



Multiple Sclerosis Society

Benefits & MS:

A **How to** guide for
committees

Introduction

Why did we develop this guide?

Changes to assessments and eligibility criteria, coupled with increasing economic deprivation have led to higher demand for support and advice on benefits from people affected by multiple sclerosis (MS).

The MS Society does not give advice on benefits but we want everyone affected by MS to be able to get up to date information. We also want everyone to be able to access specialist advice about their benefits entitlements and planned changes which will affect them.

This **How to guide** will help you support people affected by MS within the boundaries of the role of the MS Society.

What we do:

- ▲ we enable access to the information available and signpost to qualified sources of advice
- ▲ we work with local benefits advice organisations
- ▲ we emphasise the key issues people may need to consider about the impact of MS in their daily life

Who is this guide for?

It's for MS Society branches and national support groups receiving enquiries, running an information event, or involved in any information giving activity about benefits and MS.

Branches are groups of volunteers that provide local contact, services and support to everyone affected by MS in their geographical area.

National support groups exist to provide support to particular communities of interest.

Where to find documents signposted in this guide

This guide signposts to a range of more detailed resources. You can find these either:

- ▲ in the appendices at the back of this guide
- ▲ on our volunteer website, <http://volunteers.mssociety.org.uk>
- ▲ by requesting a printed copy

If you have internet access please use the website versions as this is not only cheaper, but they will be the most up to date. If you need help finding a particular document either on the MS Society website or in print, call the **Volunteering Team**.

Our key messages about benefits

- ▲ the MS Society does not give advice on benefits
- ▲ through engaging with Citizens Advice Bureaux (CAB) or other benefits advice services we can ensure people get accurate and up-to-date information and advice
- ▲ people are worried about changes to benefits so it is really important to provide practical information and seek support from a benefits advice service
- ▲ benefit forms are 'universal' with standard questions, so it is important people explain how MS affects them and their ability to do tasks
- ▲ the nature of MS makes it difficult for someone who is not aware to understand its impact – it is important to explain the impact of your symptoms, not just the symptom

Why do we provide information about benefits?

Enquiries about benefits

Our **MS helpline** takes over 100 calls per month from people concerned about benefits – more than any other MS related topic.

Changes to benefits

Benefits are complex and change regularly.

The benefits system has complex rules and criteria which make every person's situation different, depending on their means, current situation, exceptional circumstances, benefits caps, etc.

Only a qualified benefits adviser can advise on individual cases.

The impact of MS

The nature of MS makes it difficult to fill in standard benefits claim forms.

The fluctuating nature of MS and its hidden symptoms make it difficult to explain the real impact of MS on a person's daily life and their ability to do things repeatedly, reliably, safely and in a timely way.

It is important to emphasise the need to explain the impact of MS on a person's daily life in sufficient detail when applying for benefits.

Providing quality information

We produce and provide accurate, up-to-date information and signpost to benefits advice services to ensure people know their options and where they can get advice on their situation.

We have a key role in:

- ▲ enabling access to quality reviewed information
- ▲ signposting to external benefits advice services
- ▲ working and developing **partnerships** with local benefits advice organisations
- ▲ stressing the key issues people may need to consider about the impact of MS on their daily lives
- ▲ promoting additional support and services we can offer such as emotional and practical support

Providing information versus giving advice

Providing information and giving advice are very different things.

The MS Society provides information to support and enable a person to take control and make choices for themselves. This means that it is up to the person to decide what works best for them, based on the information available or knowing where to go to find out more.

Giving advice involves a person regarded as knowledgeable or authoritative making recommendations concerning future action. Benefits advice is about helping with claims form filling, queries and problems. Giving advice makes a person responsible for the outcome.

The MS Society is not insured to give advice and you must never do so.

Top tip see the **Information giving quality checklist** on our volunteer website for more information on providing quality information:
<http://volunteers.mssociety.org.uk/dealing-enquiries>.

We are not specialists on benefits. The MS Society produces information about benefits and MS written by benefits experts from Disability Rights UK to help people affected by MS make informed choices based on the options that relate to them.

Our quality reviewed information forms the basis of responses we give to enquiries from people affected by MS and must be an integral part of any information activity.

Our key resources

- ▲ Publications from the MS Society
<http://www.mssociety.org.uk/ms-support/publications-and-library>
- ▲ Publications list
- ▲ Benefits and MS (ES09)
- ▲ Claiming Personal Independence Payment (ES30)
- ▲ Employment Support Allowance (ES29)

- ▲ Carers UK <http://www.carersuk.org/help-and-advice/financial-support/help-with-benefits>
- ▲ MS Society website <http://www.mssociety.org.uk/ms-support/practical-and-financial-help/work-and-money/disability-benefits>, latest updates and information on disability benefits

Branch committee members can order these free resources in bulk through our online ordering shop at <http://shop.mssociety.org.uk> or call 0300 100 801. If you need support see the online shop frequently asked questions email shop@mssociety.org.uk or call 020 8438 0999 You can find all this information at <http://volunteers.mssociety.org.uk/shop>.

There is also further information on disability benefits on the MS Society website <http://www.mssociety.org.uk/ms-support/practical-and-financial-help/work-and-money/disability-benefits/a-guide-to-benefits>.

You can find the latest benefits related campaigns and how to get involved at <http://www.mssociety.org.uk/get-involved/campaigns/key-campaigns/uk>.

Relevant content available on our volunteer website

Making it work: A committee handbook for branches and national support groups – <http://volunteers.mssociety.org.uk/resources/154>

Planning and running an event – <http://volunteers.mssociety.org.uk/offering-support-people-affected-ms/giving-information>

Interactive benefits & MS information event poster and flyer – <http://volunteers.mssociety.org.uk/resources/618>

Benefits and MS information event presentation – <http://volunteers.mssociety.org.uk/resources/619>

Directory of key signposting organisations – <http://volunteers.mssociety.org.uk/resources/620>

Signposting to benefits advice

What is benefits advice?

Benefits advice is **quality assured** welfare rights advice and casework support. It covers all aspects of the benefit system, from eligibility for benefit, through the impact on other benefits in the household, to challenging decisions at review and appeal.

Benefits advisers undertake an assessment of a claimant's situation, giving information and advice based on their overall situation.

Their responsibilities may include:

- ▲ providing manual calculations for benefit entitlements
- ▲ ensuring timely completion of benefit verification and all benefit claim paperwork
- ▲ compiling accurate file notes of all contact with customers, their representatives and /or statutory agencies
- ▲ acting as an advocate to customers in order for them to appeal or challenge welfare benefit decisions
- ▲ identifying and signposting customers to appropriate support services

Who's who?

See **appendix 2 – directory of key signposting organisations** for national contact details. Contact the national office to identify your local branch or service.

Benefits advice organisations

Benefits advice organisations may offer an advocacy service to help fill in claim forms, deal with queries and problems.

Department for Work and Pensions (DWP) national partnership team

The department develops partnerships at a local, regional and national level to help understand the range of support and benefits that are available. <http://www.dwp.gov.uk/adviser/partnerships/>

Disability Employment Advisers

Disability Employment Advisers help people facing the greatest barriers to employment to access and remain in work. Jobcentre Plus – <https://www.gov.uk/contact-jobcentre-plus>

Specialist legal advisers

Specialist legal advisers provide a benefits casework service with relation to legal procedures, and support at any level of the legal system. Legal aid can help pay for legal advice, mediation or representation in court if you can't afford it – <https://www.gov.uk/legal-aid/overview>

Social care specialists

Involving a local social care worker in your benefits information activities can help people affected by MS to identify other sources of support. Everyone with MS is entitled to an assessment to see if they are eligible for social care.

<http://www.mssociety.org.uk/ms-support/practical-and-financial-help/care/social-care>

The nature of MS

The fluctuating and variable nature of MS can make it difficult for people with MS to describe it on standard benefits forms. It can also be a challenge for those who assess benefits to fully understand MS.

