

Constipation in Multiple Sclerosis

Appendix-1: Questionnaires

- **Cleveland Clinic Constipation Score (CCCS)**[®]
Measures the health-related quality of life and define patients' symptoms suggestive of constipation. The scoring system will clearly describe the severity of constipation and simplify evaluation and management of constipated patients.
- **Patient Assessment of Constipation Symptoms (PAC-SYM)**[®]
Used to query about patients' constipation symptoms during two weeks.
- **Patient Assessment of Constipation Quality of Live (PAC-QoL)**[®]
Measure the impact constipation has had on the patients' daily life during 2 weeks.
- **International Physical Activity questionnaire-Short Form (IPAQ-SF)**[®]
Amount and intensity of physical activity patients carried out during a week.
- **St Marks Incontinence score**[®]
About patient's perception on bowel control. The questionnaire results will be used to evaluate the severity of faecal incontinence.
- **Beighton score**[®]
Associate the Beighton score with Joint Hypermobility Syndrome (JHS), which may also have a number of other symptoms related to weaknesses in the connective tissues throughout the body. Some of these symptoms may be the reason for constipation on the audited participants.
- **Hospital Anxiety and Depression Scale (HADS)**[®]
Records the feelings patients have experienced during a period of 7 days. This would be a useful tool to monitoring patients during a specific period of time, since mood disturbance and depression occur in more than half of multiple sclerosis patients.
- **Food and Drink diary** over one week (on Saturday, Monday and Tuesday), in order to track whether patients are meeting recommended servings and nutritional intake. It has been suggested that certain dietary regimens, particularly those including polyunsaturated fatty acids (PUFAs) and vitamins, might improve outcomes in people with multiple sclerosis (MS). Diets and dietary supplements are much used by people with MS in the belief that they might improve disease outcomes and overcome the effectiveness limits of conventional treatments.
- **Bowel Diary**, which incorporates the **Bristol stool scale**[®]
Medical aid designed to classify the form of human faeces into seven categories (Types 1–2 indicate constipation, with 3 and 4 being the ideal stools, as they are easy to defecate while not containing any excess liquid, and 5, 6 and 7 tending towards diarrhoea).

Cleveland Clinic constipation score (CCCS)

This questionnaire asks you about symptoms suggestive of constipation. Please answer each question according to your symptoms, as accurately as possible. There are no correct or wrong answers. For each symptom, please indicate how severe it is by circling the respective number. Please make sure you answer every question. Thank you!

Frequency of bowel movements

- 0 1-2 times per 1-2 days
- 1 2 times per week
- 2 Once per week
- 3 Less than once per week
- 4 Less than once per month

Difficulty: painful evacuation effort

- 0 Never
- 1 Rarely
- 2 Sometimes
- 3 Usually
- 4 Always

Completeness: feeling incomplete evacuation

- 0 Never
- 1 Rarely
- 2 Sometimes
- 3 Usually
- 4 Always

Pain: abdominal pain

- 0 Never
- 1 Rarely
- 2 Sometimes
- 3 Usually
- 4 Always

Time: minutes in lavatory per attempt

- 0 Less than 5
- 1 5-10
- 2 10-20
- 3 20-30
- 4 More than 30

Assistance: type of assistance

- 0 Without assistance
- 1 Stimulative laxatives
- 2 Digital assistance or enema

Failure: unsuccessful attempt for evacuation per 24h

- 0 Never
- 1 1-3
- 2 3-6
- 3 6-9
- 4 More than 9

History: duration of constipation (yr)

- 0 0
- 1 1-5
- 2 5-10
- 3 10-20
- 4 More than 20

TOTAL SCORE: _____



Patient Assessment of Constipation – Symptoms (PAC-SYM)

This questionnaire asks you about constipation in the past **2 weeks**. Please answer each question according to your symptoms, as accurately as possible. There are no right or wrong answers.

For each symptom below, please indicate **how severe** your symptoms have been during the past **2 weeks**. If you have not had the symptom during the past 2-weeks, please check '0'. If the symptom seemed mild, check '1'. If the symptom seemed moderate, check '2'. If the symptom seemed severe, check '3'. If the symptom seemed very severe, check '4'. Please, be sure to answer every question. Thank you for your participation!

How severe have each of these symptoms been in the last 2 weeks?	Absent 0	Mild 1	Moderate 2	Severe 3	Very Severe 4
1. Discomfort in your abdomen					
2. Pain in your abdomen					
3. Bloating in your abdomen					
4. Stomach cramps					
5. Painful bowel movements					
6. Rectal burning during or after a bowel movement					
7. Rectal bleeding or tearing during or after a bowel movement					
8. Incomplete bowel movement like you 'didn't finish'					
9. Bowel movements that were too hard					
10. Bowel movements that were too small					
11. Straining or squeezing to try to pass bowel movements					
12. Feeling like you had to pass a bowel movement but you couldn't (false alarm)					

Patient Assessment of Constipation – Quality of Life (PAC-QoL)

This questionnaire has been designed to measure the impact constipation has had on your daily life **during the past 2 weeks**. For each question, please tick one box. Thank you for your participation!

