MS Awareness Week 22 – 28 April 2024 Supporter Pack

This supporter pack gives you the tools to mark MS Awareness Week 2024. There are loads of ways to get involved, from hosting an event to speaking out in the press. We hope this pack will give you all the ideas and resources you need to make the week your own.

#MSUnfiltered











About our campaign "MS Unfiltered"

- MS Awareness Week 2024 will run from 22 28 April this year. It's a chance for us to raise awareness and speak up together about the realities of life with MS.
- MS Society, MS Together, MS Trust, MS-UK, the Neuro Therapy Network, Shift.ms and Overcoming MS are all teaming up this MS Awareness Week.
- MS symptoms are different for everyone but might include sexual dysfunction, bladder problems and issues with walking. Symptoms can be upsetting to deal with, and difficult to talk about. And people with MS told us they have avoided seeking medical help due to embarrassment.
- That's why this MS Awareness Week we're launching MS Unfiltered, a sensitive and intimate campaign which will shine a light on the MS topics that can feel taboo or difficult to talk about.
- We hope MS Unfiltered will raise awareness about the huge range of symptoms and daily challenges that people with MS face. While at the same time reassuring people they aren't alone and encouraging them to seek support.
- All week the charities will be sharing unfiltered stories from the MS community. As well as resources and information for anyone affected.
- Want to talk? Nothing is off limits. Reach out to any of the seven charities to find out what support is available.

Draft Facebook or Instagram post

We know that a lot of MS symptoms can be difficult to talk about.

That's why, this MS Awareness Week, MS Society, MS Together, MS Trust, MS-UK, Neuro Therapy Network, Shift.ms and Overcoming MS are all teaming up to launch **#MSUnfiltered**.

The campaign shines a light on the MS topics that can feel taboo or difficult to talk about, from bladder control and sexual dysfunction, to navigating menopause and cultural stigma.

To mark the week we'll be.....[add information if hosting an event].

Check out any of the seven charities during the week to find out what support is available.

3 in 5

people with MS keep symptoms hidden from family and friends due to embarassment

Draft Tweets

- From bladder issues to sexual dysfunction, we know that a lot of MS symptoms can be difficult to talk about. That's why this #MSAwarenessWeek is all about breaking the silence and speaking out together. Search #MSUnfiltered to join the conversation.
- No one should feel embarrassed about their MS symptoms. This
 #MSAwarenessWeek is all about encouraging people to speak out
 and seek support. Search #MSUnfiltered to join the conversation.

Please look out for posts from all the charities during the week and share our content



Draft press release

If you have some local media contacts, you may want to send them a press release to promote what you're doing during MS Awareness Week. We've included a draft below which can be edited to suit your needs.

If journalists follow up with any questions about the statistics used in this press release, please contact pressoffice@mssociety.org.uk

EMBARGOED UNTIL 00:01 ON MONDAY 22 APRIL

MS Awareness Week: 22 - 28 April

[Insert town/city] [group/man/woman] joins national campaign to break multiple sclerosis (MS) taboos

This MS Awareness Week, [insert details of group or individual] is speaking out about living with multiple sclerosis (MS) to help break the stigma around some lesser-known symptoms.

Over 130,000 people in the UK live with MS, with 130 diagnosed each week. The condition affects the brain and spinal cord, impacting how people move, think and feel. Symptoms are different for everyone, and can be exhausting, debilitating and unpredictable.

This MS Awareness Week, a collaboration of MS charities – the MS Society, MS Together,

MS Trust, MS-UK, the Neuro Therapy Network (formerly MS National Therapy Centres), Shift.ms and Overcoming MS – are launching a new campaign, MS Unfiltered. The sensitive and intimate campaign aims to shine a light on the huge range of symptoms and daily challenges that people with MS face. It also seeks to encourage and empower people with MS to speak up and get support when they need to.

[In this paragraph, give some details of your story or details of the support provided by your group]

[Draft quote from individual or group, you can personalise this with details of your story – for example]: "I was diagnosed with MS 10 years ago, and have been dealing with bladder and bowel issues ever since. For so long I was too embarrassed to go and speak to my doctor or MS nurse about it, so I just suffered in silence. No one should feel embarrassed about their MS symptoms. That's why this MS Awareness Week I'm joining up with MS charities to encourage people to speak out and seek support."

Notes to editors

For press enquiries please contact: [please add your contact details here]

Join the conversation by searching #MSUnfiltered

Over a quarter

of people with MS would feel uncomfortable raising bowel issues with a healthcare professional

No one

should feel embarrassed by their MS symptoms

#MSUnfiltered

Session plan

Draft session plan for local groups

If you are meeting in person or virtually with a group of people during MS Awareness Week you may want to facilitate a conversation around the MS Unfiltered theme. Below we've offered some guidance and suggestions to encourage a great discussion.

• Explain the purpose

It's important to explain to people why we're talking about these sensitive topics. Be clear about the objectives of the conversation and why it's important to raise awareness of lesser-known symptoms. We know people haven't spoken to a healthcare professional about some MS symptoms due to embarrassment. Many others hide embarrassing symptoms from partners, friends and family. The purpose of the session is to encourage people to talk about and get support for symptoms that are troubling them and for others to share how they've successfully got support for their symptoms. Let people know how the session will run and the benefits of being open with others. We want to help reduce isolation and show people they are not alone dealing with these symptoms. • Create a safe space A safe space is an environment where participants feel comfortable, respected, and valued to express their views and experiences. Set some ground rules at the beginning of the session to encourage mutual respect, active listening and appreciation of differing views. Make sure to intervene if someone isn't respecting these rules and ensure everyone knows they can take a break or opt out of discussions whenever they want to.

Encourage participation

Conversations will be more beneficial if everyone has the chance to share their experience and hear from others. Ensure that everyone has an opportunity to speak if they want to. Ask open ended questions. Ensure you acknowledge all contributions and validate the feelings of participants.

Signpost to support

The seven MS charities leading on MS Awareness Week all offer a variety of support services for people struggling with their MS. Please encourage participants to visit the charities' websites and highlight the helplines available.

Lead with your own personal experience

If appropriate, lead the conversation with your own personal experience. Sharing can help set the tone for the session and give an example of what people might be able to talk about.

Follow up

Discussing sensitive symptoms might bring up a lot of emotions and questions for participants. You could offer to circulate some takeaways from the session i.e. share advice on how to raise a symptom with a healthcare professional or tips on managing difficult symptoms. It would be good to consolidate these and share with the group. You may think it appropriate to organise follow on sessions which focus on specific issues raised during the discussion. Use a follow up to reiterate the wider support available.

- **MS Society** mssociety.org.uk
- **MS Together** mstogether.org
- **MS Trust** mstrust.org.uk
- MS-UK ms-uk.org

- Neuro Therapy Network neurotherapynetwork.org.uk
- Shift.ms shift.ms
- Overcoming MS overcomingms.org

All charities offer a range of support and services for people affected by MS. For information visit any of the seven charities' websites.





