's guide 'Working with MS: Employment Resource for People with Multiple Sclerosis' provides some further information and guidance on issues to consider when deciding if and how you should tell your employer about your MS. You can find the guide at www.ms-society.ie/pages/living-with-ms/information-centre/our-publications

You may find it helpful to read this before starting to complete this form.

This form lists some of the questions you may want to ask yourself or things you may want to consider before deciding to tell your employer about your MS.

Do I have to tell my employer?

Consider if your MS symptoms may pose a potential health and safety risk to yourself or others in the workplace – if so, you will be legally obliged to disclose your MS. Some examples of potential health and safety issues are listed below. If you are unsure of whether you are legally obliged to disclose your MS, you can seek advice from Free Legal Advice Centres (FLAC) – www.flac.ie

- If your job involves driving and your eyesight is affected
- If your job involves operating equipment and you are impacted by fatigue and/or tremors
- If your job involves managing medications and your cognition is affected
- If your job involves working at height and your balance is affected

Why do I want to tell my employer?

When do I want to tell my employer?

Who am I going to tell?

(It may not be necessary to tell anyone other than your line manager/HR and possibly a few colleagues that work closely with you.)

How am I going to tell them?

How do I feel about telling them?

Is there anyone I want with me when I tell them?

What if I decide not to tell my employer? Consider what the potential advantages and disadvantages of not disclosing your MS to your employer may be.

You may find it helpful to prepare what you're going to say, and also to think about any questions you might be asked (and how you might answer them) as well as any support you are going to be asking your employer for. You can use the space below to make any notes you need to help you prepare.



This is your choice, and depends on a number of different things, including your relationship with your employer, and the nature and atmosphere of your workplace.

Reasonable Adjustments

Reasonable adjustments are changes to job duties or environment that an employer can introduce to help a person with a disability or long-term illness to accomplish their job.

Employers have a legal obligation to try and make reasonable adjustments; however there is currently no definition of what constitutes 'reasonable' under Irish law. Whether or not an adjustment would be reasonable would be considered in the context of:

- The cost of implementing the adjustment
- The feasibility of implementing the adjustment
- The size of the business
- The resources of the business
- How effective the changes would be
- How long the person has been working in the business and how long they are expected to be working there for

There are some financial supports available from the Department of Social Protection to help employers meet the costs of implementing reasonable adjustments. Further information is available on the Department of Social Protection website, or from the employer's local Intreo office.

In considering reasonable adjustments, the following areas should be explored:

- Travel to and from work
- Access to and negotiating around the work environment
- Working hours
- Managing symptoms at work
- Considering how the job is structured

Below are some examples of reasonable adjustments that may be suggested for people with MS to explore with their employer:

- Adjust start and finish times to avoid travelling to and from work in rush hour
- Reduced working hours
- Parking space reserved close to entrance of building

- Time off for appointments
- Working from home for all or part of the week
- Door entry handset for visitors to the office, to avoid getting up and down
- Moving desk nearer to the toilet and/or water cooler
- Adjustment of heating/air conditioning and/or access to a portable fan
- Access to the work building: installation of a ramp or lift, or moving workspace to the ground floor
- Installing adaptive equipment in the bathroom (e.g. grab rails)
- Rearranging work space
- Organise work area so everything is within reach
- Minimise unnecessary lifting, bending, reaching and trips to photocopier or printer
- Flexible working hours to allow for regular breaks
- Provision of a quiet space to rest
- Consideration of posture and position at desk, including arrangement of seat and keyboard
- Opportunity to sit rather than stand for tasks



Some reasonable adjustments for MS are very simple and low-cost, such as the use of a desk fan for those whose symptoms are made worse by heat



Financial support may be available from the Department of Social Protection to make office spaces accessible for people with limited mobility



Moving an employee's desk so it is nearer to the photocopier, water cooler and/or other communal areas that are regularly accessed can help with managing fatigue by reducing the need to move around. Also, moving a desk nearer to the bathroom can be an important adjustment for those with bladder issues.