The following questions ask you about the intensity of your symptoms.

To what extent during the past 2 weeks...	Not at all 0	A little bit 1	Moderately 2	Quite a bit 3	Extremely 4
1. Have you felt bloated to the point of bursting?					
2. Have you felt heavy because of your constipation?					

The next few questions ask you about the effects of constipation on your daily life.

How much of the time, during the past 2 weeks...	None of the time 0	A little of the time 1	Some of the time 2	Most of the time 3	All of the time 4
3. Have you felt any physical discomfort?					
4. Have you felt the need to open your bowel but not been able to?					
5. Have you been embarrassed to be with other people?					
6. Have you been eating less and less because of not being able to have bowel movements?					

The next few questions ask you about the effects of constipation on your daily life.

To what extent, during the past 2 weeks...	None at all 0	A little bit 1	Moderately 2	Quite a bit 3	Extremely 4
7. Have you had to be careful about what you eat?					
8. Have you had a decreased appetite?					
9. Have you been worried about not being able to choose what you eat (i.e. at friend's)?					
10. Have you been embarrassed about staying in the toilet for so long when you were away from home?					
11. Have you been embarrassed having to go to the toilet for so long when you were away from home?					
12. Have you been worried about having to change your daily routine (i.e., travelling, being away from home)?					

The next few questions ask you about your feelings.

How much of the time, during the past 2 weeks...	None of the time 0	A little of the time 1	Some of the time 2	Most of the time 3	All of the time 4
13. Have you felt irritable because of your condition?					
14. Have you been upset by your condition?					
15. Have you felt obsessed by your condition?					
16. Have you felt stressed by your condition?					
17. Have you been less self-confident because of your condition?					
18. Have you felt in control of your situation?					

The next questions ask you about your feelings.

To what extent, during the past 2 weeks...	None at all 0	A little bit 1	Moderately 2	Quite a bit 3	Extremely 4
19. Have you been worried about not knowing when you are going to be able to open your bowels?					
20. Have you been worried about not being able to open your bowels when you needed to?					
21. Have you been more and more bothered by not being able to open your bowels?					

The next questions ask about your life with constipation.

How much of the time, during the past 2 weeks...	None of the time 0	A little of the time 1	Some of the time 2	Most of the time 3	All of the time 4
22. Have you been afraid that your condition will get worse?					
23. Have you felt that your body was not working properly?					
24. Have you had fewer bowel movements than you would like?					

The next questions ask you about how satisfied you are.

To what extent during the past 2 weeks...	None at all 0	A little bit 1	Moderately 2	Quite a bit 3	Extremely 4
25. Have you been satisfied with how often you open your bowels?					
26. Have you been satisfied with the regularity with which you open your bowels?					
27. Have you been satisfied with your bowel function?					
28. Have you been satisfied with your treatment?					

International Physical Activity Questionnaire –

Short Form (IPAQ-SF)

Physical Activities are activities where you move and increase your heart rate above its resting rate, whether you do them for pleasure, work, or transportation. The following questions ask about the amount and intensity of physical activity you did during the last 7 days. There are no correct or wrong answers. Please make sure you answer every question. Thank you for participating!

- 1a)** During the last 7 days, on how many days did you do **vigorous** physical activities like heavy lifting, digging, aerobics, or fast bicycling?

Think about *only* those physical activities that you did for at least 10 minutes at a time.

Days per week: _____ →

- 1b)** How much time in total did you usually spend on one of those days doing vigorous physical activities?

_____ hours _____ minutes

Or, none

- 2a)** Again, think only about those physical activities that you did for at least 10 minutes at a time. During the last 7 days, on how many days did you do **moderate** physical activities like carrying light loads, bicycling at a regular pace, or doubles tennis? Do not include walking.

Days per week: _____ →

- 2b)** How much time in total did you usually spend on one of those days doing moderate physical activities?

_____ hours _____ minutes

Or, none

- 3a)** During the last 7 days, on how many days did you **walk** for at least 10 minutes at a time? This includes walking at work and at home, walking to travel from place to place, and any other walking that you did solely for recreation, sport, exercise or leisure.

Days per week: _____ →

- 3b)** How much time in total did you usually spend walking on one of those days?

_____ hours _____ minutes

Or, none

The last question is about the time you spent **sitting** on week days while at work, at home, while doing coursework, and during leisure time. This includes time spent sitting at a desk, visiting friends, reading traveling on a bus, or lying down to watch television.

- 4)** During the last 7 days, how much time in total did you usually spend **sitting** on a week day?

