

Psychological Support in Multiple Sclerosis

Participant information sheet

Research study aims - We are looking to explore participants' perspectives of people living with Multiple Sclerosis to better understand adjustment to diagnosis and the role of psychological support in the patient journey. The findings from this part of the study, along with other research will be used to inform the development of a psychological intervention for people with MS.

Why have I been contacted? - We have contacted you because you are living with Multiple Sclerosis, and we would like to know about your experiences of living with your diagnosis.

What does taking part involve? - This is an online questionnaire study about your well being, experience of living with your diagnosis over time, as well as your thoughts and experience of psychological support. The questions will take about 30 minutes to complete. There is a question at the end that invites you to leave your email if you wish to be interviewed via Skype at a later date.

Do I have to take part? - No, it's entirely up to you. Taking part in this study is online and completely voluntary; you may decide to stop at any time without giving a reason.

Potential benefits - This study does not provide a direct benefit to you as it seeks to understand the patient experience. However, results from this part of the study will be used to inform a psychological intervention for people with MS.

Potential disadvantages - There are very minimal risks in this online questionnaire study. There may be questions that you may not wish to engage with. These may be skipped over or you could stop at any time.

Who do I contact if I have concerns with this study? - If you have any concerns you may contact the principal investigator of the research study, Dr Aileen Ho (a.k.ho@reading.ac.uk)

How will my data be kept confidential? - This is an anonymously completed questionnaire. All responses are confidential and stored securely with access only to the principal investigator and research team.

Please feel free to ask any questions that you may have about this study by contacting Hannah Morris-Bankole (h.morris-bankole@pgr.reading.ac.uk).

This application has been reviewed by the University Research Ethics Committee and has been given a favourable ethical opinion for conduct.

Thank you for your help.

Consent

Check the following boxes to confirm your consent

- I have received and read a copy of the Participants Information Sheet for the above study and have had sufficient time to consider this.
- I have had the opportunity to ask questions which have been answered to my satisfaction.
- I understand that my personal details will be kept secure and confidential by the research team at Reading University.
- I understand that my details will be kept for a minimum of 5 years in line with University archiving policies.
- I understand that my involvement in the above study is voluntary and that I can withdraw at any time without giving a reason
- I agree to take part in the above study
- I am over the age of 18
- If you have read and understood the study information above and would like to participate in this online survey, please select the 'Yes' option below to proceed.

Section 1: About you

In this section we would like to collect information about you. This will help us to understand which type of psychological intervention will be suitable for different types of people with MS

1. Who is filling in this survey?

- I am filling it in as a MS patient, with my own opinions
- I am filling it in as a carer/companion of an MS patient, to convey the patient's opinions
- I am filling it in as a carer/companion of an MS patient, to convey my own opinions (regarding the patient)
- Other

2. How old are you?

3. What is your gender?

- Male
- Female
- Other:

4. Where are you currently resident?

- United Kingdom
- Republic of Ireland
- United States of America
- Canada
- Australia
- New Zealand

- Other:

5. What are your current living arrangements?

- Living with others (including spouse/partner, children, parents..etc..)
- Living alone
- Living in a residential care facility
- Other:

6. What is your current employment status (before the COVID-19 outbreak)?

- Employed (e.g. full time, part time, volunteering or self employed)
- Unemployed (seeking employment, training, can't work due to MS)
- Not working or seeking work for other reasons (e.g. retired)
- Other duties (e.g. household, childcare, family business)
- Other:

7. Does your MS affect your ability to do what you want in terms of employment?

- No
- I can't work at all
- I have to work reduced hours
- I cant work in my preferred field or role
- Other

Section 2: Your current MS status

In this section we would like to collect some information about your MS. This along with the rest of the information you provide in this questionnaire will help us understand the different psychological needs of people with different types of MS.

1. What type of Multiple Sclerosis are you currently diagnosed with?

- Relapse remitting
- Primary progressive
- Secondary progressive
- Clinically isolated syndrome
- Not sure
- Other:

2. How many years is it since you were first diagnosed with any type of MS?

3. How bothersome are the following MS symptoms for you on a scale of 1-5?

	I don't have this symptom	1 - Not at all bothersome	2	3	4	5 - Very bothersome
Fatigue	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Sensory issues (e.g. numbness, tingling, balance, eyesight, pain)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Motor issues (e.g. mobility, spasms, continence)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Cognitive issues (e.g. forgetfulness, concentration, attention))	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Psychological symptoms (e.g. stress, anxiety, depression)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

3b. How do your MS symptoms interfere with your everyday life?

