

Questionnaire 24

The questions in this section are about any services you have used or the costs you have had to meet **over the past three months** because of your MND condition or because of other health reasons.

1. Over the past three months, have you done any of the following because of your **condition** or **other health reasons**?

If **YES**, please tick the appropriate circle and tell us the number of times (please be sure to answer either YES or NO to every item)

a. Been to a hospital casualty department?

Yes, because of my condition

→ Please write no. times

Yes, because of other health reasons

→ Please write no. times

No

b. Been seen by a practice nurse at the GP's surgery?

Yes, because of my condition

→ Please write no. times

Yes, because of other health reasons

→ Please write no. times

No

c. Been seen by the family doctor or another GP at the surgery?

Yes, because of my condition

→ Please write no. times

Yes, because of other health reasons

→ Please write no. times

No

d. Been seen by a nurse at home?

Yes, because of my condition

→ Please write no. times

Yes, because of other health reasons

→ Please write no. times

No

e. Been seen by the family doctor or another doctor at home?

Yes, because of my condition

1

→ Please write no. times

--	--

Yes, because of other health reasons

2

→ Please write no. times

--	--

No

3

f. Been seen by a nurse at the hospital/clinic outpatient department?

Yes, because of my condition

1

→ Please write no. times

--	--

Yes, because of other health reasons

2

→ Please write no. times

--	--

No

3

g. Been seen by a doctor at the hospital/clinic outpatient department?

Yes, because of my condition

1

→ Please write no. times

--	--

Yes, because of other health reasons

2

→ Please write no. times

--	--

No

3

h. Been admitted to hospital overnight as an in-patient?

Yes, because of my condition

1

→ Please write no. times

--	--

Yes, because of other health reasons

2

→ Please write no. times

--	--

No

3

i. Done something different from these?

Yes, because of my condition

1

→ Please write in what you have done and no. times

--	--

Yes, because of other health reasons

2

→ Please write in what you have done and no. times

--	--

No

3

2. Did you make any use of the ambulance service on any of the occasions you have told us about?

- Yes, because of my condition 1
- Yes, because of other health reasons 2
- No 3

Please ring all that apply and answer a) and/or b) as appropriate

Go to Q3

a. If you made use of the ambulance service because of your condition,

Please write no. of occasions

b. If you made use of the ambulance service because of other health reasons,

Please write no. of occasions

3. Over the past three months, has your doctor referred you for any of the tests or investigations listed below, because of your condition or other health reasons?

If YES, please tell us the number of times (please be sure to answer either YES or NO to every item)

a. Blood tests?

- Yes, because of my condition 1
- Yes, because of other health reasons 2
- No 3

→ Please write no. times

→ Please write no. times

b. Urine tests?

- Yes, because of my condition 1
- Yes, because of other health reasons 2
- No 3

→ Please write no. times

→ Please write no. times

c. Ultrasound?

- Yes, because of my condition 1
- Yes, because of other health reasons 2
- No 3

→ Please write no. times

→ Please write no. times

d. X-ray?

Yes, because of my condition

1

→ Please write no. times

--	--

Yes, because of other health reasons

2

→ Please write no. times

--	--

No

3

e. CT (computerised tomography) brain scan?

Yes, because of my condition

1

→ Please write no. times

--	--

Yes, because of other health reasons

2

→ Please write no. times

--	--

No

3

f. MRI (magnetic resonance imaging) brain scan?

Yes, because of my condition

1

→ Please write no. times

--	--

Yes, because of other health reasons

2

→ Please write no. times

--	--

No

3

g. EMG (electromyography)/NCS (nerve conduction studies)?

Yes, because of my condition

1

→ Please write no. times

--	--

Yes, because of other health reasons

2

→ Please write no. times

--	--

No

3

h. Other?

Yes, because of my condition

1

→ Please write in an investigation and no. times

--	--

Yes, because of other health reasons

2

→ Please write in an investigation and no. times

--	--

No

3

4. Over the past three months, have you seen any of the following people through social services or the NHS because of your condition or other health reasons?

If YES, please tell us the number of times (please be sure to answer either YES or NO to every item)

a. A health visitor?

Yes, because of my condition

1

→ Please write no. times

--	--

Yes, because of other health reasons

2

→ Please write no. times

--	--

No

3

b. A social worker?

Yes, because of my condition

1

→ Please write no. times

--	--

Yes, because of other health reasons

2

→ Please write no. times

--	--

No

3

c. A physiotherapist or occupational therapist?

Yes, because of my condition

1

→ Please write no. times

--	--

Yes, because of other health reasons

2

→ Please write no. times

--	--

No

3

d. A psychologist?