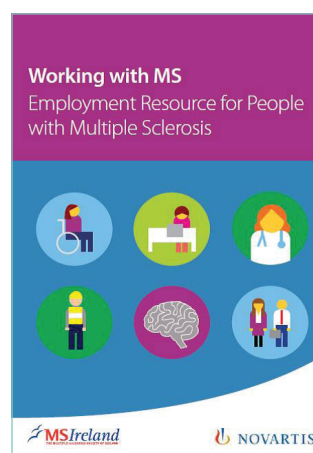
It is important to consider adjustments that may be needed to the employee's journey to and from work as well as when they are at work. Flexibility on start and finish times so the person can avoid commuting during rush hour can be a valuable option for managing fatigue.

MS Ireland Employment Resources

Clients can also be provided with a copy of *'Working with MS: Employment Resource for People with Multiple Sclerosis'* by MS Ireland. This resource provides practical information and advice for people with MS on their employment rights and options. The resource covers disclosure, employment law, reasonable accommodations and what to do in the case of unfair treatment by an employer. The resource also includes case studies of people living and working with MS.

MS Ireland has also produced *'Working out MS in the Workplace: A Practical Toolkit for Employers'*. Clients can be provided with this resource to share with their employers. This resource provides information and advice for employers on managing MS in the workplace, including reasonable accommodations, absence management and a list of the supports available from the Department of Social Protection to help employers retain employees who acquire disabilities and long term illnesses.

These resources are available to download on MS Ireland's website and hard copies can be ordered by contacting their National Office.



Section 4 – Case Studies

Matthew

Matthew was diagnosed with MS seven years ago. He is married with four children aged between 6-14 years. He previously ran his own plumbing business but he has recently given this up as he is unable to fulfil the demands of the job. While he has enjoyed minding the children through the summer he is keen to contribute financially to the household.

Assessment

1. Initial Interview

Mobility:

- Matthew mobilised with a walking stick outdoors. He mobilised up to two miles a day, depending on fatigue. He reported that he wouldn't be confident on uneven surfaces. Matthew was using a grab rail for ascending and descending the stairs.
- Matthew reported that at times his legs can feel weak and heavy and that this can affect his ability to stand. Matthew's legs were generally affected if he has walked a lot and physically exerted himself.

Activities of Daily Living:

- Matthew reported being independent with personal activities of daily living. He had learnt to do things using his left hand due to sensory loss in his right hand. Matthew had previously been given adapted cutlery but he continues to have difficulty with cutting.
- Within the home Matthew was contributing to the dinner preparation. He was independent with preparing hot drinks. Domestic tasks were being completed in standing.
- He reported that he had double vision but this has now resolved itself. He wears reading glasses. His ability to walk long distances is reduced.

Cognition/Cognitive Fatigue:

- Matthew reported difficulty with reading the paper but reports that he continues to work on this. Matthew also reported difficulty ruling out external distractions, particularly in crowds.
- Matthew also stated that his planning, organising and ability to multitask have been affected.
- Matthew administers his own medication three times a week, and sets reminders in his phone to prompt him with same.

Fatigue management:

- Matthew feels he is managing his fatigue well, only needing to lie down for half an hour approximately three times a week. Matthew was self-initiating implementing energy conservation strategies.
- Matthew goes to bed at 10:00 p.m. and gets up at 9:00 a.m. and feels this is a sufficient amount of sleep. Matthew looked after his children full time during the summer and gained enjoyment from spending time with his children.

Work history:

Matthew worked as a plumber for 18 years, and was self-employed for the last 14 years. Due to his physical limitations experienced as a result of his illness he had to close his business. Matthew's role was physically demanding, requiring a lot of fine motor skills. It involved working long hours and having to travel. Matthew was also involved in elements of managing the accounts and finances.

Leisure:

- Matthew enjoys swimming and swims five days a week
- Matthew engages in gardening and D.I.Y.
- Matthew enjoys Pilates

Finances:

Matthew is in receipt of Disability Living Allowance.

