

19 JUNE
is the longest day.

For MND carers, every day is the longest day.
#MNDAwarenessDay

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association

Campaign Toolkit

Global MND Awareness Day 2024

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Global MND Awareness Day

Friday 21 June 2024

Background

Each year on 21 June the MND Association joins with the wider MND community around the world to mark Global MND Awareness Day – a date selected because it marks the summer solstice – the longest day of the year.

Awareness Day is a day MND Association branches and groups, partners, supporter, donors and fundraisers join forces to honour and celebrate our remarkable community.

Acknowledging all the people living with MND, their carers, and those who have lost their lives to the disease. Highlighting personal stories of courage and resilience to inspire others to take action.

Objectives

- The day aims to raise awareness of motor neurone disease, its impact on people and families worldwide. **Our number one goal is to reach new people and improve our engagement with the MND community.**
- **This year, our focus is carers.** Specifically, the extensive hours unpaid MND carers dedicate and the insufficient financial support they receive.
- Awareness Day encourages education and advocacy but we also want to enable people to take action in support of MND carers. This year, we ask you to **join us in demanding better support for carers by sharing your story and asking your local election candidates to [sign the MND Guarantee](#).**

Toolkit overview

Awareness Day needs you. It cannot work without your voice, your stories, and your action - to raise awareness of MND, start conversations, inform and inspire others.

This toolkit has been created as a 'one-stop-shop' to help everyone take part in Global MND Awareness Day by amplifying key messages and includes the following:

- How to get involved
- Key messages
- Content
- Personal stories
- Key MND facts and stats
- Campaign FAQs

Campaign concept

The Longest Day

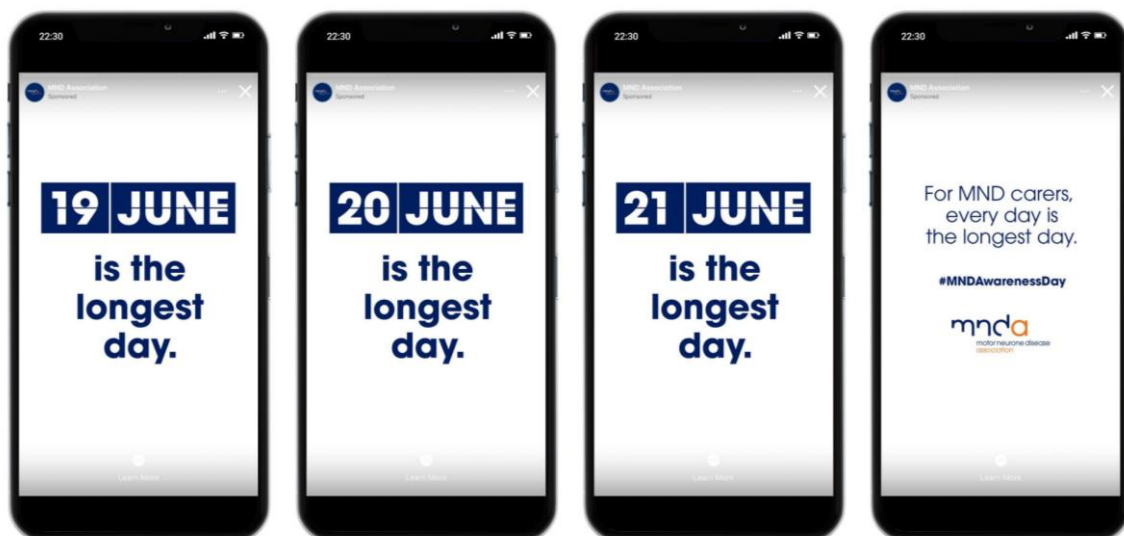
Our single focus on Global MND Awareness Day is the need for improved care and specifically, greater provision for unpaid caregivers. It's an emotive issue, one which affects almost the entire MND community, and one which deserves greater awareness.