Yes, because of my condition

1

→ Please write no. times

--	--

Yes, because of other health reasons

2

→ Please write no. times

--	--

No

3

e. A counsellor?

Yes, because of my condition

1

→ Please write no. times

--	--

Yes, because of other health reasons

2

→ Please write no. times

--	--

No

3

f. Some other person?

Yes, because of my condition

1

→ Please write in who and no. times

Yes, because of other health reasons

2

→ Please write in who and no. times

No

3

5. Over the past three months, have you taken any medicines/tablets (either prescribed or bought by yourself)? This also includes drug study treatments.

Yes

1

→

Answer a)

No

2

→

Go to Q6

If YES, a) Please provide as much information as you can in the box below about each of the medicines/tablets you have taken. (Even if you can't remember exactly how many days or times you have taken them, please can you estimate it for us)

Please give the name(s) of the medicine(s)/tablets. <i>(Brand name if possible)</i>	Was it prescribed by a doctor? <i>(Please write YES or NO)</i>	Did you buy the medicine/tablets over the counter? <i>(Please write YES or NO)</i>	What is the strength of the medicine/tablets <i>(e.g. 200mg)</i>	How many tablets (or volume of liquid) per day?

6. **Over the past three months**, did you have any other extra expenses because of your condition (e.g. Private visits with a physician or dentist, taxi fares, purchase of books or videos about your condition)?

1 Yes →

Answer a)

2 No →

Go to Q7

If YES, a) Please tell us the reason and how much you spent on each item:

Item 1:

Reason for expense



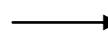
Amount spent

£

p

Item 2:

Reason for expense



Amount spent

£

p

The next set of questions are about how your condition and other health problems have affected your main daily activities **over the past three months**. Even if you are retired or unemployed and not actively looking for a job, please answer the following questions as requested.

7. IF YOU ARE WORKING, please answer a) to e) below about your PRESENT job.

IF YOU ARE RETIRED OR ARE NOT WORKING AT PRESENT, please answer a) to e) below about your LAST MAIN job.

IF YOU HAVE NEVER WORKED, please tick this box and go to Q8

a. Please write in your job title:

b. What do/did you actually do:

c. What does the firm or organisation you work(ed) for make or do?

d. Are/were you? An employee Self employed

e. Are/were you a manager, foreman or supervisor of any kind?
 Yes, manager Yes, supervisor No, neither

8. Which of the following **best** describes your current position about paid work?

In paid work: full time	(1)	} Answer Q9
In paid work: part time	(2)	
Unemployed, but looking for work or starting a new job soon	(3)	} Go to Q14
Unemployed, and not looking for work	(4)	
On a government employment or training scheme	(5)	
Retired	(6)	
Unable to work, because of long term illness or disability	(7)	
Student full time	(8)	
Looking after home and family	(9)	
Other (Please write in) _____	(10)	

9. Over the past three months, has your work situation been affected at all by your condition or other health reasons?

Yes, my work situation has been affected because of my condition

1

Yes, my work situation has been affected because of other health reasons

2

No, my work situation has not been affected

3

Please ring all that apply and answer a) and/or b) as appropriate

Go to Q10

a. If your work situation has been affected because of your condition, please tell us what happened?

I lost a paid job and still have not got another one

1

I lost a paid job at first but have since got another one

2

I changed the type of job/tasks I do

3

I changed my place of work

4

I changed the number of hours I work

5

I was unemployed at first, then got a paid job

6

I was unemployed for all the past 3 months

7

Other (Please write in) _____

8

Please ring all that apply

b. If your work situation has been affected because of other health reasons, please tell us what happened?

I lost a paid job and still have not got another one

1

I lost a paid job at first but have since got another one

2

I changed the type of job/tasks I do

3

I changed my place of work

4

I changed the number of hours I work

5

I was unemployed at first, then got a paid job

6

I was unemployed for all the past 3 months

7

Other (Please write in) _____

8

Please ring all that apply

10. **Over the past three months**, has there been any change in your gross annual earning because of your condition or other health reasons?

Yes, earnings have changed because of my condition

1

Yes, earnings have changed because of other health reasons

2

No, no change

3

Please ring all that apply and answer a) and/or b) as appropriate

Go to Q12

a. If earnings changed because of your condition,

What were your annual gross earnings 3 months ago?

£

p

What are your annual gross earnings now?

£

p

b. If earnings changed because of other health reasons,

What were your annual gross earnings 3 months ago?

£

p

What are your annual gross earnings now?

