

Being a charity spokesperson and working with the media – our guide

Your role and how you can make a difference

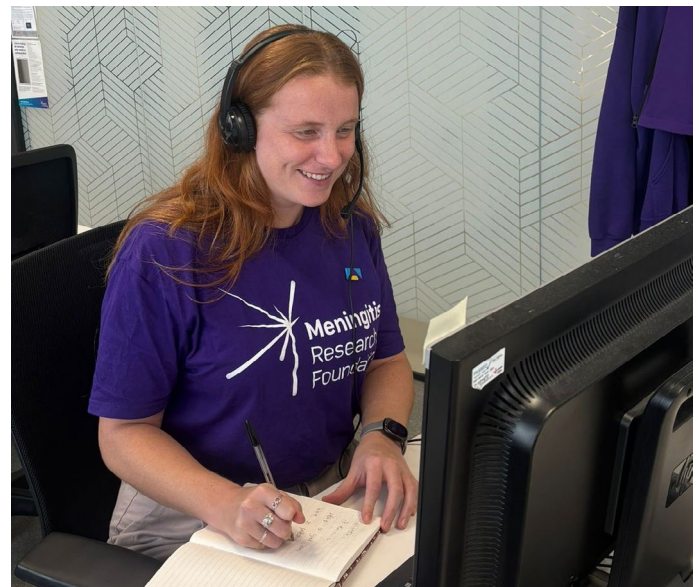
Meningitis is a public health priority. There are more than 2.3 million cases of meningitis worldwide every year. It kills one in ten people, and tragically, around 40% of deaths are children under five years old.*

When it comes to understanding this terrible disease, few things are more powerful than hearing the personal experiences of those directly affected.

That's why we ask our Ambassadors and other supporters to consider representing us in the media. If this is right for you, it would involve featuring in various media outlets, sharing your meningitis story first-hand and helping to drive greater awareness – locally, nationally and beyond.

As a media spokesperson for Meningitis Research Foundation, you would:

- **Share your experiences**
As someone who has been directly affected by meningitis, this is one of the most powerful actions you can take. It can help to raise awareness of the signs and symptoms of the disease, and encourage people to seek medical treatment quickly.
- **Let others know they aren't alone**
Your story could reach someone who has been affected too, bringing them strength and comfort at a very difficult time.
- **Represent Meningitis Research Foundation**
Help spread the word by telling others who we are and what we do. Namecheck the charity at any opportunity, and signpost our resources so that others can easily access them.



Our Support Services Manager, Caroline Hughes, remotely recording a podcast interview for The UK Sepsis Trust



Media outreach can take many forms, but will most likely involve interviews, features, or appearances across radio, TV, or newspaper publications.

It's important to stress that our media spokespeople are not expected to be medical experts, and we'll never ask you to quote data or explain the science behind the disease. All that we ask you to focus on is your own personal experience of meningitis.

*Estimates from around the world, updated annually. Last updated February 2025.

Is being a charity spokesperson right for you?

In order to successfully represent us in media-facing situations, our spokespeople need to have particular qualities and skills. It's important to understand what these are before getting involved, and to consider honestly whether you have them.

Here are some of the qualities we look for and tips to consider:

- **Contactable, flexible and available**

The media world moves quickly. Journalists often work to very tight deadlines (as little as a few hours), so if a spokesperson cannot meet their time frames, the opportunity to publish a story can disappear. Therefore, we need people who can be easily contactable and potentially available at short notice.

- **Ready to talk about personal experiences**

To be directly affected by meningitis is life-changing, and we appreciate that opening up about your experiences won't be easy. That's why it's important to be self-aware, and know when you're ready to share your story. Journalists will ask personal questions that may affect you deeply. If so, it's okay to feel emotional or get upset; and remember, our [Support Services team](#) are here to help you afterwards.

- **Comfortable interacting with different channels**

Modern media takes many forms: online and print articles, podcasts, radio interviews and TV features. We're looking for spokespeople who are confident and comfortable sharing their story through any of these means, including on-camera appearances.

- **Be discerning about opportunities**

It's important to check that you're comfortable with both the journalist and media outlet before committing to any opportunity. Don't feel you have to respond with a "yes" – take time to check the full details of who they are and how they might use your words and experiences. For instance, some stories may be syndicated to other channels. Speak to your Meningitis Research Foundation contact if you have any questions.

- **Accept that not all opportunities will work out**

Sometimes we may call you for an opportunity and get it all lined up, only for the journalist to drop out. This won't be a personal decision – it's most likely due to scheduling and the fast pace of reporting. Don't be too disheartened if this happens, as other opportunities will come along.



In addition to the above, you'll need to have an up-to-date [Meningitis in your words](#) story and photo. These often form part of the initial pitch when securing media opportunities, so having them in place is essential to getting started as a spokesperson.

Did you know?

Sometimes stories can go from local publications to receiving national coverage – and very quickly. Even if an opportunity starts small, it could grow to gain national attention. Of course it's always fantastic to reach more readers, listeners and viewers, but it's also important to be prepared for this level of attention if you decide to become a media spokesperson.

