



Personal care: a guide for MS Society volunteers

The MS Society is committed to making sure all our services, meetings and events are inclusive. People with multiple sclerosis (MS) must be able to attend MS Society activities knowing that they will be treated with dignity and respect and that they will have access to the personal care they need. For the most part, this will mean attending with their primary carer, but sometimes personal care may be provided by contracted care assistants.

Who is this guide for?

This guide is for all **MS Society group volunteers** who organise and deliver local services, meetings and events attended by people with MS. This guidance applies whether you are in England, Northern Ireland, Scotland or Wales.

This guide brings together good practice from across the UK and includes information on:

- ✓ **what personal care means**
- ✓ **how it affects MS Society group services, meetings and events**
- ✓ **how to contract care assistants**
- ✓ **sources of support**

Find out more

You can find our **personal care policy and procedure**:

- on our volunteer website
<http://volunteers.mssociety.org.uk/personal-care>
- by requesting a printed copy from the **Supporter Care Team**

What do we mean by 'personal care'?

Personal care is the support a person needs with the activities of daily living. It can include:

- eating and drinking
- toileting
- dressing
- communicating
- moving and handling
- washing
- bathing or showering
- taking medication

Access to personal care can enable a person to engage with their community, have a social life and reduce isolation. If a person requires personal care, this should be provided by their primary carer as part of their **support plan**. If they attend an activity that offers a personal care service as a break for primary carers, this must be provided by contracted care assistants.

What is a 'primary carer'?

A primary carer is the person who usually attends to the personal care needs of a person with MS. This could be a close family member or a paid personal assistant. A primary carer must only provide care to the person they are responsible for at an MS Society service, meeting or event.

What is a 'contracted care assistant'?

A contracted care assistant is a person employed by a Domiciliary Care Agency registered with the appropriate **care regulation body** (see page 8).

Contracted care assistants are trained and insured to provide personal care to people with a range of needs and may be contracted to be responsible for more than one person at an MS Society service, meeting or event.

MS Society volunteers and staff must not provide personal care.

Why can't we provide personal care?

Personal care is a regulated activity under the Safeguarding Vulnerable Groups Act 2006 and can only be provided by a family member or a paid carer with an enhanced disclosure check.

MS Society volunteers and staff are not expected to provide personal care. We don't have the resources to deliver the initial personal care training and the ongoing competency testing that would be required for staff and volunteers to safely and legally deliver personal care.

An MS Society volunteer who is also a primary carer can undertake both roles at a group activity if they feel they can safely do so. They must not provide care to other people.

Using common sense

Support plans may cover different types of personal care for a number of reasons. For example, if a person has swallowing difficulties (dysphagia),

helping them to eat or drink may be dangerous to them - their primary carer will know how to prevent choking but you haven't been trained to do so.

However, if a person has a tremor that means their food only needs to be cut up for them, this shouldn't prevent them from attending a local group service, meeting or event without their primary carer.

Here are some other situations when it may be appropriate for a person with MS to attend a local group activity without their primary carer:

If a person needs help lifting a cup

As in the example above, if a person has swallowing difficulties (dysphagia), you must not help them to drink. If they have a tremor and need only have their cup positioned correctly, you can help them to do this.

To ensure you don't endanger the person, you must have **written confirmation** from their primary carer that they do not have swallowing difficulties before providing this support.

If a person needs to be pushed in a manual wheelchair

If a person needs to be pushed, either because of distance or weakness in their arms, you should make a sensible assessment, taking these factors into account:

- the combined weight of the person and chair
- the type and condition of the surface (a gravel path/drive is more demanding than a smooth floor)
- any inclines or ramps
- any thresholds and kerbs
- are they are well positioned and using the footplates?

If a person needs help putting on a coat or cardigan

A person may need support to put on a cardigan or coat because they have a tremor or weakness in their arms. You must confirm with the person or their primary carer that they can weight bear (with or without the help of a frame) and do not have a history of falls before helping.

Staying safe

These common sense guidelines are to keep both parties safe. Please take care and consider your own health and safety when pushing wheelchairs or helping with outer clothes.

Even very simple **moving and handling** like this can lead to:

- back pain and musculoskeletal disorders
- accidents which can injure both the person being moved and the person doing the moving
- discomfort and a lack of dignity for the person being moved

What does this mean for our MS Society group?