4. Do you use any medication to treat psychological health problems such as depression or anxiety?

- Yes
- No

5. If there is anything you would like to add about your current MS status, please do so here

Section 3: Your experience of diagnosis

Here we will ask questions about your diagnosis and feelings related to your experience

1. How would you describe your emotional state then, when you were given the diagnosis of MS?

1 2 3 4 5 6 7 8 9 10

Very negative Very positive

2. How would you describe your emotional state now (before the COVID-19 outbreak)?

1 2 3 4 5 6 7 8 9 10

Very negative Very positive

3. What might be different about your emotional state between then (when first diagnosed) and now (before the COVID-19 outbreak)?

4. If there's a difference, how might this difference have come about? What might you attribute this difference to?

5. From where you are now and with hindsight, what would you like to say to your younger self then (when first diagnosed)?

6. Is there anything you would like to add about your experiences at the point of diagnosis and the first few years following this?

7. As we are now in an unusual situation brought about by the current covid-19 pandemic, we thought it timely to ask about this specifically at this point, so we have a general feel for the overall context of people's responses. What would you say has been the main impact of covid-19 on you, generally, and in terms of your MS?

- Negative impact (e.g. due to anxieties about MS medication)
- Positive impact (e.g. due to being able to spend more time with family)
- Neutral (the impact has been minimal, or neither largely positive or largely negative)

7a. Briefly, in a few words give us some insight into your answer to question 7 above.

Section 4: Your experience of psychological support

Psychological support
Mental health support
Emotional support

These are all terms that relate to support when dealing with challenging life situations using your inner resources rather than antidepressants. This input to cope with difficult emotions and feelings that you face as a result of your MS can come from different sources or different people such as:

1- FAMILY/FRIENDS/PEERS - This type of support is provided by significant others, such as friends and family. This also includes peer support from others who have MS.

2- MS ORGANISATIONS - This is support from MS organisations/charities who provide SPECIALISED support services, such as information or counselling to people living with MS. This also includes MS specific support like online self-paced courses, websites or information leaflets.

3- SPECIALIST MS NURSE - This is psychological support provided by MS nurses.

4- MENTAL HEALTH PROFESSIONALS - This type of support is usually provided by people who are NON-SPECIALISED in the field of MS specifically but are professionally trained in the field of mental health and therapy such as a counsellor or psychologist working in your local health service or private sector.

Here we will ask questions about the types of psychological support that you have encountered and your experience of it. This will help us to understand more about the psychological support you may have or haven't received.

1. What type of psychological support have you been OFFERED as a result of your MS?

	I don't remember	I was not offered this type of support	At diagnosis	Following a significant clinical event related to my MS	Following a significant personal event influenced by my MS	At another point not related to any MS related significant event
Family/friends/peers	<input checked="" type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
MS organisations	<input checked="" type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Specialist MS nurse	<input checked="" type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Mental health professional	<input checked="" type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

1b. If you have been OFFERED any other type of psychological support for your MS, please give details here

4. What did you get from each type of psychological support? (select all that apply)

	Did not receive psychological support from this person/source	Someone to talk to about my MS (emotional support)	Exploring new ways to manage my MS
Family/friends/peers	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
MS organisations	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Specialist MS nurse	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Mental health professional	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

4b. Is there anything else you got out of the psychological support provided to you?

Section 4a: Your experience of psychological support from FAMILY/FRIENDS/PEERS

This type of support is provided by significant others such as friends and family. This also includes peer support from others who have MS.

1. What was your experience of the process of trying to access psychological support from FAMILY/FRIENDS/PEERS on a scale of 1 to 5?

	I didn't access this type of support	1 - Very easy	2	3	4	5 - Very difficult
Family/friends/peer support	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

2. If you did NOT access this type of support please tell us what was holding you back? If you DID access psychological support from FAMILY/FRIENDS/PEER support, please skip to question 3.

Thank you for giving us some insight about why you didn't access psychological support from FAMILY/FRIENDS/PEERS. You may now scroll down to the bottom of this page and hit the 'next' button.

3. Who specifically did you receive psychological support from in relation to your MS? (Select all that apply)

- Family
- Friends

2. If you did NOT access this type of support please tell us what was holding you back? If you DID access psychological support from MS ORGANISATIONS, please skip to question 3.

Thank you for giving us some insight into why you didn't access psychological support from MS ORGANISATIONS. You may now scroll down to the bottom of this page and hit the 'next' button.