Here are some examples of meningitis stories in the news:

- [James Vincent talks to the BBC about his family's meningitis experience](#)
- [Hand transplant patient warns of meningitis danger](#)
- [Harvington Hall helps to light the road ahead on World Meningitis Day](#)



Ambassador Mike Davies presenting at the first high-level meeting to defeat meningitis by 2030

So, you've decided to share your story in a media interview?

We've put together our key things to remember for media opportunities.




- Share your story honestly and **in your own words**. The most impactful interviews are the ones which feel authentic and like they've come from the heart.
- Make yourself readily available **at short notice** (often less than 24 hours).
- Keep your **contact details up to date** so we can easily reach you about opportunities. Using a mobile phone number is usually best.
- Have a selection of **photos** that you are happy with the media using. Please share these with your Meningitis Research Foundation contact, along with your [Meningitis in your words](#) entry.
- **Namecheck Meningitis Research Foundation** as much as possible. Find opportunities to tell others about what we do, and highlight the support we offer. If people don't know about us, they won't be aware of the support we can provide when they need it. Please use our full name, instead of abbreviating to 'MRF'.
- **Never use inflammatory language** or words that you think may cause offence to others.
- Don't try to answer what you don't know. If you aren't sure about something, you can **signpost to our resources** (meningitis.org), or refer people to us directly instead.
- **Prepare** what you are going to talk about. The interviewer might not always ask the questions you want, but being clear on the overall message you wish to convey will help to shape the interview.
- It's perfectly fine to say "no" to opportunities you don't feel completely happy with. **Start small and gradually build up your experience** of working with the media until you feel comfortable taking on bigger opportunities.



Important:

Please do not seek out or take part in any media opportunities on behalf of Meningitis Research Foundation without speaking to us first. Some journalists or media outlets may contact you directly. If this happens, please let us know before any interview takes place, so that we can support you with it.

Here are some more practical tips to use when preparing specifically for a radio, TV or newspaper interview:

Radio 	TV 	Newspaper (may be digital, print or both) 
<ul style="list-style-type: none"> • Check your connectivity beforehand – you don't want to get cut off halfway through. • Confirm whether it is live or prerecorded so you can prepare accordingly. • Limit background noise and interruptions. • If the interview is prerecorded, say whenever you need to pause or take a break. 	<ul style="list-style-type: none"> • Wear your Meningitis Flag pin badge (and consider wearing your Meningitis Research Foundation T-shirt too). Don't have these? Let us know. • Confirm whether it is live or prerecorded so you can prepare accordingly. • If recorded remotely, check your connectivity beforehand. • Check that your background is appropriate, and make sure you're in a quiet place with no interruptions. • Make sure you have good lighting. • If the interview is prerecorded, say whenever you need to pause or take a break. 	<ul style="list-style-type: none"> • If you're having a phone interview, find a quiet, convenient space to do this, and set aside plenty of time. • Once published, share the link(s) on your social media accounts.

What should you avoid when talking to the media? Here are some of the most common issues to be aware of:

- **Blame**

As a charity, we work with a variety of different partners and organisations, so it's vital that we remain neutral and impartial at all times. In representing us, we expect you to do the same. We ask all of our media spokespeople **not to share anything that may bring a medical professional or organisation into disrepute.**

We recognise that you may have had a bad experience relating to diagnosis or treatment, and that this is a fundamental part of your meningitis story. If so, please discuss this with your Meningitis Research Foundation contact. They will work with you to identify the best platform for sharing your story, and if there are ways to do this while remaining neutral. Remember that our [Support Services team](#) are here for you, and can signpost you towards medical negligence experts.

- **Political views and opinions**

Similar to the above, because we work with a variety of different organisations and partners, we have to show particular sensitivity around certain topics. We ask all spokespeople representing us to **avoid sharing political views or opinions in media interviews.**

- **Medical explanations**

Please avoid medical explanations of meningitis. When this information is required for media interviews or features, we look to trained health experts to accurately explain the science. As a spokesperson, your role is to use your experience to help others – so **focus solely on your personal story**, and the impact meningitis has had on your life.

- **Stats**

Figures around meningitis are **always changing**. Please don't quote numbers and stats when speaking to the media, in case they are inaccurate. If you're really keen to provide this, speak to us beforehand so we can ensure you have the most accurate and up-to-date information.

Remember that we are here to support you throughout the process of becoming and being a successful media spokesperson for Meningitis Research Foundation. Here are just some of the ways in which we do that:

- Pitching your story to potential news outlets and lining up opportunities, such as local news coverage for [World Meningitis Day](#).
- Organising the logistics of interviews – including the where, when and who.
- Answering any questions you may have before, during or after the process.

We understand that sharing your story can trigger strong emotions, and that you may find yourself questioning whether you've done the right thing. That's why we're also here for you if you ever feel unsettled or upset after an interview or other media-facing experience.

Remember that you can always reach out to our [Support Services team](#) if you'd like someone to talk to afterwards.



Feedback

We also really welcome your feedback at the end of the process. Please tell us if there's anything you feel we should know – good or bad. We're constantly trying to develop our media outreach and improve the experience for our Ambassadors, so understanding how you found the process is incredibly helpful.

If you would like to share your meningitis story in the media, please speak to your Meningitis Research Foundation contact to discuss opportunities. We're looking forward to working with you to share your story.