_____ hours _____ minutes

Examples of physical activity intensity levels:

<p>Light activities</p> <ul style="list-style-type: none">• your heart beats slightly faster than normal• you can talk and sing	 <p>Walking Leisurely</p>  <p>Stretching</p>  <p>Vacuuming or Light Yard Work</p>
<p>Moderate activities</p> <ul style="list-style-type: none">• your heart beats faster than normal• you can talk but not sing	 <p>Fast Walking</p>  <p>Aerobics Class</p>  <p>Strength Training</p>  <p>Swimming Gently</p>
<p>Vigorous activities</p> <ul style="list-style-type: none">• your heart rate increases a lot• you can't talk or your talking is broken up by large breaths	 <p>Stair Machine</p>  <p>Jogging or Running</p>  <p>Tennis, Racquetball, Pickleball or Badminton</p>

St Marks Incontinence Score

This questionnaire asks you about your perception on bowel control. Its results will be used to evaluate the severity of faecal incontinence. Please answer each question according to your experience, by checking the boxes as accurately as possible. Please be sure you answer every question. Thank you for your cooperation!

Do you experience the following:	Never	Rarely	Sometimes	Weekly	Daily
1. Incontinence for solid stool	0	1	2	3	4
2. Incontinence for liquid stool	0	1	2	3	4
3. Incontinence for gas	0	1	2	3	4
4. Alteration in lifestyle	0	1	2	3	4
				No	Yes
5. Need to wear a pad or plug				0	2
6. Taking constipation medicines				0	2
7. Lack of ability to defer defecation for 15 minutes				0	4

Beighton Score -

The Beighton 9-point scoring system has been used for many years as an indicator of widespread hypermobility. However, it is more of a research tool and an indicator of generalized hypermobility.

	<p>Can you now (or could you ever) place your hands flat on the floor without bending your knees?</p>	<p>Yes</p>	<p>No</p>
	<p>Can you now (or could you ever) bend your elbows backwards?</p>		
	<p>Can you now (or could you ever) bend your knees backwards?</p>		
	<p>Can you now (or could you ever) touch your forearm with your thumb?</p>		
	<p>Can you now (or could you ever) bend your little fingers backwards beyond 90 degrees?</p>		

Additional questions:

As a child could you: Do the splits? Contort your body?
 Do you have: Scars in elbows, knees, shin? Stretch marks? Thin and stretchy skin?
 High, narrow palate? Dental crowding?

Score calculation:

1. One point if while standing forward bending you can place palms on the ground with legs straight
2. One point for each elbow that bends backwards
3. One point for each knee that bends backwards
4. One point for each thumb that touches the forearm when bent backwards
5. One point for each little finger that bends backwards beyond 90 degrees.

Hospital Anxiety and Depression Scale (HADS)

Doctors are aware that emotions play an important part in most illnesses. If your doctor knows about these feelings he or she will be able to help you more. This questionnaire is designed to help your doctor know how you feel. Please read each item and circle the reply which comes closest to how you have been feeling in the past week. Don't take too long over your replies: your immediate reaction to each item will probably be more accurate than a long thought out response. Thank you!

I feel tense or 'wound up':	A
Most of the time	3
A lot of the time	2
Time to time, occasionally	1
Not at all	0

I feel as if I am slowed down:	D
Nearly all of the time	3
Very often	2
Sometimes	1
Not at all	0

I still enjoy the things I used to enjoy:	D
Definitely as much	0
Not quite so much	1
Only a little	2
Not at all	3

I get a sort of frightened feeling like 'butterflies in the stomach':	A
Not at all	0
Occasionally	1
Quite often	2
Very often	3

I get a sort of frightened feeling like something awful is about to happen:	A
Very definitely and quite badly	3
Yes, but not too badly	2
A little, but it doesn't worry me	1
Not at all	0

I have lost interest in my appearance:	D
Definitely	3
I don't take as much care as I should	2
I may not take quite as much care	1
I take just as much care as ever	0

I can laugh and see the funny side of things:	D
As much as I always could	0
Not quite so much now	1
Definitely not so much now	2
Not at all	3

I feel restless as if I have to be on the move:	A
Very much indeed	3
Quite a lot	2
Not very much	1
Not at all	0

Hospital Anxiety and Depression Scale (continued)

Worrying thoughts go through my mind:	A	I look forward with enjoyment to things:	D
A great deal of the time	3	A much as I ever did	0
A lot of the time	2	Rather less than I used to	1
From time to time but not too often	1	Definitely less than I used to	3
Only occasionally	0	Hardly at all	2
I feel cheerful:	D	I get sudden feelings of panic:	A
Not at all	3	Very often indeed	3
Not often	2	Quite often	2
Sometimes	1	Not very often	1
Most of the time	0	Not at all	0
I can sit at ease and feel relaxed:	A	I can enjoy a good book or radio or TV programme:	D
Definitely	0	Often	0
Usually	1	Sometimes	1
Not often	2	Not often	2
Not at all	3	Very seldom	3

Questions relating to anxiety are indicated by an 'A' while those relating to depression are shown by a 'D'. Scores of 0-7 in respective subscales are considered normal, with 8-10 borderline and 11 or over indicating clinical 'caseness'