



Participant Number: **xxx**

Information Sheet: Assessment and management of sleep disturbance in people with multiple sclerosis (MS): a survey of clinical practice

Invitation to participate in this survey

We would like you to participate in this survey asking you about your practice concerning the assessment and management of sleep disturbance in people with MS. This study has been reviewed by the Ethics Committee of the Faculty of Health, Education and Society at Plymouth University.

What is the overall aim of the survey?

Sleep disturbance, which has been described as “any disorder that affects, disrupts or involves sleep”, is common in people with MS. Unfortunately, little is known about how nurses and allied health professionals working in the UK assess and manage this in people with MS. This survey aims to gain an overview of current practice in relation to this.

Who is undertaking this study?

This is being undertaken by members of the Research Project Team of “Therapists in MS” (TiMS). The question was developed following consultation with UK therapists through the TiMS network.

What do I need to do if I choose to take part in this survey?

This survey will take approximately 5 minutes to complete. Once you have filled out the questionnaire please place it in the collection boxes available outside the sessions at this conference.

Do I have to take part?

No. Participation in this survey is entirely voluntary. I understand that by completing and handing in this questionnaire that I am consenting for my anonymised data to be analysed and published.

Will my survey results be confidential?

All questionnaires are allocated a unique identifying number to ensure anonymity of the data collected. No names or personal data which could identify you is collected.

Right to withdraw:

You have the right to decide not to hand in this survey questionnaire. If you do choose to hand it in but then wish to withdraw it, you may do so without it affecting your relationship with any member of the research team or with Plymouth University. Should you wish to withdraw your information please contact Jenny Freeman either by telephone: 01752 588835 or e-mail: jenny.freeman@plymouth.ac.uk

Contact for further information:

Should you have any further questions please do not hesitate to discuss this with any of the research team members who will be available at the TiMS stand throughout the conference. Following the conference Jenny Freeman (contact details above) will be able to answer your questions.



Assessment and management of sleep disturbance in people with multiple sclerosis (MS): a survey of clinical practice

Participant Number: **xxx**

Please answer ALL questions, by ticking the appropriate box(es).

ABOUT YOU:

1. What is your role and banding level (or equivalent)?:

	Band 4	Band 5	Band 6	Band7	Band 8
Nurse					
Occupational Therapist					
Physiotherapist					
Psychologist					
Speech and Language Therapist					
Technical Instructor					
Lecturer / Researcher					
Other (please state)					

2. How many years is it since you qualified?

0-5years 6-10 years 11-15 years >15 years

3. How many years have you been working with people with MS?:

0-5years 6-10 years 11-15 years >15 years

4. Are you: male or female

5. In which setting are you currently working? (more than one box may be ticked)

- Social Services
- Community Rehabilitation
- Hospital Inpatients
- Hospital Outpatients
- Rehabilitation Unit
- Charitable Centre
- Private Practice
- Higher Education / Research
- Other

6. Do you work as:

- Part of a multi-disciplinary team
- A uni-disciplinary service
- Not applicable; I work in research or education

7. Do you work in an:

- MS Specialist Service
- Neurological Specialist Service
- Generic Service
- Not applicable; I work in research or education

For those people who are NOT currently working with patients, please stop here.

ASSESSMENT AND EVALUATION

8. Do you consider sleep management to be part of your role?

Yes No Unsure

9. How do you identify sleep disturbance with your clients? (more than one box may be ticked)

- I don't identify sleep disturbance as part of my assessment
- I include sleep disturbance routinely as a specific question in my initial client interview
- Through direct questioning as part of my Fatigue Management Programme
- Indirectly when I question about other symptoms (e.g. spasticity, pain, bladder)
- As a specific question incorporated within a mood assessment
- I don't specifically ask questions about sleep disturbance, but clients sometimes tell me despite not being prompted to do so
- Other – please describe briefly: _____

10. When do you identify sleep disturbance? (more than one box may be ticked)

- I don't at any time
- During my initial assessment
- As an ongoing part of my subsequent intervention
- At relapse
- Only when the client tells me
- Other (please describe briefly): _____