Your group may organise and deliver a range of activities, including:

- **Services** - things like exercise classes and complementary therapies
- **Meetings** - including information talks, committee meetings, social get-togethers and parties
- **Events** - such as trips to places of interest, stalls at fetes, exercise equipment taster sessions and fundraising collections

Find out more

You'll find a comprehensive range of **event, activity and meeting risk assessments and guidance:**

- on our **volunteer website**
<https://volunteers.mssociety.org.uk/risk-management>
- by requesting printed copies from the **Supporter Care Team**

The purpose of most of these activities is to enable people with MS to engage with their community or to socialise, meaning your group is **not** responsible for providing personal care. Personal care should be provided by a person's own primary carer as part of their support plan.

If however, you organise an activity that aims to give primary carers a break, your MS Society group must supply contracted care assistants to provide personal care.

Publicising events

To enable people with MS to plan, it is important to make it clear on promotional materials and in correspondence whether personal care is provided at a service, meeting or event organised by your MS Society group. For activities where it isn't, this statement can be used:

“MS Society staff and volunteers are not able to provide personal care, so please ensure you attend (event) with your primary carer. If this isn't possible, contact (name and contact details) by (date) to discuss what support (if any) we can provide.”

This statement allows for times when a person's primary carer is unable to attend an activity with them, even though it **isn't** advertised as including personal care. Your MS Society group is **not** responsible for meeting this care

need but it may be appropriate to do so if it means the person with MS isn't excluded from taking part on that occasion.

If someone who requires personal care attends an MS Society event without their carer, you should discuss with them if and how their care needs can be met. This may mean contacting their primary carer and asking them to attend, or they are not available asking them to attend an event in the future with their carer.

Assessing care needs

Before you agree to provide contracted care, it is important to know what support a person needs. You are not expected to perform a formal care assessment, but you should have asked some basic questions before approaching a care agency.

See **Appendix A: Care needs questionnaire** at the back of this guide for a list of questions you should ask.

Contracting care assistants

How do we contract care assistants?

Provision of care is a regulated industry. All domiciliary care agencies have to be registered with the care regulation authority in their country.

These bodies regulate the care industry and carry out regular inspections of care agencies to ensure that their work meets the required standards to maintain their registration.

Find out more

To find a care agency in your area visit the website of the appropriate regulator. You can find links to these websites:

- under **Care regulatory bodies** on page 8 of this guide
- on our **volunteer website**

<http://volunteers.mssociety.org.uk/personal-care>

To provide care, the agency will need to understand the level of support a person or group of people will need. How this assessment is carried out will need to be discussed with the agency. If specific support is required for one or two individuals with high levels of need then an individual assessment of the needs of those people will most probably be required. The agency may be able to do this by speaking directly with the person's current care provider.

Service Level Agreement (SLA)

All care agencies have their own terms and conditions of business. However, if you are going to require care assistants on a regular basis you may find it

appropriate to enter into a Service Level Agreement (SLA) with an agency to ensure that each party understands each others' requirements.

**Find out
more**

You'll find a **Service Level Agreement template and guidance:**

- on our **volunteer website**,
<http://volunteers.mssociety.org.uk/personal-care>
- by requesting a printed copy from the **Supporter Care Team**

Funding contracted care

A number of factors will affect the cost of contracting care assistants:

- the level of care required by each person
- the number of people who require care
- the duration of the activity

When you plan an activity that includes personal care as a break for primary carers, you should include the cost of contracted care in the budget and ensure you allow plenty of time to organise it.

Providing personal care at other group activities shouldn't happen frequently, but your committee should ensure it includes funds for this sort of support in the group's annual spending plan.

If you are concerned you don't have enough funds to provide personal care at MS Society group activities, contact your **Local Networks Officer**. They can work with your committee, supporting you to develop your spending plan and identify new fundraising initiatives to enable you to achieve your group objectives.

Sources of support

Our volunteer website

Whatever you do as an MS Society volunteer, you'll find the latest news and information to help you carry out your role on our **volunteer website**,
www.volunteers.mssociety.org.uk

Personal care policy and procedure and supporting documents

<http://volunteers.mssociety.org.uk/personal-care>

Risk management paperwork and guidance

<https://volunteers.mssociety.org.uk/risk-management>

Managing your finances

<http://volunteers.mssociety.org.uk/finances>

Staff support

Your **Local Networks Officer** is your main contact, supporting your group to offer safe, effective services and support to people affected by MS. They should be your first point of contact for support implementing our personal care policy.