Benefit forms are 'universal' with standard questions, so it may not seem obvious at first how someone's MS relates to a question or to the assessment. The nature of MS makes it difficult to understand its impact – it is important that people explain the impact of their MS symptoms, not just the symptom itself:

- ▲ if their condition fluctuates, explain how
- ▲ explain how MS affects them and their ability to complete tasks repeatedly, reliably, safely and timely
- ▲ encourage people to give as much information as possible and supply relevant extra supporting evidence
- ▲ explain any hidden symptoms like fatigue and pain in detail – how does it actually impact on the ability to go through the day, what needs to be organised, etc

These are general statements which can be accompanied with specific examples to help people think about their own symptoms and how it actually has an impact on their mobility, need for care, ability to work, etc.

Making benefits and MS information available

- ▲ hold copies of the latest versions of MS Society publications
- ▲ keep abreast of the latest news on the MS Society website and share this
- ▲ display leaflets or posters, provide specific information at events, in your nearest hospital, therapy centre, info point and other locations where people affected by MS go
- ▲ provide the latest information and publications in your newsletter, on the telephone, at socials, conferences, meetings, waiting rooms, online (Facebook, forums)

Dealing with enquiries

Here's an example of how you could deal with a benefits enquiry by providing information and signposting to specialist advice.

“At present I work 17 hours per week but am finding it harder and harder to cope with the pain and fatigue but can't afford to reduce my hours any further. Someone said that I could claim Disability Living Allowance or some other benefit to help but as I've never claimed anything except child benefit I'm not sure if I would be eligible or not. If you could help me, I would appreciate it.”

This person is coming to us to find out what they can do next to resolve their situation. We can help through the information we provide and the benefits advice we signpost them to.

Work and reasonable adjustments

- ▲ **Provide information:** MS Society information about employment and MS, occupational health
- ▲ **Signpost to advice:** we can signpost them to a Disability Employment Adviser at Jobcentre Plus, occupational therapy, the Equality and Human Rights commission or the Business Disability Forum

Claiming Personal Independence Payment (PIP)

- ▲ **Provide information:** MS Society information about Claiming Personal Independence Payment (ES30)
- ▲ **Signpost to advice:** Benefits Enquiry Line, local benefits advice agency and/or other agencies (see **appendix 2 – directory of key signposting organisations**)

Eligibility for other benefits

- ▲ **Provide information:** MS Society information about Benefits and MS (ES09) and see our volunteer website for details about helping people to understand benefits – <http://volunteers.mssociety.org.uk/news/2012/08/helping-people-understand-benefits>
- ▲ **Signpost to advice:** Benefits Enquiry Line, Turn To Us, and/or other agencies listed in **appendix 2**

Organising a benefits and MS event

Before you start to plan an event, it's a good idea for everyone to agree what you're trying to achieve. Running an event involves considerable investment in time and resources.

Who needs to be involved?

Chairperson – you need to agree who will chair your event. This person should be an MS Society representative with a good understanding of the work of the MS Society and our strategy. This role could be fulfilled by a branch chair, council member, trustee, staff or support volunteer experienced or trained to give presentations.

You can find an **event chairperson brief** in **appendix 3**.

Benefits adviser – you need to plan your benefits and MS event with a specialist benefits adviser who will deliver a session on the support available.

You can find a **benefits expert brief** in **appendix 4**. You can also find an **MS insight** for external speakers in **appendix 5**.

MS focus speaker – an MS focus session can be delivered by someone who has MS, a support volunteer or an MS nurse.

You can find an **MS focus brief** in **appendix 6**.

Information to make available

An event is an opportunity to provide information and details of further support and services available. You should offer the following information:

- ▲ **MS Society booklets:** have copies available or tell people how they can order them directly – see <http://www.mssociety.org.uk/ms-support/publications-and-library>
- ▲ Signpost to local services of information and advice: see **appendix 2 – directory of key signposting organisations**
- ▲ MS Society **national and local** support and services – <http://www.mssociety.org.uk/about-us/what-we-do>
- ▲ How people can get involved: <http://www.mssociety.org.uk/get-involved>

Further event resources

You can find **presentation notes** for the MS Society and MS focus sessions in **appendix 7** and a sample **event programme** in **appendix 8**.

You can find a number of resources to help you plan and organise your event, presentation slides and notes for the MS Society and MS focus sessions on our volunteer website, <http://volunteers.mssociety.org.uk/offering-support-people-affected-ms/giving-information>

These include guidance on:

- ▲ where to start – event planning template, deciding objectives, finding a venue and planning your publicity
- ▲ on the day – briefing your helpers, registration and refreshments, and feedback forms
- ▲ afterwards – evaluating your event, recording useful information and thanking those involved

Risk management

If your branch or national support group committee has received events risk management training, you must complete the appropriate risk assessment and ensure you address all actions as you plan your event. Speak to your **local staff member** or the **Branch Health and Safety Officer** if you have any questions.

Evaluating your event

Gathering data (monitoring) to evaluate your information event can help us all improve the way we support people affected by – it can provide a wealth of useful information to help you:

- ▲ find out whether the event met your delegates' **expectations**
- ▲ produce an event evaluation report and share it with members at your branch or group **annual meeting**
- ▲ publicise your branch or group locally with a **press release** about how your event went
- ▲ **inspire** other branches and groups by sharing details of your event at forums or meetings organised by your local staff team
- ▲ **identify** local issues and needs
- ▲ establish future MS Society **priorities**
- ▲ **demonstrate** to health and social care professionals or potential funding sources how you support your MS community

Appendix 1 – Contact information

Helpline

Phone: 0808 800 8000

Email: helpline@mssociety.org.uk

Development Team (Northern Ireland)

Phone: 02890 802802

Email: NIDevelopmentTeam@mssociety.org.uk

Volunteering Team

Phone: 020 8438 0944

Email: volunteering@mssociety.org.uk

Where are these people based?

The contacts in the list above are based at the UK MS National Centre (address below) unless a specific nation is given in brackets, in which case they are at the relevant national office listed below.

Your local staff member

Local network officers (LNO) are there to work alongside you. Please contact the LNO in your area.

MS Society offices

MS National Centre

372 Edgware Road, London NW2 6ND

Phone: 020 8438 0700

Email: info@mssociety.org.uk

MS Society Scotland

Ratho Park, 88 Glasgow Road, Ratho Station, Newbridge EH28 8PP

Phone: 0131 335 4050

Email: enquiries@mssocietyscotland.org.uk

MS Society Cymru

Temple Court, Cathedral Road, Cardiff CF11 9HA

Phone: 029 20 786676

Email: mscymru@mssociety.org.uk

MS Society Northern Ireland

The Resource Centre

34 Annadale Avenue, Belfast BT7 3JJ

Phone: 028 9080 2802

Email: info@mssocietyni.org.uk

The MS Helpline

The MS Helpline offers emotional support and information to anyone affected by MS in the UK. You should give the helpline contact details to anyone you think could benefit:

- ▲ Freephone helpline 0808 800 8000
- ▲ Helpline email service: helpline@mssociety.org.uk

Appendix 2 – Directory of resources and organisations

All benefits information and advice

Organisation	Relevant Service Information	Contact	Website
Benefits entitlements	Online benefits adviser tool for benefits and tax credits.	For contact details see specific benefits for new claims or once claim is made (not free phone line) – see PIP, ESA, DLA and AA (Attendance Allowance)	https://www.gov.uk/disability-benefits-helpline https://www.gov.uk/benefits-adviser
Turn 2 Us	Money, Benefits and grants information Benefits checks online free confidential helpline	Tel: 0808 802 2000 (Mon to Fri 8am to 8pm)	http://www.turn2us.org.uk www.benefitsawareness.org.uk
Citizens Advice	Advice including benefits, housing, employment, etc with UK nations specific networks	Tel: 08444 111 444 or TextRelay users should call 08444 111 445	www.citizensadvice.co.uk and local bureau's contact details
DIAL / SCOPE (Disability Information and Advice Line)	DIAL is an independent network of local disability information and advice services run by and for disabled people.	SCOPE helpline: 01302 310123 dialnetwork@scope.org.uk.	http://www.scope.org.uk/dial To find DIAL local group
Money Advice Service	Free and impartial advice service. An independent service, set up by government, working in partnership with other organisations to help people make the most of their money.	Tel: 0300 500 5000 (Mon-Fri 8am-8pm; Sat 9am-1pm)	https://www.moneyadvice.service.org.uk/en/categories/universal-credit-and-other-benefits
Disability Rights UK	Provides information on benefits – does not give individual advice.	enquiries@disabilityrightsuk.org see Equality Advisory Support Service (EASS)	www.disabilityrightsuk.org