This year the longest day falls on 20 June, so we will in fact launch on that day with static and video teasers - running into 21 June when we'll switch on all other Awareness Day messages and creative. You'll see this across the MND Association website and social media channels.

Our concept this year: *'Every Day Is the Longest Day'* for unpaid carers.

Everything we do on the day will be about highlighting the long hours carers put in for those with MND and how little support they receive. We'll touch on the value of carers to the MND community and the value of an increased carers allowance.

Juxtaposing the admiration, we have for unpaid MND carers and the long hours they dedicate with indignation for the lack of financial support they receive.



How to get involved

We need you at the heart of Global MND Awareness Day.

Getting involved is simple and impactful, whether you are a carer, someone living with MND, a volunteer, a health or social care professional, a partner, or employee. Start by sharing our campaign messages and visual assets on your social media platforms using the hashtags **#GlobalMNDAwarenessDay** and **#SupportMNDcarers** to spread the word.

- **If you are a carer or someone living with MND**, share your personal story to shed light on the challenges and triumphs you face daily.
- **If you are a volunteer**, speak to your community, share information materials, and encourage others to participate.
- **Anyone can amplify the message** by promoting the campaign within their networks and advocating for better support for unpaid carers.

Our goal is that Global MND Awareness Day is inclusive and accessible to all. By uniting our voices and efforts, we can raise awareness, spark meaningful conversations, and drive positive change for the MND community.

So, get creative in any way you can, share a few words, a video, or an image. Tell us how you're feeling or write a short blog. Whatever you do, every single person that takes part will be doing their bit to reach beyond our MND community, to inform and inspire others to take action for MND.

Key messages

To raise awareness of MND and the experience of unpaid MND carers we're asking everyone who can take part to send a clear message of support to the global MND community. To ensure that message is clear consistent we've provided examples of campaign key messages you can use on, before or after 21 June.

Primary message

For MND carers every day is the longest day. Many MND carers dedicate over 100 hours to caring a week with little or no financial support.

Secondary message

Share your story in the comments and ask your local candidates to sign the MND Guarantee - pledging their support for people with MND and their carers if elected.

Campaign hashtags

Using the campaign hashtags holds the key to amplifying the campaign's reach and impact, unifying all your content and contributions under a single banner. Be sure to use:

#GlobalMNDAwarenessDay

#SupportMNDcarers

Example Short-form Messages

- **For MND carers, every day is the longest day.** Many provide over 100 hours of care a week with little or no financial support. Join us in demanding better support for carers by sharing your story and asking your local General Election candidates to [sign the MND Guarantee](#).
- **Unpaid carers play a vital role in the lives of those affected by MND**, working tirelessly with minimal support. This Global MND Awareness Day, let's join together and demand a carers allowance that recognises their true value.
- **This Global MND Awareness Day, we stand together** to recognise the efforts of unpaid carers and advocate for the financial support they deserve. Share your experiences and [reach out to your local General Election candidates to demand change](#).
- **21 June is Global MND Awareness Day.** A day on which we stand with the global MND community to recognise those who care for people living with MND.
- Today, on Global MND Awareness Day, come together, **share your experiences, tell your story and inspire** all those living with or affected by MND.
- This Global MND Awareness Day **let's challenge perceptions about MND and demand better support for unpaid MND carers**.
- 21 June marks Global MND Awareness Day. **This year we invite you to raise awareness and [demand better support from politicians for unpaid MND carers](#).**

Example long-form messages

- **Motor neurone disease is devastating. It robs people of their independence - their ability to move, speak and ultimately breathe. Every day in the UK, six more people are diagnosed.** And it doesn't only affect those people, it impacts their families and friends too. The unsung heroes who provide, in some cases over 100 hours of care a week, of round-the-clock care with little or no financial support. This Global MND Awareness Day, join me, help spread the word, and let's [demand a fair allowance for unpaid MND carers](#).
- **For MND carers every day is the longest day. Unpaid carers, whether family or friends, selflessly devote their time and energy to support people with MND.** They are there – day and night – to provide assistance, emotional support, and love - doing all they can so that a person with MND can live with dignity. Yet there's little or no financial support

to help them. Join me this Global MND Awareness Day – share this post and let's [demand unpaid carers receive an allowance that reflects their true value](#).