Ambition:

Matthew had always wanted to work as a plumber and has never given consideration to other employment possibilities. Matthew now realises, that due to his physical limitation he will not be able to return to this line of employment and is very keen to return to gainful employment and has begun to consider completing further education. Matthew was referred to Occupational therapy to explore options around returning to the workplace.

2. Assessment

The following work-related skills were assessed:

- Ability to visually discriminate size
- Hand eye co-ordination and bilateral manual and finger dexterity
- Ability to make decisions while performing work tasks requiring physical manipulation and visual discrimination
- Ability to perform work involving visual comparison
- Reasoning
- General learning ability – ability to take onboard new information
- Endurance

Matthew had no issues with visually discriminating size. His speed was good using his left hand for assembly. He struggled with using both hands simultaneously at a fair speed for disassembly, as his right upper limb could not keep up with left. Matthew displayed excellent accuracy with tasks that required visual discrimination, however overall assessments indicated that his work speed was slow.

- Impairments: Balance, endurance, sensory loss, reduced dexterity, reduced attention and memory.
- Activity limitations: Unable to manage his own company and unable to complete dexterous plumbing related tasks.
- Participation restrictions: Difficulty with engaging in gainful employment that he had several years experience in.

Next Steps

Explore viability of retraining:

Matthew was advised to liaise with his wife regarding whether returning to gainful employment is of priority due to financial pressures or whether it is viable for Matthew to take the time to retrain.

Increase cognitive demands of his week:

Prior to return to work or studying Matthew was advised to focus on exposing himself to more cognitively demanding activities, to build his insight and confidence regarding his ability to complete work/study-specific tasks and develop strategies which he can use in work or whilst studying.

Explore work roles with flexible conditions:

Matthew wished to explore imminent return to work; he was advised that he considers jobs where accommodations can be made in terms of allowing additional time for task completion if necessary, scope to sit whilst doing the job and flexible working hours.

Explore training courses:

- Although Matthew's mobility was good, it is not at a level where he would be able to do heavy manual tasks such as using heavy machinery. Matthew's reduced upper limb strength and altered sensation would also impact on his ability to complete fine motor tasks which would have been a fundamental part of his job, he was therefore advised to consider re-training.
- Matthew was advised to contact SOLAS regarding available courses in his area, to get a sense of the course content and what level of support is available to him.
- Matthew was supported in completing an online search for possible courses being run, he expressed an interest in basic computer skills, book-keeping/payroll, employment skills and skills based foundation courses.

- Matthew was encouraged to consider the administrative skills he developed whilst managing his own business, and whether he wished to develop these skills further through formal education.
- Matthew was advised to register early with SOLAS, as places on courses are likely to fill up quickly.
- He was also provided with information regarding courses run by the National Learning Network, such as the Access course in his local area. Matthew was advised that the NLN were more likely to accommodate completing the course at his own pace. He was advised to visit the NLN campus to see the centre, and get a sense of the course content.
- Although Matthew was managing his fatigue levels within his current routine, he was advised that the extra demand of returning to work or studying will challenge his fatigue levels and that it was important for him to consider his fatigue levels in relation to work-life balance when choosing a course or job.
- He was also encouraged to consider whether a part-time or full-time course would be more manageable, as it is important for him to be able to manage the course and still have time and energy to engage in family life.

Recommendations for work/ reasonable adjustments:

- If Matthew felt financially obligated to return to work, it was recommended that he has a gradual return to work both in terms of hours per day/week and exposure to complex tasks. He was advised to try half-days initially, with a gradual increase of hours. In terms of work tasks, he was advised to start with the more routine, less complex tasks.
- Matthew was advised to allow extra time to complete cognitively demanding work tasks, which require a considerable amount of concentration over a prolonged period initially.
- As Matthew was using reminders on his phone to prompt him to take his medication, it was recommended that he uses a notebook or phone to record important day-to-day information in work, to avoid forgetting important detail particularly if he is tired.