Benefit specific information and advice

Organisation	Relevant Service Information	Contact	Website
Personal Independence Payment (PIP)	Enquiry line for new claims and once you have made a claim for Personal Independence Payment (PIP)	<p>New claims only: Tel: 0800 917 2222 Textphone: 0800 917 7777 (Mon-Fri 8am to 6pm)</p> <p>Once you've made a claim: Tel: 0845 850 3322 Textphone: 0845 601 6677 (Mon-Fri 8am to 6pm)</p>	<p>https://www.gov.uk/pip/how-to-claim</p> <p>PIP checker: https://www.gov.uk/pip-checker</p>
Employment Support Allowance (ESA) via Jobcentre Plus	You can start your claim for ESA by calling the Jobcentre Plus claim-line The claim-line should put you through to your nearest Jobcentre Plus contact centre Phone or email your local Jobcentre Plus office about a claim you've already made.	<p>New benefit claims only (Mon-Fri 8am to 6pm) Tel: 0800 055 6688 Textphone: 0800 023 4888</p>	<p>https://www.gov.uk/contact-jobcentre-plus</p>
Universal Credit claim process and helpline	Initial claim is done online. Local council will be able to provide internet access and face-to-face advice or use computers at your local Jobcentre. The phone helpline is only after you've made a claim and if your circumstances change.	<p>Telephone: 0845 600 0723 Textphone: 0845 600 0743</p>	<p>https://www.gov.uk/universal-credit/what-you-need-to-do</p> <p>https://www.gov.uk/universal-credit/after-youve-made-your-claim</p>
Disability Living Allowance (DLA)	Enquiry line for DLA (Disability Living Allowance)	<p>Tel: 08457 123 456 Textphone: 08457 224 433 (Mon-Fri 8am to 6pm) dcpu.customer-services@dwp.gsi.gov.uk (if 16 or over) midlands-dbc-customer-services@dwp.gsi.gov.uk (if you're under 16)</p>	<p>http://www.scope.org.uk/dial To find DIAL local group</p>

Organisation	Relevant Service Information	Contact	Website
Attendance Allowance (AA)	Enquiry line once you have made a claim for AA (Attendance Allowance)	Tel: 08457 123 456 Textphone: 08457 224 433 (Mon-Fri 8am to 6pm) attendance.allowance.enquiries@dwp.gsi.gov.uk	https://www.gov.uk/disability-benefits-helpline
Carers Allowance Unit (enquiries)	Info on Carers Allowance	Tel: 0845 608 4321	www.dwp.gov.uk ; direct.gov.uk/disabledpeople
Tax Credits Helpline	If you're new to tax credits, contact the Tax Credit Helpline for a claim form. You can't apply online or download the form and it takes up to 2 weeks to arrive. You don't need a claim form if you're already claiming tax credits – just call the helpline to update your claim.	Tel: 0345 300 3900 Textphone: 0345 300 3909 Outside the UK: +44 2890 538 192 (Mon-Fri, 8am to 8pm and Sat 8am to 4pm)	https://www.gov.uk/claim-tax-credits
Council Tax reduction	Local Council Tax Reduction schemes have replaced Council Tax Benefit and Second Adult Rebate. This tool is currently being updated – contact your local council about Council Tax Reduction.	Available in England, Scotland and Wales. If you live in Scotland or Wales, contact your council directly Not available in Northern Ireland.	https://www.gov.uk/council-tax-reduction
Social Security and Child Support (SCSS)	Information about child maintenance from the Child Support Agency (CSA). Appeal to the Social Security and Child Support Tribunal if you disagree with a decision about benefits, tax credits or a child support payment See 'Venue Finder' on website to find details of local offices.	Tel: 0845 713 3133 Textphone: 0845 713 8924 (Mon to Fri 8am to 8pm; Sat 9am to 5pm)	https://www.gov.uk/child-support-agency https://www.gov.uk/social-security-child-support-tribunal

Other organisations for information and advice related to claiming benefits

Organisation	Relevant Service Information	Contact	Website
Equality Advisory Support Service (EASS)	A government funded helpline on discrimination issues – replaced the Equality and Human Rights Commission (EHRC) Helpline.	Tel: 0808 800 0082 Textphone 0808 800 0084 (Mon-Fri 9am to 8pm; Sat 10am to 2pm – closed on Sundays and Bank Holidays)	http://www.equalityhumanrights.com/about-us/equality-advisory-support-service/ http://www.equalityadvisoryservice.com/
Motability	A UK-wide charity that allows disabled people to lease a car, scooter or electric chair, using their government-funded mobility allowance	Tel: 0845 456 4566 Textphone: 0845 675 0009	www.motability.co.uk http://www.motability.co.uk/understanding-the-scheme/pip-and-motability/q-and-a-transitional-support-package
Carers and Benefits	Carers UK information on benefits for carers	Tel: 020 7378 4999 info@carersuk.org	Carers UK FAQs Carers UK guide to carers' rights and benefits 2012/13
ATOS Healthcare	Their role is to give medical advice to help DWP decision makers reach an appropriate decision on entitlement to benefit. You can contact them directly to discuss you appointment relating with a claim for PIP or ESA	PIP Customer Service: Appointment line & Customer Service PIP-customerservice@atos.net ESA/WCA Customer Service: 0800 2888 77 Email: WCA Customer Service Atos helpline for clinicians: 0800 288 8777	http://www.atoshealthcare.com/services/disability_assessment
Capita Health & wellbeing	Their role is to run disability assessment services to students, employers, employees and people looking to help DWP decision makers reach an appropriate decision on entitlement to Personal Independent Payments claim	haqeeq.bostan@capita.co.uk	http://www.capitahealthandwellbeing.co.uk/our-services/medical-and-wellbeing-services/disability-assessments

Legal, advocacy and debt management organisations

Organisation	Relevant Service Information	Contact	Website
Disability Law Service (DLS)	DLS provides advice and information on welfare benefits. They also provide a casework service, and support at any level of the legal system. – not available in Scotland	Tel: 020 7791 9800 Email: msadvice@dls.org.uk Post: Disability Law Service, 39-45 Cavell Street, London, E1 2BP Filling in the enquiry form	http://www.dls.org.uk/advice/ms/index.html
Community Legal Advice	Legal aid can help you pay for legal advice, mediation or representation in court if you can't afford it. This could include help for housing, debt, work, family, benefits or education problems	Tel: 0845 345 4 345 Minicom: 0845 609 6677 (Mon-Fri: 9am-8pm – Sat: 9am-12:30pm)	https://www.gov.uk/legal-aid/overview Community Legal Advice online: https://claonlineadvice.justice.gov.uk/
Advice Now	Advicenow is an independent, not-for-profit website providing accurate, up-to-date information on rights and legal issues for the general public. They do not give advice or respond to queries.	Information and signposting website only	http://www.advicenow.org.uk/
National Debtline	A national helpline that provides free confidential and independent advice on how to deal with debt problems.	Tel: 0808 808 4000 (Mon-Fri 9am-9pm / Sat 9.30am-1pm)	www.nationaldebtline.co.uk
Payplan	A national organisation that provides free debt advice.	Freephone: 0800 280 2816 (Mon-Fri 8am-9pm) Mobile phone call cheaper on 0207 760 8980 Web form enquiry via I enquiry	www.payplan.com