- **It's time for change. We must demand greater support for unpaid MND carers.** They deserve an allowance that reflects their true value—their sacrifice, their commitment, and their love. It's not just about recognition; it's about ensuring they can continue to provide the best care possible and not feel they're doing this alone. Hit share and ask your local General Election candidates to [sign the MND Guarantee](#) - pledging their support for people with MND and their carers if elected. Together we can make change happen. Thank you.
- **When supporting someone who has MND, taking care of yourself often takes second place.** It may feel impossible to think about eating and sleeping well, let alone keeping fit, taking breaks or getting outside. As difficult as it can be, there may come a time when you need help – and the MND Association is here for you. For suggestions and guidance on wellbeing search 'MND Support for carers' or call MND Connect on 0808 802 6262. You are not alone.
- **For Global MND Awareness Day 2024, we are launching a campaign moment - an extension of our 'The Love Inside' campaign - under the theme "Every Day Is The Longest Day" for unpaid carers.** Our objective is to raise awareness about the extensive hours unpaid MND carers provide and the lack of financial support they receive, communicating the urgent need for improved care provisions. Everything we do on the run up to and on the day will be about highlighting the true value of unpaid carers to people living with MND and how little support they receive - Juxtaposing the admiration with indignation. We'll share compelling personal stories, encourage others to do the same, and using bold, creative visuals, create a groundswell of public support for unpaid carers. We will also empower the MND community and the wider public to take action and advocate for better financial support and recognition for unpaid carers, [asking candidates standing in the 2024 General Election to sign the MND Guarantee](#), a commitment that they'll champion people living with and affected by MND in the next Parliament.

Email/letter copy - for the Care Community

As we approach Global MND Awareness Day on 21 June, the MND Association extends our deepest gratitude to you, the unpaid carers, who dedicate countless hours to support people living with MND. This year, our campaign theme is "**Every Day Is the Longest Day**", a poignant reminder of the long hours and tireless efforts you put in daily.

We know that many of you dedicate over 100 hours a week with little or no financial support. Your commitment and compassion are vital to the wellbeing of those you care for, and we want your invaluable contributions to be recognised and supported.

You have a vital role to play in this campaign. Here's how:

- **Share Your Story:** Your personal experiences are powerful. Share your story on social media to highlight the challenges and triumphs of caring for someone with MND. Use the hashtags #GlobalMNDAwarenessDay and #SupportMNDcarers.

- **Engage with the Campaign:** Follow the MND Association on social media and share our campaign posts. By amplifying our message, we can reach a wider audience.
- **Advocate for Change:** Ask your local General Election candidates to [sign the MND Guarantee](#) - pledging their support for people with MND and their carers if elected. Your voice can help drive the change we need.
- **Connect with Others:** Join online forums and support groups to connect with other carers. Sharing experiences and advice can provide mutual support and strength.

We are committed to advocating for better financial support and recognition for all unpaid MND carers. Your dedication deserves to be acknowledged, and together, we can raise awareness and drive meaningful change.

Thank you for your unwavering dedication and strength.

Email/letter copy - for Volunteers and Supporters

On 21 June the MND Association is joining the global community to recognise Global MND Awareness Day. Our campaign theme, "**Every Day Is the Longest Day**" for unpaid carers, highlights the incredible dedication of those who provide care for people with Motor neurone disease (MND) and the insufficient financial support they receive.

Many unpaid carers dedicate over 100 hours a week, often without the recognition or financial assistance they deserve. On this day we aim to raise awareness about their challenges and to advocate for better support.