11. Do you use a specific sleep assessment, and if so which one do you use?
(more than one box may be ticked)

	For assessment only	As an outcome measure pre and post intervention to evaluate effectiveness
I don't use any specific assessment		
I am not aware of any specific assessments		
I have developed my own assessment		
I ask the client whether they experience sleep disturbance as part of subjective history		
Pittsburgh Sleep Quality Index		
Sleep Questionnaire described in the Birmingham Fatigue Management Manual (developed by Paralyzed Veterans Association)		
Epworth Sleepiness Scale		
National Sleep Foundation Diary		
Pittsburgh Sleep Diary		
Patient Diary		
Leeds Sleep Evaluation		
Insomnia Symptom Questionnaire		
Insomnia Impact Scale		
Jenkins Sleep Evaluation Questionnaire		
Functional Outcomes of Sleep Questionnaire		
Medical Outcomes Study Sleep Scale		
Visual Analogue Scale		
Other, (please describe)		

MANAGEMENT

12. When you do identify sleep disturbance in your clients, what interventions do you use, and how often do you use them? (please tick one box for each intervention)

Intervention	Frequency of use				
	Never	Occasionally	Often	Always	I don't provide but refer on to specialist service(s)
General Verbal advice					
General Written advice					
Verbal advice tailored to the individual					
Written advice tailored to the individual					
As part of a general Information leaflet (e.g. healthy lifestyles, fatigue management)					
A specific sleep hygiene / advice leaflet					
Fatigue Management / Energy Conservation Approach					
Cognitive Behavioural Therapy for Sleep					
Coaching / Goal Setting for sleep					
Anxiety /Depression management					
Relaxation					

Intervention	Never	Occasionally	Often	Always	I don't provide but refer on to specialist service(s)
Mindfulness					
Incorporated within other symptom management (e.g. spasticity, pain, bladder, posture management)					
Exercise Programme					
Prescribe Medication					
Review Medication					
Specialist Sleep Clinic					
Other including alternative therapies (please specify)					

13. How do you provide sleep management? (more than one box may be ticked)

	Individual basis	Group basis
Not applicable, I don't provide sleep interventions		
Face to face		
Web-based		
Telephone		
Information sheets		

14. Based on your experience, in general how would you rate the effectiveness of the following interventions (please tick one box for each intervention)

Intervention	Your opinion of effectiveness				
	Very	Somewhat	Not at all	Unsure	I don't have experience of using this intervention
General Verbal advice					
General Written advice					
Verbal advice tailored to the individual					
Written advice tailored to the individual					
As part of a general Information leaflet (e.g. healthy lifestyles, fatigue management)					
A specific sleep hygiene / advice leaflet					
Fatigue Management / Energy Conservation Approach					
Cognitive Behavioural Therapy for Sleep					
Coaching / Goal Setting for sleep					
Anxiety /Depression management					

Intervention	Very	Somewhat	Not at all	Unsure	I don't have experience of using this intervention
Relaxation					
Mindfulness					
Incorporated within other symptom management (e.g. spasticity, pain, bladder, posture management)					
Exercise Programme					
Prescribe Medication					
Review Medication					
Specialist Sleep Clinic					
Other including alternative therapies (please specify)					

KNOWLEDGE AND TRAINING

15. How confident are you in your....

	Very	Somewhat	Not at all
Knowledge about sleep disturbance in MS			
Ability to undertake an assessment of sleep disturbance			
Knowledge about interventions available for the management of sleep disturbance			
Awareness of services available for onward referral for sleep disturbances			

16. Have you undertaken any training specifically related to sleep disturbance?
(more than one box may be ticked)

	Yes – general training	Yes- MS specific training	No training	I would value further training
In-service education				
E-learning / Web-based				
Study day / Course				
Informal Self-directed learning (eg reading, peer discussions)				



17. Do you have any further comments?

If you have any information such as assessment sheets, information leaflets, contacts, or resources you have found particularly useful (such as web sites) then can you please share this with us by sending to TiMS at the MS Trust E:therapists@mstrust.org.uk

Thank- you for taking part in this survey.

A summary of the results of the survey will be posted on the TiMS website