Northern Ireland, Scotland and Wales

Organisation	Relevant Service Information	Contact	Website
Benefit Enquiry Line Northern Ireland	Benefits info	Tel: 0800 22 06 74; Minicom: 0800 243 787 (for deaf & hard of hearing users only)	www.nidirect.gov.uk/benefit-enquiry-line
Citizens Advice Northern Ireland Scotland Wales	Advice including benefits, housing, employment, etc with UK nations specific networks	Scotland Citizens Advice Direct: 0808 800 9060 Wales: 08444 77 20 20	Scotland please go to www.cas.org.uk Northern Ireland go to www.citizensadvice.co.uk and local bureau's contact details Wales local bureau's contact details
ESA (Employment Support Allowance) via Jobcentre Plus Northern Ireland	You can start your claim for ESA by calling the Jobcentre Plus claim-line The claim-line should put you through to your nearest Jobcentre Plus contact centre Phone or email your local Jobcentre Plus office about a claim you've already made.	New benefit claims only (Mon-Fri, 8am to 6pm): Northern Ireland: 0800 085 6318 – textphone: 0800 328 3419	https://www.gov.uk/contact-jobcentre-plus
Update Scotland	Disability information, advice and signposting to individuals and organisations in Scotland	Tel: 0131 669 1600 (free confidential helpline) info@update.org.uk	http://www.update.org.uk

Appendix 3 – Event chairperson brief

MS Society information events aim to help people understand the options, support and services available to enable them make informed decisions about their lives.

Benefits & MS information events

Benefits and MS events aim to provide people affected by MS with up-to-date information about benefits entitlements, the application, assessment and appeals processes, and where to access support and specialist advice.

Audience

Anyone affected by MS who wants to find out more about benefits and understand how changes might affect them. *[Or more specific audience depending on which benefit(s) the event will focus on]*

The aims of the benefits and MS session are to:

- ▲ Provide an overview of disability benefits, with details of entitlements and application, assessment and appeals process.
[the benefit(s) in focus will depend on MS Society assessed local needs, targeted audience and situation of benefits at the time of the event following guidance from the benefits adviser]
- ▲ Provide an overview of what people may need to explain about their MS if applying for benefits or being reassessed
- ▲ Provide an overview of the MS Society role and work with benefits advice organisations
- ▲ Signpost people affected by MS to local services providing benefits advice

By the end of the session, participants will:

- ▲ Know about their entitlements and the application, assessment and appeals processes
- ▲ Know about the planned changes *[any changes still under consultation can be mentioned but details should be avoided to focus on what people can do at the time of the event and where they can find out more when the changes are in place]*
- ▲ Understand the importance of explaining the impact of MS in detail
- ▲ Know where to access information, support and advice on benefits

MS Society role

- ▲ The role of the MS Society in the context of these events is to provide information and an overview of some of the issues people may need to consider due to the nature of MS.
- ▲ The MS Society does not give advice on benefits but we are pleased to be able to work with other agencies that do.
- ▲ The MS Society produce information, provide support through a local network of volunteers and helpline and campaign for the rights of people affected by MS.

Benefits adviser role

This part is to be delivered by a qualified benefits adviser from an external agency

- ▲ To provide an overview of disability benefit(s) entitlements criteria, application, assessment and appeal process and planned changes.
 - *The benefit(s) in focus will depend on MS Society assessed local needs, targeted audience and situation of benefits at the time of the event following guidance from the benefits adviser*
 - *Any changes still under consultation can be mentioned but details should be avoided to focus on what people can do at the time of the event and where they can find out more when the changes are in place*
- ▲ If knowledgeable about MS, having experience with MS clients or available to work with the MS Society about key aspects of MS (see MS focus brief) to provide an overview of some of the issues people may need to consider due to the nature of MS.
- ▲ If available as an option on the day, to answer individual enquiries from delegates, a benefits checker session or written enquiries to be answered after the event (following a workable deadline agreed with the adviser)

MS focus role

This part is to be delivered by someone with experience of MS (who has MS, lives with someone with MS, a specialist professional or someone who works or supports people affected by MS)

- ▲ To provide an overview of some of the issues people may need to consider when applying for or being assessed for benefits, with particular emphasis to reflect MS in forms and assessment.

This overview aims to give people practical insights about giving details of the impact of their MS in their daily life:

- ▲ providing detailed information about how MS impacts on their ability to do activities
- ▲ ensuring they get relevant supporting medical evidence.

Event programme (sample based on a 2.5 hours seminar and Q&A)

- ▲ Welcome and overview of the event (15mins)
 - The role of the MS Society
 - Further Information and support available
- ▲ Overview of benefits entitlements, process and planned changes (this may include PIP or ESA) – (45mins to 1 hour)
 - Application, assessment and appeals process
 - Importance and details about supporting information, what to expect?
- ▲ MS focus: the impact of MS (30mins)
 - Thinking about how to reflect MS in universal application and assessment tools
- ▲ Further Information and support available
Handouts, publications and signposting list
- ▲ Questions and answers (45mins)
General Q&A session to the panel of speakers

- ▲ Individual enquiries, if planned and agreed with the benefits adviser could be:
 - additional individual questions time on the day
 - a planned benefits checker session
 - written enquiries to be answered after the event (with deadline agreed with the adviser)

Other format and session options can include:

- ▲ questions shared in advance to ensure speakers can address in their presentation
- ▲ question time (with questions put to speakers in advance of the session)
- ▲ benefits checker session
- ▲ written enquiries to be answered after the event (following a workable deadline agreed with the adviser)

[These suggestions can be customised to meet your activity plans]

Suggested introduction (5-10 minutes) – chairperson

- ▲ Thank you all for coming and welcome to this event
- ▲ Introducing yourself (biographies in handouts)
- ▲ Health and safety and accessible facilities
- ▲ Format of the event
Describing the programme and format of the event
- ▲ Delegate's pack – you have been given a delegate's pack which includes today's speakers' biographies and presentations, and further resources and information on benefits from the MS Society and services and support available, including detailed information booklets.
- ▲ Speakers and questions – there will be time after the talk to ask questions of the speakers. Speakers have limited time and will not be able to stay much longer than the allocated time.
- ▲ If available as an option on the day – answers to individual enquiries from delegates, a benefits checker session or written enquiries to be answered after the event (following a workable deadline agreed with the adviser)
- ▲ Introduce MS Society representatives present on the day (list) and identify their roles and how they can help.

Chairperson presentation slides (10-15 minutes)

- ▲ Slides: Welcome and overview
The MS Society does not give advice on benefits but we are pleased to be able to work with other agencies that do. This is because:
 - Benefits are complex and change regularly.
 - We risk doing a disservice to people if we provide information based on out of date information or training.
 - Through engaging with CABs or other benefits advice services as guest speakers at events we can continue to develop effective partnerships locally, providing support to people with and affected by MS.
 - The MS Society is not insured to give advice

▲ Slides: Further information and support

Provide an overview of the information and support the MS Society can provide:

- Helpline for emotional support
- Lobbying and campaigning: The MS Society works to ensure that these changes have the least impact on you. We know that some benefit assessment processes don't work as well as they should for people with MS and we campaign to improve them. We would welcome any feedback on how the assessment process was for you so we can inform this work.
- Encourage people to share their stories to help us campaign – see handout for details – link to survey on our website.
- Current changes in benefits can bring concerns and make people worry so it is really important you understand your entitlements and know where to seek support and get advice from a benefits advice service – signpost people to the handout with details of a range of national and local support services
- Across the UK, billions of pounds are unclaimed each year – make sure you get what you are entitled to. Political and media rhetoric can have a detrimental effect on public perceptions of benefits claimants. Despite what is said, in 2012 only 0.7% of total benefit expenditure was overpaid due to fraud and fraud made up a smaller share of the welfare bill last year than it did in 2010/11 or 2009/10 – following the **Department for Work and Pension's own figures** (http://statistics.dwp.gov.uk/asd/asd2/index.php?page=fraud_error).

