

FREQUENTLY ASKED QUESTIONS:

PROVISION OF PERSONAL CARE AT MS SOCIETY SERVICES, MEETINGS AND EVENTS

What is the MS Society Policy for staff & volunteers in relation to people with MS who need assistance with personal care?

In order to ensure appropriate support is in place for PwMS, the MS Society requires that at all MS Society services, meetings and events, if a PwMS needs personal care and has not been accompanied by their own primary carer, paid or unpaid, then the delivery of any personal care must be by contracted care assistants and not by MS Society staff or volunteers. Primary carers, paid or unpaid, must only provide personal care to the individual for whom they are responsible.

Why are you introducing this now?

This is not a change as the MS Society's position has always been that people who require assistance with personal care should bring a carer with them or that care is provided and that MS Society staff or volunteers should not be providing personal care.

Is this just in relation to branch events?

No this covers all activity in relation to people with MS including:

- Branch services, events and meetings
- MS National Centres' events, meetings, training across the UK

What do you mean by primary carer?

A person who usually attends to the personal care needs of the individual person with MS, this could be a close family member or a paid personal assistant.

I am the primary carer for my partner; can I provide personal care for them when we attend something organised by the MS Society?

Yes, you are best placed to provide personal care for your partner

If I am providing personal care, can I also fulfil my volunteer role as say the Chair or organiser of the event?

Yes; if you feel you have the capacity to act as carer to that individual as well as fulfilling your volunteer role that is fine.

Can I provide care to others who need it?

No, you must only provide personal care to the individual for whom you are accompanying as their primary carer..



As a Branch we provide personal care as a matter of course, we see it as enabling members to attend events without added cost or fuss. Can we continue to provide this service?

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We have used agencies in the past to provide Social Care Workers and they did not provide a good service. Different people were sent every time and they did not really care about our members. How do we deal with this?

A Service Level Agreement (SLA) (POPC: 001) along with guidance (POPC: 002) have been developed that will help Branches set up the type of agreement that they want with an agency providing social care workers. Further support and advice is available from local staff or the Care & Support Services Team.

What is a SLA?

A SLA is a simple form of contract which ensures that both parties are clear about the nature of the arrangement and their responsibilities. The document records the details of the service provider and details the specifications of the service to be provided.

What information is needed in a SLA?

A guidance document (POPC: 002) that details the completion of an SLA is available on the volunteer microsite, the operations drive, the Intranet or from the Care & Support Services Team.

What do you mean by Personal Care?

Personal Care is provided to support people with activities of daily living and **can** include dressing, washing, bathing or showering, toileting, getting in or out of bed, eating, drinking, taking medication and communication

What if someone just needs help at mealtimes or with a drink because they have a tremor or because they have a weakness in their upper limbs?

There may be occasions when a person with MS attends an event without a carer and needs support to lift a cup or cutlery because they have a tremor. The member of staff or volunteer must confirm and document with the person or carer that there are no swallowing difficulties or previous history of choking before offering assistance in this scenario.

Why can't I provide support to everyone who needs assistance with eating and drinking?

A large number of people with multiple sclerosis experience some changes in their swallowing (dysphagia) at some time. For some people, these changes come and go, or happen during a relapse and never re-appear. But for others, they can be an ongoing issue. The severity of dysphagia can vary from individuals having difficulties with certain consistencies of food, liquids, fluids or saliva to being



completely unable to swallow. These difficulties may be caused by mechanical (physical), neurological or behavioural problems. Difficulties with swallowing may mean that there is a chance that small particles of food or fluids can enter into the lungs and could cause a serious and possible fatal lung infection (Aspiration Pneumonia). It is therefore important that individuals with dysphagia are risk assessed and supported by trained carers.

What are the signs of swallowing problems?

- Problems Chewing
- Coughing or spluttering during and after eating
- Excessive saliva, which may cause dribbling
- Food sticking in a person's throat
- Food or drink coming back up
- Sluggish movement of food going down, or difficulty moving food to the back of the mouth

A change to speech can be an indication of swallowing difficulties.

What are the indications that someone might be at risk of choking?

- They have a weak or ineffectual cough
- They have difficulty in swallowing
- They are known to aspirate (makes a sound whilst breathing)
- They have difficulty with breathing
- They eat rapidly
- They drink rapidly
- They are on a modified consistency diet
- They require thickened fluids
- They require specialist aids designed to reduce choking to eat and drink
- They store food and drink in their mouth
- They continue to eat or whilst coughing
- Swallowing food without chewing
- Overloading of mouth with food or drink
- Wearing dentures
- Poor posture
- Poor head control
- Epilepsy



- Confusion/disorientation/cognitive issues
- Incidents in the past of choking

What is moving and handling of people?

Quite simply it is helping someone move around and in respect of people with MS attending services, meetings, events and functions includes activities such as:

- Helping them use the toilet
- Helping them get in and out of a chair
- Helping them transfer from a wheelchair to a static chair
- Adjusting their seating position in a chair
- Helping them to stand
- Helping them to walk
- Helping them get from the floor after a fall
- Helping them get in and out of a vehicle

Why can't staff and volunteers do moving and handling of people?

To move and handle people safely appropriate training is required to ensure the task is being done competently. Lack of appropriate training leads to poor moving and handling practice which in turn can lead to:

- Back pain and musculoskeletal disorders.
- Moving and handling 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

The society cannot provide and update the training that would be required across its staff and volunteers to ensure good practice is observed on all occasions.

What if someone needs help with an outer garment such as a cardigan or coat?

There may be occasions when a person with MS attends an event without a carer and needs support to put on a cardigan/coat because they have a tremor or weakness in an upper limb. The member of staff or volunteer must confirm with the person that they can weight bear (with or without the help of a frame) and do not have a history of falls before offering assistance in his scenario.

Can I push someone who is in a wheelchair?

If someone is struggling to propel themselves in a manual wheelchair due to distance or lack of strength in their arms and you want to assist you need to make a sensible assessment of the situation by considering:

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.