Prior to return to work, he should consistently use this technique at home, for it to become an established habit.

- It was recommended that going forward Matthew uses a fatigue diary to monitor his levels of fatigue, identifying any work specific tasks that contribute to fatigue.

Andrew

Andrew is a 42-year-old man with secondary progressive MS. He first presented to MDT for assessment in 2015. His mobility had declined and he was only going 200 meters with a rollator/ zimmer frame and reporting falls at home. He lives alone in a ground floor apartment. He was struggling with ADLs and had some difficulty with manual dexterity. He was experiencing problems with urinary frequency and urgency. His speech and cognition were good but he struggled with fatigue including cognitive fatigue. He had just changed his car to an automatic car with capacity to take a wheelchair via a ramp at the rear of the vehicle.

He worked for a local magazine that involved interviewing, phone calls and typing. There was no access to his workplace. At work he was experiencing fatigue, his typing had slowed down and he was not as productive as he used to be. He had disclosed his MS to his manager who was willing to make some adjustments to facilitate him to stay in employment.

Assessment

1. Initial Interview

Andrew completed a self-assessment form and identified the following items as challenges to remain in work:

- Mobility
- Managing fatigue
- Managing typing and handwriting
- Difficulty toileting at work
- Managing ADLs
- Getting to work

This was followed up by an assessment.

2. Assessment

- An occupational therapy assessment was completed with Andrew. It included an assessment of his ability to complete his ADL.
- He completed the Fatigue Impact Scale.
- He completed various hand function tests, grip strength, pinch and ROM. He completed 9 hole peg test, Box and Blocks and a timed typing test.
- He had a full seating and posture assessment including seating for typing.

Next Steps

Interventions for activities of daily living:

His ADLs were possible but very effortful so he agreed to carer support to facilitate his morning routine and conserve energy for his work day.

Interventions for symptom management:

He agreed to return to the hospital later in the year to complete a six week fatigue management course.

Interventions for mobility:

He concluded that it was time to explore powered mobility. He planned to leave the power-chair at work to avoid transportation issues. This would minimise the risk of falls at work but also the tilt function of his chair enabled him to take rest breaks in a reclined position. A pressure relieving cushion and back support were selected to maximise postural support while freeing his arms for typing.

Recommendations for work/ reasonable adjustments:

- He explored Dragon speech recognition software to facilitate typing. He was not able to use this for all of his work.
- His manager agreed to put a wheelchair accessible toilet off his office. He also agreed to modify the work station to facilitate working from the powered chair. The powered chair enabled him to access the town at lunch-time; something that had not been possible in the past due to his poor mobility. He could now socialize with his workmates.

Review and modifications:

On Andrew's return for the fatigue management course his mobility had declined significantly and he was now a full time wheelchair user. His carer was now driving him to and from work. Different typing postures were reviewed and speed and fatigue levels were compared. He opted for a keyboard on a lap tray with wrist supports. One hand fatigued quicker than the other so he adopted one finger typing with that hand. He rearranged his work day so that any note-taking took place in the morning when he was at his best. He arranged mini breaks throughout his day and modified his hours. He continues to enjoy his work but put pressure on himself to try and maintain his productivity. His manager and workmates remain understanding.

Michelle

Michelle is a 35 year old woman with relapsing remitting MS. She was diagnosed 11 years ago but has been experiencing symptoms since she was a teenager. As a teenager these symptoms were put down to stress and were not investigated until a relapse when she was aged 23.

Michelle mobilises with a crutch over distances greater than 300 meters. Around the house she does not use the crutch but uses furniture at times to help her get around. She falls relatively frequently (2-3 times per month) both inside and outside the house. On one occasion she broke her

wrist and on another she fell down three steps and sprained her ankle.

She rents a city centre apartment which she lives in with her 13 month old son and partner. Her apartment is on the second floor but can be accessed with a lift. There are three steps between the kitchen and living room inside the apartment.