Questions and answer session (30 mins)

Facilitated by the chairperson

Speakers, MS Society representatives and other organisations in attendance available for questions.

There will be 1 roving microphone available for delegates (people must use them to ensure everyone in the room can hear them)

Suggested end of talk (5-10 mins) – chairperson

Thank you to everyone for coming today, and thanks to the speakers for their insight.

For the latest on benefits changes and what the MS Society is doing about it, visit our website <http://www.mssociety.org.uk>

How you can get involved:

▲ Share your story about your experience

▲ Get involved in the campaigns network

▲ Other ways

See campaigns <http://www.mssociety.org.uk/get-involved/campaigns>

Feedback

At the end of the pack you will also find a feedback and monitoring form which we will ask you to complete and hand to one of the MS Society representatives at the end of the talk.

Appendix 4 – Benefits expert brief

[This brief can be customised to meet your activity plans]

MS Society information events aim to help people understand the options, support and services available to enable them make informed decisions about their lives.

Benefits & MS information events

Benefits and MS events aim to provide people affected by MS with up-to-date information about benefits entitlements, the application, assessment and appeals processes, and where to access support and specialist advice.

Audience

Anyone affected by MS who wants to find out more about benefits and understand how changes might affect them. *[Or more specific audience depending on which benefit(s) the event will focus on]*

The aims of the benefits and MS session are to:

- ▲ Provide an overview of disability benefits, with details of entitlements and application, assessment and appeals process.
[the benefit(s) in focus will depend on MS Society assessed local needs, targeted audience and situation of benefits at the time of the event following guidance from the benefits adviser]
- ▲ Provide an overview of what people may need to explain about their MS if applying for benefits or being reassessed
- ▲ Provide an overview of the MS Society role and work with benefits advice organisations
- ▲ Signpost people affected by MS to local services providing benefits advice

By the end of the session, participants will:

- ▲ Know about their entitlements and the application, assessment and appeals processes
- ▲ Know about the planned changes *[any changes still under consultation can be mentioned but details should be avoided to focus on what people can do at the time of the event and where they can find out more when the changes are in place]*
- ▲ Understand the importance of explaining the impact of MS in detail
- ▲ Know where to access information, support and advice on benefits

MS Society role

- ▲ The role of the MS Society in the context of these events is to provide information and an overview of some of the issues people may need to consider due to the nature of MS.
- ▲ The MS Society does not give advice on benefits but we are pleased to be able to work with other agencies that do.
- ▲ The MS Society produce information, provide support through a local network of volunteers and helpline and campaign for the rights of people affected by MS.

Benefits adviser role

This part is to be delivered by a qualified benefits adviser from an external agency

- ▲ To provide an overview of disability benefit(s) entitlements criteria, application, assessment and appeal process and planned changes.
 - *The benefit(s) in focus will depend on MS Society assessed local needs, targeted audience and situation of benefits at the time of the event following guidance from the benefits adviser*
 - *Any changes still under consultation can be mentioned but details should be avoided to focus on what people can do at the time of the event and where they can find out more when the changes are in place*
- ▲ If knowledgeable about MS, having experience with MS clients or available to work with the MS Society about key aspects of MS (see MS focus brief) to provide an overview of some of the issues people may need to consider due to the nature of MS.
- ▲ If available as an option on the day, to answer individual enquiries from delegates, a benefits checker session or written enquiries to be answered after the event (following a workable deadline agreed with the adviser)

Event programme (sample based on a 2.5 hours seminar and Q&A)

- ▲ Welcome and overview of the event (15mins)
 - The role of the MS Society
 - Further Information and support available
- ▲ Overview of benefits entitlements, process and planned changes (this may include PIP or ESA) – (45mins to 1 hour)
 - Application, assessment and appeals process
 - Importance and details about supporting information, what to expect?
- ▲ MS focus : the impact of MS (30mins)
 - Thinking about how to reflect MS in universal application and assessment tools
- ▲ Further Information and support available
Handouts, publications and signposting list
- ▲ Questions and answers (45mins)
General Q&A session to the panel of speakers
- ▲ Individual enquiries – if planned and agreed with the benefits adviser could be:
 - Additional individual questions time on the day
 - a planned benefits checker session
 - written enquiries to be answered after the event (with deadline agreed with the adviser)

Other format and session options can include:

- ▲ questions shared in advance to ensure speakers can address in their presentation
- ▲ question time (with questions put to speakers in advance of the session)
- ▲ benefits checker session
- ▲ written enquiries to be answered after the event (following a workable deadline agreed with the adviser)

Benefits (45mins-1 hour)

For each benefit covered:

Overview of benefits planned changes

- ▲ What are the key changes being planned? (with dates and details of who it may impact)

Application process

- ▲ How to apply
- ▲ The importance of supporting evidence and what to expect.
What evidence to provide (supporting statements, diaries)
- ▲ Exceptional circumstances

Assessment

- ▲ Examples of tasks being assessed and the focus of questions: fluctuating nature of MS (refer to resources in the handouts, MS Society publications)

Appeals

- ▲ The appeals and tribunals process and things to consider
- ▲ Exceptional circumstances
- ▲ Signpost to advice agencies

MS focus role

This part is to be delivered by someone with experience of MS (who has MS, lives with someone with MS, a specialist professional or someone who works or supports people affected by MS)

- ▲ To provide an overview of some of the issues people may need to consider when applying for or being assessed for benefits, with particular emphasis to reflect MS in forms and assessment.

This overview aims to give people practical insights about giving details of the impact of their MS in their daily life:

- ▲ Providing detailed information about how MS impacts on their ability to do activities
- ▲ Ensuring they get relevant supporting medical evidence

Resources:

- ▲ MS Society website www.mssociety.org.uk

Publications:

- ▲ What is MS?
- ▲ Benefits and MS (ES09)
- ▲ Claiming Personal Independence Payment (ES30)
- ▲ Employment and Support Allowance (ESA) (ES29)
- ▲ MS insight
- ▲ MS focus brief

Presentation and reference material

- ▲ A projector will be available to use PowerPoint slides for your presentation.
- ▲ Please email your presentation and any reference material and signposting details at least a week before the event so that we can organise printed handouts for all participants.
- ▲ Participants often value having a handout of the presentation slides.
Please confirm that you would be happy for us to make print outs of your presentation.

Many thanks for supporting us by taking part in this event.

Appendix 5 – MS insight for external speaker

Resources:

- ▲ MS Society website www.mssociety.org.uk
- ▲ Publications:
 - What is MS?
 - Benefits and MS (ES09)
 - Claiming Personal Independence Payment (ES30)
 - Employment and Support Allowance (ES29)

Common areas of daily life where functional restriction occurs:

[What areas of daily life will a person with MS find challenging?]

Multiple sclerosis (MS) is a neurological condition – it affects the brain and the spinal cord. The particular symptoms that someone has will depend on which part of the brain or spinal cord is involved, and the function of the affected nerves.

MS is a very individual condition, so no two people will be affected in the same way.

Because of the wide-ranging nature of MS symptoms, they can affect all areas of daily life.

Someone's symptoms can fluctuate from day-to-day and from hour-to-hour: a task that they could complete easily one day might be impossible the next, or they may complete the task but be unable to do anything else for the rest of the day.

