

MULTIPLE SCLEROSIS

PIP FACTSHEET

EATING AND DRINKING:

This question focuses on your ability to prepare and cook a simple one-course meal for one person from fresh ingredients. Stages you could find difficult if you have hand tremors/weakness or poor dexterity:

- Using cooking utensils
- Turning taps on and off
- Prepare food ie, chopping and peeling • checking food is not out of date, if you need to buy pre chopped vegetables because of this, say so.
- Pouring a drink,
- Opening cans.
- Cooking food, including using a hob or microwave above waist height safely.
- It does not include any difficulties you have in bending down to use an oven.

If you have balance problems, poor coordination or blurred//double vision it could be dangerous for you to use hot pans should you lose your balance, fall and perhaps hurt or scald yourself. Have you cut yourself with knives, burnt yourself on hot pans? Let them know of any accidents that have happened in the past and if you had to see your GP or go for hospital treatment.

With memory or concentration difficulties, you may have problems in planning your meals, checking the ingredients, timing the cooking, or become confused, making sure the food is cooked properly i.e. not under or overcooked. Also if heat from cooking aggravates your symptoms.

Explain if a hand tremor/poor dexterity makes it difficult to use cutlery properly or;

- Manage hot drinks safely.
- You can cut up some food but cannot cut up tougher items, i.e. meat.
- You tend to drop food or spill drinks, and if you then need help in cleaning up afterwards.
- Have difficulty in swallowing and need your food/drink to be specially prepared.
- Are so exhausted after cooking a meal that you could not do it again that day.

MANAGING THERAPY:

This focuses on the support you need from someone to manage your medication, therapies, or monitor your health condition. It also looks at the amount of time you need this support, if due to poor dexterity or hand tremors you have difficulties with the tasks below;

- Unscrewing tablet bottles or pouring medicine.
- Need reminding to take medication at the right time or
- To take the right amount of medication.
- If you have blurred or double vision do you need someone to read the labels and instructions on your medication.
- Are there any side effects from medications, do you need any extra help because of these.
- Have been advised to do exercises at home, and if you need help doing them.

Give examples of any occasions when you have missed taking your medication or have taken too much by accident and whether there were any side effects.

WASHING AND BATHING:

Write down any aids or adaptations you use to wash or bathe yourself ie, if there are parts of your body you cannot reach using aids ie, if you cannot wash your back properly. These could include;

- Long-handled sponge
- Shower seat
- Bath rail.
- Explain if you have fallen trying to get in/out of the bath or shower by yourself.
- You need to bathe or shower more often due to either bladder or bowel problems
- If you need someone's help to get washed and bathed.

MANAGING TOILET NEEDS:

This can be one of the most difficult parts of the form because the questions are of such a personal nature. Try to put as much information down as you can.

Mention any difficulties you have;

- Using the toilet including sitting down or getting up from it
- Wiping yourself
- Adjusting your clothing and washing afterwards
- You need to visit the toilet more often than usual, explain why.
- Have bladder or bowel frequency, and you don't get enough warning
- You have bladder or bowel incontinence, write about the help you need in dealing with it This can include cleaning yourself afterwards

DRESSING AND UNDRRESSING:

Looks at your ability to;

- Put on and take off un-adapted clothing (which could include using fastenings such as zips or buttons).
- Putting on and taking off socks and shoes
- Your ability to select appropriate clothing, for the weather and time of the day
- Put your clothes on in the correct order.
- Have difficulties with laces, buttons and other types of fastenings.

Muscle pain or coordination problems can create difficulties with articles of clothing. Write down if;

- It takes a long time to dress yourself
- If you have to rest after putting on each piece of clothing due to fatigue
- You need to change your clothes during the day if you have either bladder or bowel problems.
- **Fatigue could well be a symptom that affects you more than any other;**
- You are able to carry out an activity, but it takes a long time
- Have to take several rests, or give up until you have more energy.
- The activity leaves you so fatigued you are unable to do anything else for some time

Live alone;

- Are there days when you don't dress because of pain or discomfort involved or
- You avoid putting on certain clothes, which you would like to wear for the same reason.
- You need someone to choose clothing that is clean and appropriate i.e. you have blurred or double vision and cannot see stains or marks on clothing
- List any aids you use to help you dress, i.e. modified buttons, zips, front fastening bras, trousers, Velcro fastenings and shoe aids.
- Explain if you still need assistance, despite using these aids, even if this doesn't take long.

COMMUNICATING:

If your speech is slurred or slow it may be difficult communicating with people;

- To find the right words to express your thoughts
- You may need help 'word-finding'
- Have difficulties concentrating during conversations
- Remembering what has been said, or
- Adequately processing the information you have been given.
- Understanding or being understood when having a conversation.
- Dealing with visitors to your door
- Telephone calls
- Communicating in places like shops, buses or taxis.

Give examples where you might need help

READING, UNDERSTANDING SIGNS, SYMBOLS AND WORDS:

If you have blurred or double vision, you may need someone to;

- Read things to you
- Check medication labels.
- Check sell-by dates on food,

- Read your post/paperwork, or
- Read radio and TV listings or the newspaper.