£

p

11. If the earnings changed because of your condition, was the change in your earnings due to:

A change in the number of hours you work

1

Promotion (either in the same or a new place of work)

2

A demotion (either in the same or a new place of work)

3

Loss of a job

4

Does not apply, earnings changed because of other health reasons

5

Answer a) and b)

Go to Q12

If your hours change,

a) How many hours per week were you working 3 months ago?

hours

b) How many hours per week do you work now?

hours

12. Over the past three months, have you been unemployed at all because of your condition or other health reasons?

Yes, because of my condition 1

Yes, because of other health reasons 2

No, no change 3

Please ring all that apply and answer a) and/or b) as appropriate

Go to Q13

a. If you have been unemployed because of your condition,

How many days were you unemployed altogether in that time? No. days

How much earnings did you lose while unemployed? £ p

Please write in amount

Does not apply - no loss of earnings

b. If you have been unemployed because of other health reasons,

How many days were you unemployed altogether in that time? No. days

How much earnings did you lose while unemployed? £ p

Please write in amount

Does not apply— no loss of earnings

13. Over the past three months, were you on sick leave at all because of your condition or other health reasons?

Yes, because of my condition 1

Yes, because of other health reasons 2

No 3

Please ring all that apply and answer a) and/or b) as appropriate

Go to Q14

a. If you have been on sick leave because of your condition,

How many days of sick leave did you take altogether in that time? No. days

How much earnings did you lose while on sick leave? £ p

Please write in amount

Does not apply - no loss of earnings

b. If you have been on sick leave because of other health reasons,

How many days of sick leave did you take altogether in that time?

No. days

How much earnings did you lose while on sick leave?

£

p

Please write in amount

Does not apply—no loss of earnings

14. Over the past three months, did you?

Go on long-term sickness benefit(s) because of your condition?

1

Go on long-term sickness benefit(s) because of other health reasons?

2

Retire early from work because of your condition?

3

Retire from work because of other health reasons?

4

Give up work altogether because of your condition?

5

Give up work altogether because of other health reasons?

6

Or did none of these happen over the past three months?

7

14b. Please tick one of following, to indicate your highest level of educational qualification.

Primary school only

1

Secondary school with no qualifications

2

GCSEs, O levels, Scottish standard, BTEC or NVQ level 1-2

3

A levels, Scottish highers, BTEC or N/SVQ level 3

4

Higher National Certificates or Higher National Diplomas (2 years or less full time)

5

Bachelors degree (eg BSc, BA)

6

Masters degree (eg MSc, MPhil, MA) or medicine/dentistry/veterinary qualifications

7

Doctorate (eg PhD, DPhil, LL.D, D.Lit,D.Sc,MD)

8

Finally, it would be helpful if you could tell us:

15. Are you currently receiving any of the following allowances?

Please tick ✓ all that apply.

Jobseeker's allowance (JSA) (EX-Unemployment benefit)	1
Income support	2
Family tax credit	3
Statutory sick pay. First 28 weeks	4
Incapacity benefit (EX-Invalidity benefit)	5
Severe disablement allowance	6
Disability Living Allowance (DLA)	7
Attendance allowance (over 65)	8
Carers allowance	9
Carers credit	10
Council Tax Benefit	11
Housing benefit	12
State pension	13
Child tax credit	14
Disabled Tax Credit	15
Pension Credit	16
Employment and Support Allowance (ESA)	17
Industrial Injuries Allowance	18
Personal Independence Payment (PIP) over 16 under 65	19
Access to work support	20
Other (Please write in what) _____	21
Not receiving any	22

16. What are your personal gross earnings (before tax, national insurance and other deductions) from paid employment (excluding any allowances)?

Per week (approximately)

Per year (approximately)

None	<input type="checkbox"/>	None
Less than £218	<input type="checkbox"/>	Less than £11,070
£218 to less than £263	<input type="checkbox"/>	£11,070 to less than £13,357
£263 to less than £312	<input type="checkbox"/>	£13,357 to less than £15,867
£312 to less than £365	<input type="checkbox"/>	£15,867 to less than £18,580
£365 to less than £419	<input type="checkbox"/>	£18,580 to less than £21,300
£419 to less than £513	<input type="checkbox"/>	£21,300 to less than £26,100
£513 to less than £608	<input type="checkbox"/>	£26,100 to less than £30,900
£608 to less than £768	<input type="checkbox"/>	£30,900 to less than £39,033
£768 to less than £993	<input type="checkbox"/>	£39,033 to less than £50,500
More than £993	<input type="checkbox"/>	More than £50,500

17. Is there anything else you would like to say about your condition and/or the related costs you have had to meet and/or this questionnaire?

Empty text box for providing additional information.