Common symptoms include:

- ▲ Fatigue – an overwhelming sense of tiredness making physical or mental activity difficult or even impossible
- ▲ Sensory problems – such as numbness or tingling
- ▲ Visual problems – such as blurred or double vision, or a temporary loss of sight in one or both eyes
- ▲ Dizziness – sometimes called vertigo, which can make it difficult for someone to move about safely
- ▲ Pain – which can make sitting or standing in one position for any length of time difficult or impossible
- ▲ Loss of muscle strength and dexterity – which can affect almost all daily activities, including getting up, getting dressed, personal care, preparing food etc
- ▲ Problems with walking, balance and coordination - which can make it difficult for someone to move about safely
- ▲ Muscle stiffness and spasms – tightening or rigidity in particular muscle groups, sometimes known as spasticity, which can limit their movement
- ▲ Difficulties with speech – which can make it difficult for other people to understand them
- ▲ Difficulties swallowing – which can make eating and drinking difficult

- ▲ Bladder and bowel problems – these can include incontinence, constipation/urinary retention, and frequency
- ▲ Problems with memory and thinking, also known as ‘cognitive problems’ – such as forgetting names and words, finding it difficult to concentrate, or taking longer to process information

More information about the symptoms of MS can be found on our website:

<http://www.mssociety.org.uk/what-is-ms/signs-and-symptoms>

Commonly reported variability in functional restrictions:

[Does the impact of MS on daily life can vary from time to time?

What aspects of daily living can be worse and what might be constant?]

Different types of MS

There are different types of MS. Most people are diagnosed with relapsing remitting MS, which means they will have relapses or attacks of symptoms, followed by periods of remission. In many cases, this progresses over a period of 10-15 years to become secondary progressive, which means that symptoms get progressively worse with no periods of remission.

Variability of symptoms

Don't assume when you're talking to someone with MS that this is how they always are – they may be having a good day. MS symptoms can vary enormously from one day to the next – even from one hour to the next. They might last for a few hours, or for days, weeks or months. Some people find certain triggers – such as heat, stress, exertion or tiredness – make their symptoms worse, or make old symptoms reappear.

Unreliability of repetition

The criteria for assessing whether someone can do an activity, repeatedly, reliably, safely and in a timely manner will be particularly applicable to those with MS

- ▲ If someone is having a ‘good day’ they may be able to complete a task which would be impossible for them on a ‘bad day’.
- ▲ They may be able to carry out a task once, but be unable to do anything else for the rest of the day. For example, someone may only be able to walk a short distance before symptoms such as pain, muscle weakness, vertigo or fatigue mean they need to sit down and rest.
- ▲ They may be able to carry out a task in some circumstances, but under different circumstances – in a busy environment, in a set time, or following other activities – they may be unable to.

Difficulty managing MS

MS is a progressive condition, so it will not get better over time, nor can it be completely controlled with medication. There are disease modifying drugs that can reduce the number of relapses or ‘attacks’ that someone has – but only if they have the relapsing remitting form of MS, and even with this medication someone will still have symptoms. There is, as yet, no medication that can slow or stop progression in MS.

Common misconceptions about MS:

[What kind of areas might a claimant find hard to mention or perhaps understate the importance? What areas which might impact on daily living are least well understood or hardest to identify? How is it best to ask about these elements? What kind of evidence is likely to best convey the impact of MS on an individual?]

MS affects everyone differently. No two people will have the same symptoms, and it's impossible to predict how someone will be affected. The only way to know how someone is affected is to ask them.

Many of the symptoms are invisible to other people. Someone may appear to look well but may be experiencing debilitating fatigue, pain or other problems.

People with MS have good days and bad days. How they are on any given day is not how they are going to be all the time.

Fatigue – an overwhelming sense of tiredness with no obvious cause – is one of the most common symptoms of MS. For many people, it is the symptom that affects them most, and can stop them from carrying out even basic actions.

Bladder and bowel problems are common in people with MS, but many people don't feel comfortable talking about them. Some people may be reluctant to leave their house for fear of having a bladder or bowel accident.

Depression is far more common among people with MS than the general population. Someone who is depressed may be reluctant to talk about it.

Relapses can come on very suddenly, with no warning. They can last anything from 24 hours to weeks or even months. In some cases, people may recover completely between relapses, particularly in the early stages of MS, but in other cases they may be left with residual symptoms.

MS is progressive, and there is no cure. As the condition progresses, the person with MS will need more and more care and support.

Communication approach to claimant with MS recommended to assessors:

[What are the best communication approaches to engage with someone with MS?]

Some people with MS may have cognitive difficulties, which may mean they find it difficult to take in and process information. They may need longer than other people to respond to questions. Some people with MS may have speech difficulties which make it harder for them to speak clearly.

Communication tips:

- ▲ Give the person time and wait for their response. Some people with MS find it difficult to think properly when they're put on the spot – so try to put them at ease, and don't pressure them to answer immediately
- ▲ Make your questions as clear as possible, and be prepared to repeat a question if necessary
- ▲ Don't assume that because someone has speech difficulties that they have cognitive difficulties
- ▲ If you haven't understood something, say so. If necessary, repeat it back to them to make sure you've understood
- ▲ Remember that speaking can be tiring for someone with MS, particularly if they have speech difficulties
- ▲ If someone has a carer or supporter with them, ask them for clarification on anything you don't understand or the person with MS is unable to explain

Appendix 6 – MS focus brief

[This brief can be customised to meet your activity plans]

MS Society information events aim to help people understand the options, support and services available to enable them make informed decisions about their lives.

Benefits & MS information events

Benefits and MS events aim to provide people affected by MS with up-to-date information about benefits entitlements, the application, assessment and appeals processes, and where to access support and specialist advice.

Audience

Anyone affected by MS who wants to find out more about benefits and understand how changes might affect them. *[Or more specific audience depending on which benefit(s) the event will focus on]*

The aims of the benefits and MS session are to:

- ▲ Provide an overview of disability benefits, with details of entitlements and application, assessment and appeals process.
[the benefit(s) in focus will depend on MS Society assessed local needs, targeted audience and situation of benefits at the time of the event following guidance from the benefits adviser]
- ▲ Provide an overview of what people may need to explain about their MS if applying for benefits or being reassessed
- ▲ Provide an overview of the MS Society role and work with benefits advice organisations
- ▲ Signpost people affected by MS to local services providing benefits advice

By the end of the session, participants will:

- ▲ Know about their entitlements and the application, assessment and appeals processes
- ▲ Know about planned changes to benefits *[any changes still under consultation can be mentioned but details should be avoided to focus on what people can do at the time of the event and where they can find out more when the changes are in place]*
- ▲ Understand the importance of explaining the impact of MS in detail
- ▲ Know where to access information, support and advice on benefits

MS Society role

- ▲ The role of the MS Society in the context of these events is to provide information and an overview of some of the issues people may need to consider due to the nature of MS.
- ▲ The MS Society does not give advice on benefits but we are pleased to be able to work with other agencies that do.
- ▲ The MS Society produces information, provides support through a local network of volunteers and helpline, and campaigns for the rights of people affected by MS.

Benefits adviser role

This part is to be delivered by a qualified benefits adviser from an external agency

- ▲ To provide an overview of disability benefit entitlement criteria, application, assessment and appeal process and planned changes.
 - *The benefit(s) in focus will depend on MS Society assessed local needs, targeted audience and situation of benefits at the time of the event following guidance from the benefits adviser*
 - *Any changes still under consultation can be mentioned but details should be avoided to focus on what people can do at the time of the event and where they can find out more when the changes are in place*
- ▲ If knowledgeable about MS, having experience with MS clients or available to work with the MS Society about key aspects of MS (see MS focus brief), to provide an overview of some of the issues people may need to consider due to the nature of MS.
- ▲ If available as an option on the day, to answer individual enquiries from delegates, a benefits checker session or written enquiries to be answered after the event (following a workable deadline agreed with the adviser)

MS focus role

This part is to be delivered by someone with experience of MS (who has MS, lives with someone with MS, a specialist professional or someone who works or supports people affected by MS)

- ▲ To provide an overview of some of the issues people may need to consider when applying for or being assessed for benefits, with particular emphasis to reflect MS in forms and assessment.