During her pregnancy she was well and had an uncomplicated birth. Following the birth, however, she had a severe relapse that lasted four weeks during which time she was unable to leave the house independently and was unable to care for her son. Her mother moved in to assist with childcare and to help her during the day. She did not return to the same level that she was at before this relapse and has begun to find work and home life more challenging.

Michelle works in a nursery as a child care worker. She returned to work following maternity leave last month. Her son attends the same nursery. Since returning to full-time work Michelle reports finding it challenging to keep up with the demands of the job as she had before.

Michelle was referred to occupational therapy by her GP to explore options around maintaining work and addressing some of the challenges she is experiencing.

Assessment

1. Initial Interview

The Occupational Performance History Interview (OPHI); Kielhofner et al., 2004) II was used to guide the initial interview. During the initial interview with the occupational therapist Michelle reported that her main challenges at present were the following:

- Concentrating and organising herself at work
- Fatigue at work and at home following her day at work
- Frustrations and anxiety associated with her reported challenges

Following the initial interview a number of further assessments were completed to get an accurate view of Michelle's current function.

2. Assessment

- Symbol Digit Modality Test (SDMT) (Smith, 1982)- The SDMT was chosen to measure Michelle's processing speed and working memory. It is a strong predictor of future cognitive decline and a significant predictor of employment status (Strober et al., 2014).
- Everyday Memory Questionnaire - Revised (EMQ) (Royle & Lincoln, 2008)- measure of Michelle's self-reported memory difficulties in daily life.
- The Fatigue Severity Scale (FSS) (Krupp et al., 1989)- to measure the impact of fatigue in her life.
- Multiple Sclerosis Quality of Life (MSQOL) 54 Instrument (Vickrey, 1995) was completed to get an estimate of QoL and overview of different areas of functioning.
- Occupational Self-Assessment – Daily Living Scales (OSA-DLS) (Scott, 2016) was completed to assess functioning in daily activities.

Next Steps

Following on from the assessment session and incorporating the results a goal setting session took place [Goal Attainment Scaling (Kiresuk & Sherman, 1968) or the Canadian Occupational Performance Measure (Law et al., 1998) could be useful tools here]. During this session Michelle worked with the occupational therapy to set goals and prioritise what she wanted to focus on in therapy. It was also a chance to speak with Michelle about her strengths.

On overview of some of the areas that Michelle worked on during her occupational therapy sessions were as follows:

Interventions for cognition:

Cognitive strategies were trialled and practiced with Michelle in an attempt to find a strategy that could be useful for her to use in work. Goal Management Training (Levine et al., 2011) was successfully implemented, as was the modified Story Memory Technique (Allen et al., 1998).

Michelle began to also use a diary and phone reminders for her daily and weekly appointment. She also uses a daily planner with her diary to help

her to plan her days, which she does in the evening after dinner.

Interventions for fatigue:

Michelle began to take more frequent breaks during her day at work. She worked with the OT to be able to recognise when she was becoming physically and cognitively fatigued and was proactive about resting before any escalation in fatigue.

Michelle spoke to her partner about her fatigue and he became more involved in child-care duties when they were at home. Michelle began to delegate more to help with her stress.

Michelle followed a fatigue management programme with the OT, based on Packer et al, (1995).

Interventions for mood/psychology:

Michelle has plans to participate in a mindfulness course when it begins in the coming months (evidence of effectiveness in MS has yet to be definitively proven).

Reasonable adjustments:

Michelle plans to discuss options around work modification and a reduced working week with her manager. She does not think that she needs this at present but wants to have a future plan in place.

Review and modifications:

Michelle has reported benefits from the cognitive strategies employed (some mentioned above) and continues to implement them in her daily life. Her partner has taken on more of the duties at home which has reduced her fatigue and self-reported stress at home. Michelle is looking at the possibility of working a four-day week (taking Wednesday off) and her partner will take their son to nursery on that day. At home her son is sleeping through the night and Michelle is resultantly getting more sleep.