3. Which types of psychological support have you accessed from MS ORGANISATIONS? (select all that apply)

- Self guided information/skill seeking to manage psychological issues (provided by MS organisation website or information leaflet)
- Local meet ups (arranged by MS organisation)
- Email or telephone advice (one off)
- Counselling (Talking through problems related to my MS)
- Cognitive Behavioural Therapy/CBT (Exploring ways to change thinking and behaviour)
- Other:

4. What made you choose to access psychological support from MS organisations?

5. How helpful was the psychological support you received from MS organisations on a scale of 1-10

1 2 3 4 5 6 7 8 9 10

Not at all helpful Very helpful

5a. What WAS helpful about the psychological support you received from MS organisations? (think about things such as accessibility, content, who provided the support..etc..)

5b. What was NOT helpful about the psychological support you received from MS organisations? (think about things such as accessibility, content, who provided the support..etc..)

5a. What WAS helpful about the support you received from specialist MS nurses? (think about things such as accessibility, content, who provided the support..etc..)

5b. What was NOT helpful about the psychological support you received from specialist MS nurses? (think about things such as accessibility, content, who provided the support..etc..)

Section 4d: Your experience of psychological support from MENTAL HEALTH PROFESSIONALS

This type of support is usually provided by a mental health professional, such as a counsellor or psychologist.

1. What was your experience of the process of trying to access psychological support from mental health professionals on a scale of 1 to 5?

	I didn't access this type of support	1 - Very easy	2	3	4	5 - Very difficult
Mental health professional support	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

2. If you did NOT access any psychological support from MENTAL HEALTH PROFESSIONALS, please tell us what was holding you back. Please select all that apply. If you DID access this type of support, please skip to question 3.

- I am happy with the support i receive from family/friends/peers
- I am happy with the support i receive from lay/charity/health organisations
- The medication i use for psychological problems is keeping me stable enough already
- I am not happy with the professional support options available to me
- I'm not aware of what is available to me
- I don't feel like I need it
- I don't know how to find it
- I don't feel comfortable discussing psychological matters with professionals
- They don't understand my MS
- They have minimal knowledge of MS
- They have little experience of working with people with MS
- Other:

Thank you for giving us some insight into why you didn't access psychological support from MENTAL HEALTH PROFESSIONALS. You may now scroll down to the bottom of this page and hit the 'next' button.

3. What type(s) of psychological therapy did you receive from MENTAL HEALTH PROFESSIONALS? Select all that you received.

- Patient education programme (Exploring ways of seeing and understanding my MS)
- Self management programme (Exploring ways to actively manage my MS)
- Counselling (Talking through problems related to my MS)

- Behavioural therapy such as a stress management programme (Exploring ways to change behaviour)
- Cognitive therapy (Exploring ways to change thinking)
- Cognitive Behavioural Therapy/CBT (Exploring ways to change thinking and behaviour)
- Mindfulness based therapies, acceptance and commitment therapy (Exploring how to change my relationship with my thoughts and feelings)
- Psychoanalytic therapy (Exploring changing problematic behaviours, feelings and thoughts by discovering their unconscious meanings and motivations)
- Client centered therapy, gestalt therapy, existential therapy (Exploring my capacity to make rational choices and develop to my maximum potential)
- Group psychotherapy, family therapy (Exploring how to manage my relationships)
- Not sure
- Other

3b. If would like to provide further information regarding your answer to question 3 above, please do so here.

4. In what format did you receive psychological support from MENTAL HEALTH PROFESSIONALS (select all that apply)

- In person/face to face - one-to-one
- In person/face to face - group
- Online - group with support (with interactive support)
- Online - one-to-one (with interactive support)
- Online non-interactive (self-guided/paced)
- Other:

5. How helpful was the psychological support you received from MENTAL HEALTH PROFESSIONALS on a scale of 1-10

1 2 3 4 5 6 7 8 9 10

Not at all helpful Very helpful

5b. What WAS helpful about the psychological support your received from mental health professionals? (think about things such as accessibility, content, who provided the support..etc..)

5c. What was NOT helpful about the psychological support you received from mental health professionals? (think about things such as accessibility, content, who provided the support..etc..)

Section 5: Psychological health, mental health and well-being - your opinion wanted

In this section we would like to understand your emotional health, concerns and psychological experience of living with MS. We are interested in your thoughts about what your psychological support needs might be, and

your opinion on what might be helpful. We will do this by asking questions about:

- 1 - Your MS related CONCERNS
- 2 - The CONTENT that you feel is important and would be helpful
- 3 - HOW you would like it to be delivered.