If you need contact details for your **Local Networks Officer**, see the **volunteer website**, <https://volunteers.mssociety.org.uk/local-networks-team>.

Or contact the **Supporter Care Team** for assistance:

Supporter Care Team

volunteering@mssociety.org.uk

Tel: 020 8438 0944

The MS Helpline

The MS Helpline offers emotional support and information to anyone affected by MS in the UK, including MS Society volunteers.

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

MS Society offices

MS National Centre

372 Edgware Road, London, NW2 6ND

info@mssociety.org.uk

Tel: 020 8438 0700

MS Society Northern Ireland

The Resource Centre, 34 Annadale Avenue, Belfast, BT7 3JJ

nireception@mssociety.org.uk

Tel: 028 9080 2802

MS Society Scotland

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

enquiries@mssocietyscotland.org.uk

Tel: 0131 335 4050

MS Society Cymru

Temple Court, Cathedral Road, Cardiff, CF11 9HA

mscymru@mssociety.org.uk

Tel: 029 20 786 676

Care regulatory bodies

Provision of care is a regulated industry. All Domiciliary Care Agencies must be registered with the appropriate authority.

The Care Quality Commission (England)

<http://www.cqc.org.uk/>

Tel: 03000 616161

The Regulation and Quality Improvement Authority (Northern Ireland)

<http://www.rqia.org.uk/>

Tel: 028 9051 7500

The Care Inspectorate (Scotland)

<http://www.scswis.com/>

Tel: 0845 600 9527

The Care and Social Services Inspectorate (Wales)

<http://cssiw.org.uk/>

Tel: 0300 7900 126

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Appendix A: Care needs questionnaire

Before you agree to provide contracted care, use this questionnaire to establish what support a person needs.

Eating & Drinking	✓
No problem - can eat and drink without assistance	
Can eat as long as food is cut up	
Can eat or drink without assistance using special cutlery/crockery	
Needs assistance but only due to tremor/spasm	
If any of the above ticked, then <u>as long as someone is willing</u> and primary carer has confirmed no swallowing or communication difficulties, assistance can be provided. Contracted care assistants or primary carer will be needed if any of the below ticked:	
Needs assistance with eating including thickened drinks etc.	
Needs strict supervision for management of Peg feeding/loss of appetite/swallowing difficulties/choking problems	

Mobility/Transfers/Falls	✓
No assistance needed	
Needs supervision to transfer and/or mobilise but no history of falling	
Occasionally needs manual assistance to transfer, can weight bear, has no history of falling.	
If any of the above ticked then <u>as long as someone is willing to assist</u> and primary carer has confirmed there is no history of falls or other difficulties, assistance can be provided. Contracted care assistants or primary carer will be needed if any of the below ticked:	
Needs manual assistance to transfer at all times but has some degree of mobility, has history of falling during previous six months with infrequent falls	
Unable to transfer independently & needs supervision to mobilise or has history of falling during previous three months with occasional falls	
Unable to transfer & mobilise independently or has history of falling during previous month with frequent falls	

Freedom of Movement	✓
Ambulant or ambulant with use of sticks or frame	
Uses electric wheel chair/mobility scooter or can self propel a manual wheel chair	
Needs pushing in manual wheelchair	
Needs electric chair steering	
If any of the above ticked then <u>as long as someone is willing</u> and has considered size, weight, surface and inclines/ramps before doing so, assistance can be provided. Otherwise and for the below, contracted care assistants or primary carer needed (Note: some care agencies will not let staff assist with assistance into	

and out of vehicles):	
Needs assistance in and out of non wheelchair accessible transport	
Needs wheelchair or scooter lifted out of vehicle	
Uses large specialist manual chair	

Medication	✓
No assistance needed, self medicating can open all containers and dispense medication themselves	
Above shouldn't be a problem. Contracted care assistants <u>trained to give medication</u> or primary carer will be needed if any of the below ticked:	
Needs assistance with oral medication or administration of medication by other specialist routes e.g. PEG (percutaneous endoscopic gastrostomy), intramuscular or other injection	

Continence	✓
Needs guiding to location of toilet and door opened, can use toilet without assistance	
Needs pushing in manual wheelchair to toilet and door opened, can transfer on/off and use toilet without assistance	
Above shouldn't be a problem. Contracted care assistants or primary carer will be needed if any of the below ticked:	
Uses toilet with assistance	
Uses catheter/has urostomy which will need attention	