This overview aims to give people practical insights about giving details of the impact of their MS in their daily life:

- ▲ Providing detailed information about how MS impacts on their ability to do activities
- ▲ Ensuring they get relevant supporting medical evidence

MS focus and key messages:

MS focus on:

- ▲ What to consider when applying for benefits depending on how your MS affects you
- ▲ What you may need to explain about the nature of MS and its impact on your ability to do tasks
- ▲ Further Information & support available

Key messages:

- ▲ The forms are 'universal' with standard questions – everyone who applies for that benefit fills in that form so it may not seem obvious at first how you relate your MS to the questions
- ▲ People assessing your form may not know anything about MS
- ▲ Many of the people who read the forms will have read lots before, but they don't know you or anything about you, other than what you put on the form

It is important to explain:

- ▲ how your symptoms affect you most of the time
- ▲ how your condition / symptoms fluctuate
- ▲ how your condition impacts on your ability to do tasks repeatedly, reliably and safely

Resources:

Presentation PowerPoint slides and notes for more details and guidance on each of these points.

Event programme (sample based on a 2.5 hours seminar and Q&A)

- ▲ Welcome and overview of the event (15mins)
 - The role of the MS Society
 - Further Information and support available
- ▲ Overview of benefits entitlements, process and planned changes (this may include PIP or ESA) – (45mins to 1 hour)
 - Application, assessment and appeals process
 - Importance and details about supporting information, and what to expect
- ▲ MS focus : the impact of MS (30mins)
 - Thinking about how to reflect MS in universal application and assessment tools
- ▲ Further Information and support available
Handouts, publications and signposting list
- ▲ Questions and answers (45mins)
General Q&A session to the panel of speakers
- ▲ Individual enquiries, if planned and agreed with the benefits adviser could be:
 - additional individual questions time on the day
 - a planned benefits checker session
 - written enquiries to be answered after the event (with deadline agreed with the adviser)

Other format and session options can include:

- ▲ Questions shared in advance to ensure speakers can address in their presentation
- ▲ Question time (with questions put to speakers in advance of the session)
- ▲ Benefits checker session
- ▲ Written enquiries to be answered after the event (following a workable deadline agreed with the adviser)

Appendix 7 – Presentation notes

The aims of the session are to:

- ▲ Provide an overview of the disability benefits PIP and ESA with details of the application, assessment and appeals process
- ▲ Provide an overview of what people may need to explain if applying for benefits or being reassessed
- ▲ Provide an overview of the MS Society role and work with benefits advice organisations
- ▲ Signpost people with and affected by MS to local services providing support and benefits advice

By the end of the session, participants will be able to:

- ▲ Recognise the main changes to disability benefits
- ▲ Know where to access information, support and advice on benefits
- ▲ Acknowledge the possible difficulty and stress of the process
- ▲ Know where and how to access the support available

Audience:

- ▲ Anyone affected by MS who wants to find out more about DLA, PIP and ESA benefits and understand how changes might affect them.

Programme:

- ▲ Welcome and overview of the event
- ▲ The role of the MS Society
- ▲ Further information and support available
- ▲ Overview of PIP and ESA, led by a guest speaker
- ▲ Application, Assessment and Appeals process, led by a guest speaker
- ▲ What to consider when applying for benefits
- ▲ What you may need to explain
- ▲ Further Information & support available
- ▲ Q&A and opportunity for people to meet other organisations and services

Information about delivery

The role of the MS Society in the context of these events is to provide information and an overview of some of the issues people may need to consider when they are applying for or being reassessed for benefits.

The MS Society does not give advice on benefits but we are pleased to be able to work with other agencies that do.

We would encourage MS Society staff and volunteers to work with local agencies to source guest speakers to provide benefits expertise at awareness raising events and signpost to further individual support available after the event.

Agenda – Overview, running times and slides used

Section/objectives	Method	Materials	Time	Start time
1 Welcome and overview, including role of MS Society	Presentation	PowerPoint slides 1-6 Handout of presentation slides for all participants.	10 mins	
2 Overview of disability benefits, led by a guest speaker	Presentation	Dependant on guest speaker A separate PowerPoint presentation providing examples of the range of themes we require the guest speaker to cover, however they will submit their own presentation for this part.	45 mins	
3.1 What to consider when applying for benefits or being reassessed for benefits and why you need to consider this	Presentation	Slides 7-8 Handout as for section 1	5 mins	
3.2 What you may need to explain – fluctuation, hidden/silent symptoms and doing actions repeatedly, reliably, safely and timely	Presentation	Slides 9-11 Handout as for section 1	10 mins	
3.3 Summary and further information and support available	Presentation	Slides 12-13 Handout as for section 1	5 mins	
4 Discussion, Q&As	Facilitated discussion by Chair	Slide 14	30 mins	

1 Welcome & Introduction

Section objectives	Method	Materials	Time	Start time
Welcome and overview, including role of MS Society	Presentation	PowerPoint slides 1-6	10 mins	

Slide 2

Welcome and overview

- Purpose: overview of PIP and ESA.
- The MS Society does not give advice on benefits.
- But we are pleased to be able to work with other agencies that do.



- Welcome – safety / fire-exits, refreshments, toilets; guidelines for group
- Overview of the session: The purpose of today's session is to provide an overview of the disability benefits PIP and ESA
- The MS Society does not give advice on benefits but we are pleased to be able to work with other agencies that do, this is because:
 - Benefits are complex and change regularly and we may be at risk of doing a disservice to people if we provide information based on out of date information or training.
 - Through engaging with CABs or other benefits advice services as guest speakers at events we can continue to develop effective partnerships locally, providing support to people with and affected by MS.

Slides 3-4

MS Society Information

Information online or in publications:

- Benefits and MS
- Personal Independence Payments (PIP)
- Employment Support Allowance (ESA)



MS Society - Support

Developing local partnerships with advice agencies to ensure you get help when you need it.

Lobbying and campaigning to ensure fairness for people with MS.

Helpline 0808 800 8000



- Provide an overview of the information and support the MS Society can provide –
 - publications focused on Benefits, ESA and PIP
 - Helpline for emotional support
 - Lobbying and campaigning: The MS Society works to ensure that these changes have the least impact on you. We know that some benefit assessment processes aren't always working

as well as they should be for people with MS and we are looking to improve them. We would welcome any feedback on how the assessment process was for you so we can inform this work. Encourage people to share their stories to help us campaign – see handout for details – link to survey on our website.

- ▲ It is important to be clear about your entitlements and access the right support
- ▲ The current changes in benefits can bring concerns and make people worry so it is really important you seek support and get advice from a benefits advice service – signpost people to the handout with details of a range of national and local support services
- ▲ Across the UK, billions of pounds are unclaimed each year – make sure you get what you are entitled to. Political and media rhetoric can have a detrimental effect to the public perceptions of benefits claimants. Despite what is heard, in 2012 only 0.7% of total benefit expenditure was overpaid due to fraud, fraud made up a smaller share of the welfare bill last year than it did in 2010/11 or 2009/10 – following the **Department for Work and Pension's own figures** http://statistics.dwp.gov.uk/asd/asd2/index.php?page=fraud_error

Slide 5

Introductions

Name, MS Society role

- introducing and facilitating the event.

Name, Benefits advisor title

- giving an overview of recent and planned changes to disability benefits and of the application and assessment process.

Name, connection to MS / role

- providing an overview about some of the issues you may need to consider when you are applying for or being reassessed for benefits.

Also present today:



- ▲ Introduce the key speakers at the session
- ▲ Introduce any other professionals also in attendance – for example representatives from other organisations who may not actually be presenting i.e. Job Centre plus decision makers, DWP visiting service, local MS Specialist, MS Society volunteers and staff

Slide 6

Benefits Overview

Add details of external speaker:

Welfare rights advisor, CAB

Brief biography of speaker



- ▲ Introduce and welcome the guest speaker from a local benefits advice organisation and pass over to them to present about Disability Benefits: PIP & ESA
- ▲ This section will cover the Application, Assessment & Appeals process of both benefits

3.1 Considerations – general


Section objectives	Method	Materials	Time	Start time
What to consider when applying for benefits and why	Presentation	Slides 7-8	5 mins	

Slide 7

Focus on MS: impact of multiple sclerosis

Name, MS Society branch representative

- Brief Biography of speaker



- ▲ MS Society representative to present Focus on MS
- ▲ Introduction about the speaker – staff or volunteer role and involvement with the MS Society


Slide 8

What to consider when applying

It may not seem obvious at first how you relate your MS to the questions.