Here's how you can get involved and show your support:

- **Share our message and spread the word:** Use your social media platforms to share our campaign messages and visuals. Use the hashtags #GlobalMNDAwarenessDay and #SupportMNDcarers.
- **Tell your story:** Share your personal experiences or stories about caring for someone with MND. Your story can inspire and encourage others.
- **Advocate for change:** Use your social media posts to ask your local General Election candidates to [sign the MND Guarantee](#) - pledging their support for people with MND and their carers if elected.

Your support is vital in raising awareness and driving meaningful change for unpaid MND carers. Together, we can make a difference.

Email/letter copy – for partner employees

This year, the MND Association is marking Global MND Awareness Day on 21 June with a special campaign focusing on unpaid carers. Our theme, "**The Longest Day**", highlights the immense dedication and lack of financial support faced by those caring for people with Motor Neurone Disease (MND).

Unpaid carers often dedicate over 100 hours a week, providing essential care with little to no financial assistance. This campaign aims to raise awareness about their challenges and advocate for better support.

We encourage you to participate in the following ways:

- **Share our campaign:** Use your personal and professional social media accounts to share our campaign messages and visuals. Use hashtags #GlobalMNDAwarenessDay and #SupportMNDcarers.
- **Advocate for change:** Ask your local General Election candidates to [sign the MND Guarantee](#) - pledging their support for people with MND and their carers if elected.

Your involvement will help amplify our message and bring much-needed attention to the vital role of unpaid carers.

Content

Example social media content

The day before - 20 June

1: Personal story teaser

Tomorrow is #GlobalMNDAwarenessDay, and I'm sharing my story as an unpaid carer for my [dad/mum/son/daughter/friend]. Stay tuned to learn about the long hours and the love that goes into every day. #SupportMNDcarers.

2: Informational teaser

Did you know many MND carers dedicate over 100 hours a week with little support? Tomorrow, join us to raise awareness and push for change. #GlobalMNDAwarenessDay #SupportMNDcarers.

3: Call to action teaser

Tomorrow, we highlight the incredible dedication of unpaid MND carers. Share your story and help us make a difference. #GlobalMNDAwarenessDay #SupportMNDcarers

4: Community teaser

Let's come together tomorrow for #GlobalMNDAwarenessDay to honour the tireless efforts of unpaid MND carers. Your support matters. #SupportMNDcarers"

5: Stat teaser

MND carers often dedicate over 100 hours a week with little support. Tomorrow, we shine a light on their stories. #GlobalMNDAwarenessDay #SupportMNDcarers"

5: Gratitude teaser

Unpaid MND carers are our everyday heroes. Tomorrow let's all show our gratitude and support for these incredible people. #GlobalMNDAwarenessDay #SupportMNDcarers"

On the day itself (21 June)

1: Personal story highlight

For MND carers like me, every day is the longest day. Today, I share my journey to raise awareness. #SupportMNDcarers this #GlobalMNDAwarenessDay"

2: Advocacy call

Unpaid MND carers dedicate tirelessly with little support. Ask your local General Election candidates to [sign the MND Guarantee](#) - pledging their support for people with MND and their carers if elected. #GlobalMNDAwarenessDay #SupportMNDcarers"

3: Community support

Today, we stand with unpaid MND carers. Share your story and spread the word. #SupportMNDcarers this #GlobalMNDAwarenessDay"

4: Informational post

Many unpaid MND carers dedicate over 100 hours a week. Learn more about their challenges and how you can help. #GlobalMNDAwarenessDay #SupportMNDcarers"

5: Thank you

Thank you to all unpaid MND carers for your endless dedication. Today, we honour and support you. Today we #SupportMNDcarers on #GlobalMNDAwarenessDay"

6: Testimonial

Hear from [Carer's Name], an unpaid carer for [Relation], about the daily challenges and the love that gets them through. #GlobalMNDAwarenessDay #SupportMNDcarers"