1. When thinking about your MS, to what extent do the following things concern you on a scale of 1 to 3?

	1 - Doesn't concern me	2 - Concerns me somewhat	3 - Concerns me a lot
Feelings of anxiety	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Worry about MS disease progression	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Worry about impact on my family	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Feelings low/sad	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Feelings of loss	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Lack of control of my MS	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Impact on my life goals	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Impact on relationships with others	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Uncertainty about the future	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Having to make lifestyle changes	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Ability to function as I want (e.g. social, employment, family roles)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Lack of resources to cope	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Fatigue	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

1b. Is there anything else about your psychological state relating to your MS that concerns you?

In this next part we ask about the type of CONTENT that you feel is important in psychological support.

2a. How important are the following aspects of emotional support in improving your psychological well-being to you on a scale of 1 - 3?

	1 - Not important	2 - Somewhat important	3 - Very important
Having someone to talk to	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Having someone to listen	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Feeling supported	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Feeling valued	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Feeling cared for	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

2b. How important are these topics/areas in terms of learning how to manage your MS and improving your psychological well-being to you on a scale of 1 – 3 (1 – not important, 2 – a bit important, 3- very important)

- Learning skills to manage emotions
- Accepting my feelings
- Improved emotional strength
- Improved mood
- Viewing my circumstances in a positive light
- Making the most of my strengths
- Improved sense of hope
- Appreciation for life in general
- Personal growth
- Remaining committed to my values and beliefs
- Reducing the negative impact of my condition on factors such as career and relationships
- Gaining competency in matters related to my MS
- Gaining some control over what i can
- Improved self-confidence
- Improved motivation
- Goal setting
- Adjusting to life with MS

Commented [AH1]: - skype f/bk earlier, plus confidence, mood, motivation, hope
- consider ordering of items/rows

Commented [HM2R1]:

Commented [HM3R1]:

2c. If there are any other things that you feel you need to promote your psychological well being In relation to your MS that are not listed here in questions 2a and b, please discuss further here.

3. Who would you feel most comfortable to receive these components of psychological support from? (select all that apply)

	I wouldn't feel comfortable to seek psychological support from these people	Having someone to talk to (emotional support)	Exploring ways to manage my MS
Self guided learning	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Friends/family	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
MS organisations	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Other people with MS	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Mental health professional (e.g. counsellor, psychologist)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
MS nurse	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

3b. If there anyone else you would feel comfortable to receive psychological support from, please discuss further here.

3c. Why do you feel more comfortable to receive psychological support from the people you have selected above in question 3?

4. What type(s) of professional psychological support would you like? Select all that that apply.

- Exploring ways of seeing and understanding my MS (e.g. patient education programme)
- Exploring ways to actively manage my MS (e.g. self management programme)
- Talking through problems related to my MS (e.g. counselling)
- Exploring ways to change behaviour (e.g. behavioural therapy, stress management)
- Exploring ways to change thinking (e.g. cognitive therapy)
- Exploring how to change my relationship with my thoughts and feelings (e.g mindfulness based therapies, acceptance and commitment therapy)
- Exploring changing problematic behaviours, feelings and thoughts by discovering their unconscious meanings and motivations
- Exploring my capacity to make rational choices and develop to my maximum potential (e.g. client centered therapy, gestalt therapy, existential therapy)
- Exploring how to manage my relationships (e.g. group psychotherapy, family therapy)
- Not sure
- Other
- None, I'm happy with the psychological support i receive from other sources

4b. Why would you like this type of support?

In the next few questions we ask about HOW you would like to access to psychological support.

5. What are the most important things about how psychological support is provided for you on a scale of 1 to 3?

1 Not at all important 2 - A bit important 3 - Very important

	1 Not at all important	2 - A bit important	3 - Very important
Its available on demand and not by appointment	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Sessions are structured and regular	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Its provided by people who know me or my condition well	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
The support comes from a qualified professional	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
A significant other can be involved	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Meeting other people with MS	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I don't have to travel far or even leave my house	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I can seek it anonymously	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I can get advice	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

5b. If there are any other things that are important in the way psychological support is provided to you, please discuss further here.

6. In what format would you prefer to receive psychological support? (select all that apply)

- In person/face to face - one-to-one

- In person/face to face - group
- Online - one-to-one (interactive)
- Online - group (interactive)
- Online website (non-interactive/self-guided)
- Telephone
- E-mail
- Other:

6c. Why would you prefer it were delivered in this format?

7. What would make you more likely to engage with psychological support?

8. If there is anything else about your psychological support needs that you would like to let us know, or suggestions for things that would help to improve your psychological well being, please do so here.

Further research

If you would like to receive a summary or the findings from this study, please leave your email here. _____

We would like to invite a selection of people who completed this questionnaire to be considered to take part in a further interview study building on the information provided here relating to their experience of psychological support. If you would like to be considered, please leave your email address here. _____

Submit