If you need to use aids to help you read, e.g. a magnifier or magnifying glass. If you can manage indoors, but cannot read signs outdoors adequately, let them know.

MIXING WITH OTHERS FACE TO FACE:

It considers your ability to engage socially **so** any inability you have to mix with others must result from your condition, rather than shyness.

- If you can only mix with those you know well, unable to deal with strangers.
- If you avoid mixing with others because you have no one to help you,
- How would you feel mixing with others without any support? Would you get panicky or angry, or difficulty understanding the behaviour of others?

MAKING BUDGETING DECISIONS:

- Do you have problems buying a few items from local shop; are you be able to give the assistant the correct money? Would you know if the change was correct?
- If going to the local shop would pose no problems, but you have problems with more complex decisions, ie, working out household budget for the month or sorting out a gas bill? If you can do most of the task by yourself, but would still need some support to finish it properly let them know.

THE MOBILITY COMPONENT

PLANNING AND FOLLOWING JOURNEYS:

This assesses your ability to work out and follow a route safely and reliably.

- If you have difficulties with memory or concentration, you may find it impossible to plan the route of a journey or to follow a route without another person.
- As a result of your M.S. you have blurred or double vision you may need to be accompanied by another person, particularly on an unfamiliar journey, if you need to have someone with you to get somewhere, let them know.

Would you need support just on unfamiliar routes, or would you also need it in places you know well?

If you have no one to support you outdoors so unable to do go out alone, make this clear. Where would like to go if you had someone with you, let them know.

List any incidents that have already occurred when you have been outdoors;

- If you've become lost, confused or disorientated, or dangerous situations have arisen that could have been avoided if help had been at hand.
- Are you unable to use buses/trains due to stress/anxiety.
- Would find small disruptions or unexpected changes difficult to deal with, e.g. road works where you normally cross the road or your bus stop has been moved.

MOVING AROUND:

This activity focuses on your physical ability to stand and move around without severe discomfort. 'Severe discomfort' does not just mean pain, but includes muscle tightness and rigidity or extreme fatigue.

- Normally, when you are in severe discomfort you wouldn't want to go any further, until symptoms ease.
- Your ability to move around should be judged to the type of surface normally expected outdoors ie, pavements, roads and kerbs.
- Identify how far you can walk, **safely in a reasonable time and without severe discomfort.** Using, if necessary, any aids ie, walking stick, frame or crutches.
- If you could walk 50 metres, but would be in severe discomfort over the last 30 metres, then you're walking ability will be considered to be limited to 20 metres.

If you tick 'It varies' box, explain what you mean e.g. 'On an average week, on 2 days I manage to walk about 40 metres before I can go no further; on another 4 days this distance is 20 metres, and one day I cannot walk at all without severe discomfort.' A diary kept over a week, identifying your walking limit on each day, may help you.

EXTRA INFORMATION

Describe your gait (the way you walk) ie, do you find it hard to balance or do you limp?

- If you need physical support from someone to help you walk.
- You need support due to poor coordination or balance, or
- If one of your legs keeps giving way due to spasm or muscle weakness.
- Give an idea of your speed. If you walk slowly and were to cover 20 metres, what distance would someone without a disability or health condition cover in that time?
- You may fall or stumble because of poor coordination or balance, or because one of your legs gives way due to spasm or muscle weakness, or you may fall over things because you have blurred/double vision,
- You may fall at different times for different reasons, or for a combination of reasons.

List any injuries you have received when you have fallen and any treatment you needed afterwards.

- Give examples of occasions when you were unable to get up for any length of time following a fall.
- Why were you unable to get up?
- Did someone have to help you?
- Alternatively, has someone else stopped you from falling?

This box provides you with more space to explain how your condition affects you. Here you can expand in more detail any difficulties you mention in previous questions.

If you run out of space, you can use an extra sheet of paper, which you need to write your name and National Insurance number. They prefer not to read through reams of paperwork so keep it simple and to the point.

KEEPING A DIARY

MS being a fluctuating condition it can be difficult to answer some questions, it helps to keep a record of how your symptoms affect you on a daily basis.

Keep a symptom diary for at least a week before completing your form this gives you the chance to describe how MS affects you.

If you are not well enough to complete this, someone can do it for you.

A diary is useful as evidence to help the assessor understand how you manage day to day. Covering a typical week should give them an idea of what you are like on good and bad days.

You can include;

- If you need aids or appliances to help you manage the activity on your own.
- Need prompting or supervision.
- Need assistance from someone else.
- You are unsafe managing on your own; accidents have happened or almost happened.
- You are unable to complete the activity to an acceptable standard, nor repeat the activity as often as is reasonably required.
- You can manage on your own, but it takes twice as long as someone without your condition.
- Tell them about any pain or tiredness you feel, or would feel, while carrying out each activity, and how you feel afterwards ie, fatigued.
- How you would feel if you had to do the same task repeatedly.
- If you need reminding or encouraging completing each activity let them know.

Don't overestimate your ability to do things. If your condition varies, tell them what you are like on bad days and good days. The assessor's opinion should not be based on how you are on the day of the assessment.

Once you have finished writing the diary, put your name and National Insurance number at the top of each page and make several copies,