She is working with older children in the nursery so is not involved with as much physical work and floor play. Her manager is supportive of her needs and continues to support her. She continues to implement the fatigue management strategies and is beginning a mindfulness group (not specific to MS) in the next week. Michelle plans to continue working in her current job.

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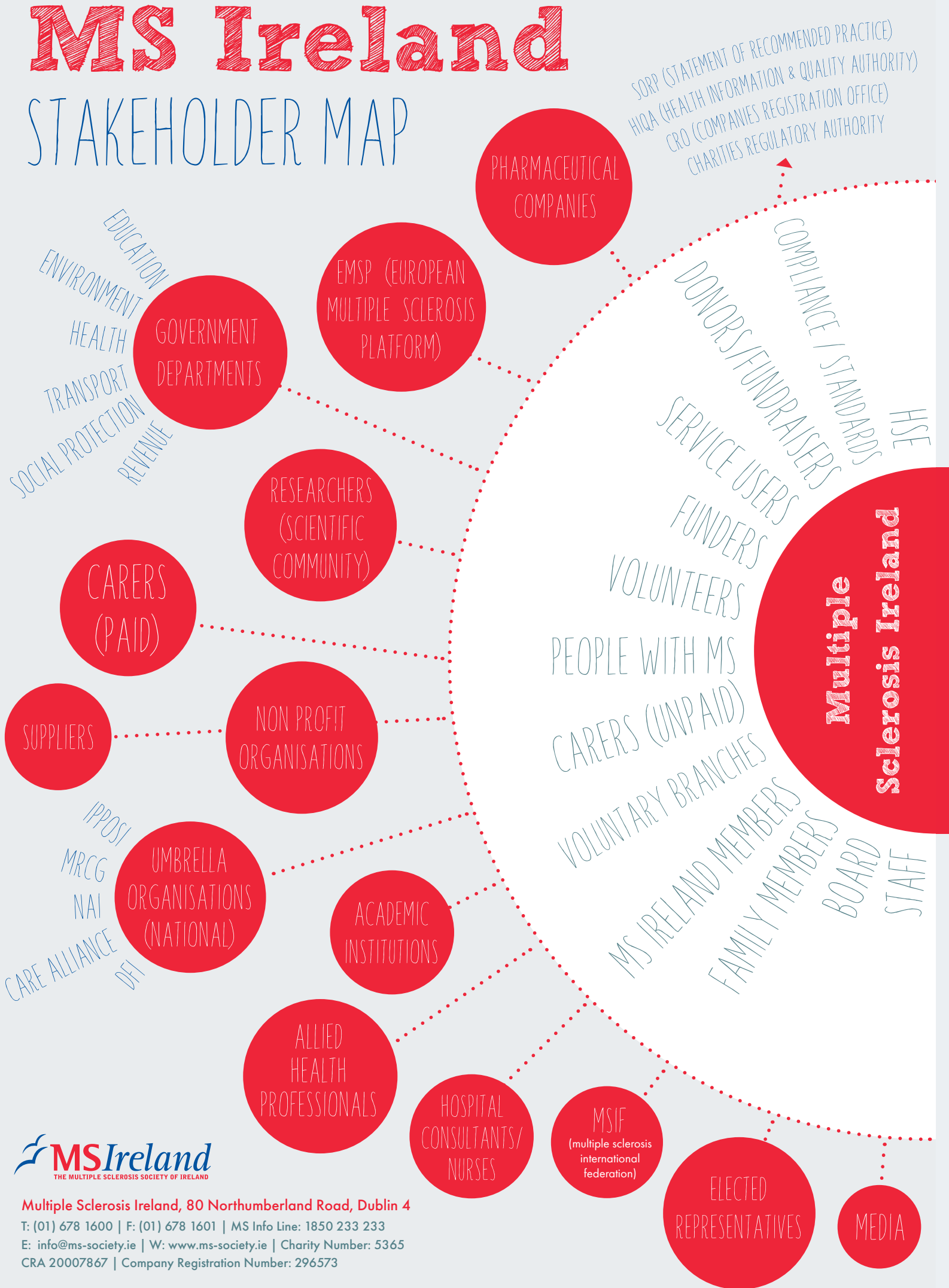
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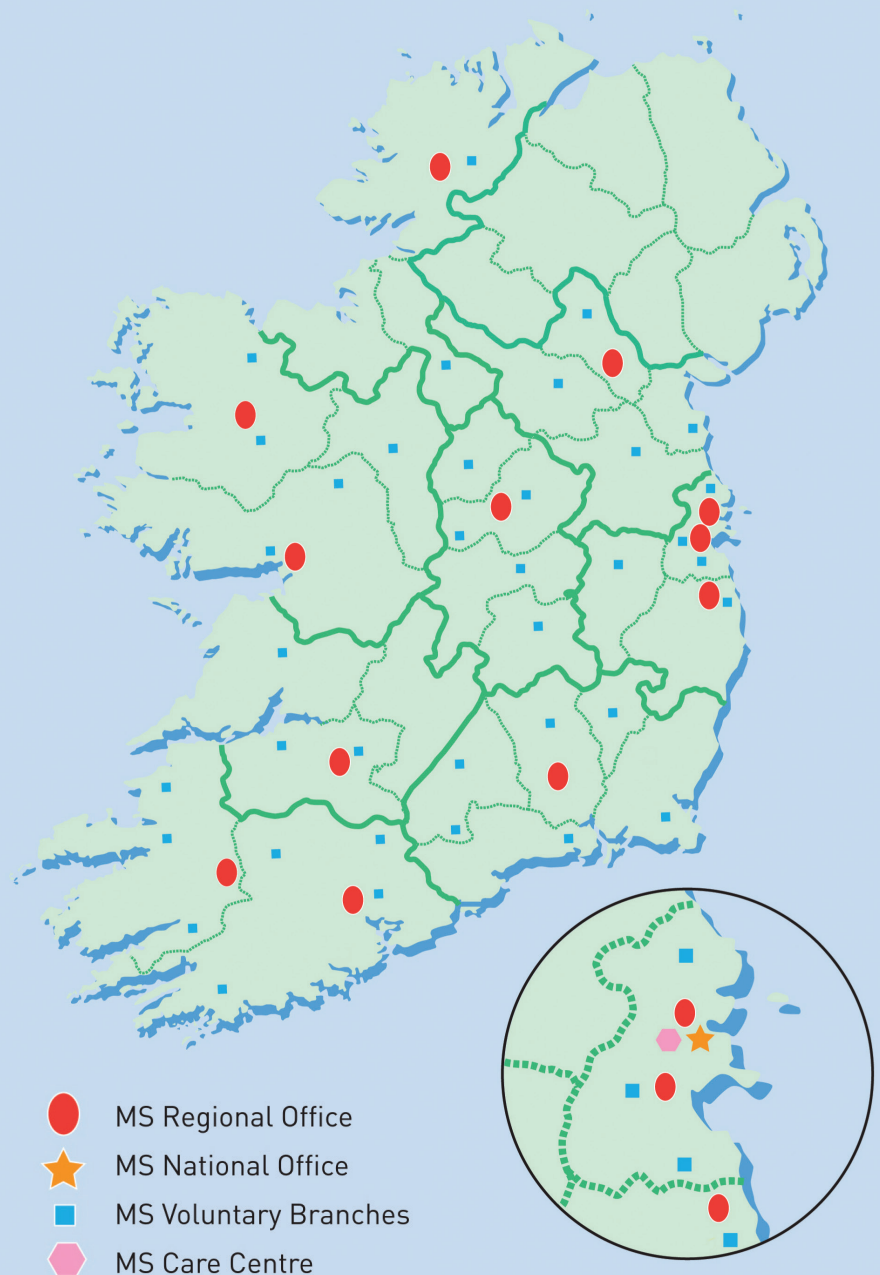
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