7: Awareness challenge

Take the challenge! If you're an unpaid MND carer or somebody living with MND, share your experiences and help raise awareness. #GlobalMNDAwarenessDay #SupportMNDcarers"

8: Collaborative

This #GlobalMNDAwarenessDay, we're partnering with the MND Association to support unpaid MND carers. Learn how you can join the effort and make a difference. #GlobalMNDAwarenessDay #SupportMNDcarers"





Personal stories

To raise awareness of MND and the tireless efforts of unpaid MND carers the MND Association will be sharing the stories of three people caring for someone with MND, demonstrating their incredible resilience, strength and commitment. People who in the face of such a life changing diagnosis face, physical, financial and social challenges. Inspiring others through their actions, achievements, and words.

Keep your eyes on our social channels and share your own personal stories and experiences.

Campaign social assets

You can use campaign visual assets by incorporating them into your social media posts, emails, and presentations to create a cohesive and visually appealing message that highlights the dedication of unpaid MND carers and the need for greater support.

Asset	File name	
 <p>Tomorrow is the longest day.</p>	<p>TEASER - For use on 20 JUNE 2024 ONLY</p> <p>Tomorrow is the longest day video_1x1.mp4 [SQUARE]</p>	<p>Download video</p>
 <p>Tomorrow is the longest day.</p>	<p>TEASER - For use on 20 JUNE 2024 ONLY</p> <p>Tomorrow is the longest day video_9x16.mp4 [PORTRAIT]</p>	<p>Download video</p>
 <p>21 JUNE is the longest day.</p>	<p>For use on or after 21 JUNE 2024</p> <p>Calendar video_4x5.mp4</p>	<p>Download video</p>
 <p>Support MND carers</p> <p>mnda motor neurone disease association</p>	<p>MNDA Awareness Day_v4Carousel Images</p>	<p>Open Folder</p>

Key MND facts and stats

For more information contact the MND Association's communications team.

- MND is a fatal, rapidly progressing disease that affects the brain and spinal cord.
- MND has no cure.
- Six people per day are diagnosed with MND in the UK.
- It kills six people per day in the UK, this is just under 2,200 per year.
- It affects more than 5,000 adults in the UK at any one time.

- There are thousands of unpaid carers of people with MND, and many of them face financial hardship because of their caring role:
 - 47% of unpaid carers report worrying about money.
 - Almost half (49%) report that caring had caused them financial difficulty.
 - Increasing the rate of Carer's Allowance would make a difference to unpaid MND carers.

- MND attacks the nerves that control movement so muscles no longer work. MND does not usually affect the senses such as sight, hearing, touch etc.
- It can leave people locked in a failing body, unable to move, talk and eventually breathe.
- Over 80% of people with MND experience changes to their speech, which may become slurred or quieter. Some people lose their ability to speak entirely.
- MND affects people from all backgrounds.
- Around 50% of people with MND experience some form of cognitive change while living with the disease. This can affect their thinking or behaviour. This percentage rises to around 80% for people who are in the advanced stages of the disease.
- It kills a third of people within a year and more than half within two years of diagnosis.
- A person's lifetime risk of developing MND is around 1 in 300.

Campaign FAQs

1. What is 'The Longest Day' campaign?

- The campaign will launch on 21 June 2024 to help raise awareness of the challenges of caring for someone living with MND
- The campaign will be promoted by the MND Association with the global MND community at the heart activity on the day.

2. Where did the campaign theme originate?

- The campaign was devised by the MND Association.

3. Why do we recognise Global MND Awareness Day?

- The campaign is a vital piece of our mission to raise awareness of the challenges of living with MND
- It's a day on which we celebrate the courage, spirit and resilience of all of those living with and affected by MND around the world, whoever and wherever they are.
- Global MND Awareness Day is not about celebrating Motor Neurine Disease. It is about standing in solidarity with all of those living with and affected by MND and celebrating their incredible spirit.