On the form and in supporting evidence it is important to:

- consider each of your symptoms
- and give as much information as possible as to how MS affects you



- ▲ The forms are ‘universal’ with standard questions – everyone who applies for that benefit fills in that form so it **may not seem obvious at first how you relate your MS to the questions**
- ▲ The form is written so that it can be filled in by people with lots of different conditions
- ▲ People assessing your form may not know anything about MS
- ▲ Many of the people who read the forms will have read lots before, but they don’t know you or anything about you, other than what you put on the form
- ▲ The forms aim to establish **how your condition impacts on you and your ability to work/stay independent** (depending on the benefit). So you need to **explain the impact of your symptoms**, not just what the symptoms are
- ▲ You have to explain how MS affects you – remember, MS affects everyone differently. The person reading the form needs to understand how MS affects you and your ability to do activities – you are the only person who can tell them so give as much detail as possible


3.2 Considerations – specifically relating to MS


Section objectives	Method	Materials	Time	Start time
What you may need to explain – fluctuation, silent & hidden symptoms and doing actions reliably, repeatedly and safely.	Presentation	Slides 9-11	10 mins	

Slide 9

What you may need to explain: fluctuation

- How your symptoms affect you *most of the time.*
- How your condition/ symptoms affects, fluctuates, or impacts on your ability to do tasks





- ▲ Explain how your symptoms affect you most of the time
- ▲ Explain how your condition / symptoms affects, fluctuates, or impacts on your ability to do tasks:
 - Do they affect you all day, every day, or just sometimes?
 - If sometimes, how often?
 - Explain about fluctuations – from hour to hour / day to day / week to week
 - Talk about bad and good days
 - Think about if there is anything you've stopped doing as a result of a symptom, or any extra support you need to do everyday things – and include this on the form.
- ▲ Might need to explain the difference between fluctuations and relapses
- ▲ A **relapse** is defined as new symptoms that appear, or old symptoms that reappear, “in the absence of infection”. (This is important – see below) Hopefully the symptoms will disappear altogether, but sometimes they don't. Remember the person reading your form may not understand or have heard the term 'relapse' before. You must explain what this means in your own situation.
- ▲ A **pseudo-relapse** is the appearance of new symptoms or the reappearance of old symptoms, usually triggered by something, such as infection (this could be a urine infection, an infected toenail etc). Once the infection is treated (typically with antibiotics), the symptoms disappear.
- ▲ **Fluctuations** of symptoms affect many people with MS. Typically, there will be times of the day / week / month when symptoms are worse than at other times (or conversely, are better than at other times!)
- ▲ Think **WHY** you've stopped doing something? Was there another way you could do it?
- ▲ How did this impact on you? (Socially, emotionally, physically)
- ▲ Think about any extra support you need to do everyday activities

Slide 10

What you may need to explain: silent / hidden symptoms

Many of the symptoms of MS
are 'silent' or 'hidden'

- Examples include pain, fatigue, cognitive difficulties, altered mood, continence problems.
- Explain how these symptoms affect you – physically, emotionally and socially.



- ▲ Many of the symptoms of MS are 'silent' or 'hidden' – you experience them but they cannot be seen
- ▲ It is important that you explain all the symptoms that affect you, including the ones that might be called 'hidden / silent' (because an observer can't see anything but you feel / experience it)
- ▲ Because they can't be seen by an observer, it is really important that you describe exactly how it / they affect you. Also, write down what you do to try and lessen it, as well as what, if anything, you can't do as a result of it
- ▲ It might be useful to provide examples about some of these hidden symptoms – fatigue, continence, cognition, vision

Slide 11

What you need to explain:

Whether you can or cannot do things

- Repeatedly
- Reliably
- Safely
- Timely



- ▲ Whether you can or cannot do things
 - **Repeatedly:** as often during the day as the individual activity requires. Think about whether doing an activity would cause any pain or fatigue that would mean you couldn't do it more than once. e.g. if you're able to walk 50m to get to the shops with effort, but if that would wipe you out for the whole day, or you'd need to get a taxi home, say so! If you can pick things up, write or type but it makes your hands or arms painful, say so.
 - **Reliably:** Your MS may fluctuate and mean that on some days you can do an activity and on other days you cannot.
 - **Safely:** without risk of harm to you or others. Are you worried about stumbling or falling if you walk or bend over? Does heat insensitivity mean that you might scald yourself when cooking or making tea?
 - **Timely:** within a reasonable time period
- ▲ **Look at the ESA booklet for examples of descriptors and symptoms**
 - For example, if you're able to walk or wheel your wheelchair for 100 metres but you are actually in severe discomfort after only 50 metres, then you could argue 50 metres is the limit of your ability.

3.3 Summary

Section objectives	Method	Materials	Time	Start time
Summary and further information & support available	Presentation	Slides 12-13	5 mins	

Slide 12

Summary

- It may not seem obvious at first how you relate your MS to the questions and assessments.
- Be clear about how MS affects you and your ability to complete tasks.
- If your condition fluctuates explain how
- Don't forget any hidden symptoms like fatigue and pain
- Give as much information as possible and supply extra supporting evidence wherever possible.



- ▲ The more you write about YOUR experience, the clearer the picture will be for the person reading the form
- ▲ Be clear about how MS affects you and your ability to complete tasks – be as detailed as possible and provide as much supporting evidence as possible

Slide 13

MS Society Further Information & Support

Information online or in publications
 Signposting and local partnerships with advice agencies
 Lobbying and campaigning to ensure fairness for people with MS.
 Helpline 0808 800 8000



- ▲ Just a reminder about the range of information and support from the MS Society
- ▲ Also signpost people to the handout with details of a range of national and local support services
- ▲ The current changes in benefits can bring concerns and make people worry so it is really important you seek support and get advice from a benefits advice service

4 Discussion & questions

Section objectives	Method	Materials	Time	Start time
Discussion; Q&As	Facilitated discussion	Slide 14	15-20 mins	

Slide 14

Questions?



- ▲ Invite guest speaker to the floor to answer questions
- ▲ Ensure people use a microphone so that everyone can hear questions and answers
- ▲ State questions should be of a general nature, not related to individual cases. We recognise people may need individual advice about their situation – we would encourage them to make an appointment with their local benefits advice service as a follow up to this event
- ▲ If guest speaker no longer available, answer any questions if possible or direct to sources of support locally / nationally or note the question and contact details and arrange for an answer to be provided at a later date.

Appendix 8 – Sample programme

Seminar programme (2.5 to 3 hours)

Session	Time total
<p>Event chair (MS Society representative)</p> <ul style="list-style-type: none"> ▲ Welcome, health & safety and overview of the event ▲ The role of the MS Society ▲ Further information and support available <p><i>See Event chair brief</i></p>	15 minutes
<p>External speaker (Benefits advisor)</p> <ul style="list-style-type: none"> ▲ Overview of current entitlements / planned changes by audience ▲ Overview of application, assessment and appeal process ▲ Importance of supporting evidence and what to expect ▲ Exceptional circumstances <p><i>See External speaker brief</i></p>	45 minutes
<p>MS focus (MS Society representative)</p> <ul style="list-style-type: none"> ▲ What to consider when applying for benefits ▲ What you may need to explain ▲ Further Information and support available <p><i>See MS focus brief</i></p>	30 minutes
<p>Question and answer session (facilitated by event chair)</p> <ul style="list-style-type: none"> ▲ Speakers, MS Society representatives, and other organisations representatives in attendance available to respond to questions. 	30 minutes (can be extended)
<p>Event chair close the talk</p>	5-10 mins
<p>Additional discussion time</p> <ul style="list-style-type: none"> ▲ Opportunity for more questions to MS Society representatives, discussion among delegates and an opportunity for people to meet representatives of other organisations and ask questions. 	30 minutes

Notes