

Huntington's Disease Association Ambassadors

Huntington's disease ambassadors are people from the community who work with the charity to help raise awareness by public speaking, talking to press and media and providing valuable assets such as videos and soundbites for us to use on our website and social media.

What does it involve?

Being an ambassador will require you to join a WhatApp group that will be sent requests as and when they come through. These requests could be, but are not limited to:

- Press and media requests
- Quotes or interviews with publications or researchers
- Speakers for conferences, lectures, talks or fundraising events
- Social media content such as videos or soundbites
- Sharing content for big campaigns such as awareness month, parliamentary news or surveys etc

Who can become an ambassador

Anyone from the Huntington's disease community who is happy to talk and share their story in a public-facing setting.

- With Huntington's disease
- At risk or negative
- Carers
- Family members

How do I become a Huntington's Disease Association ambassador?

Please fill out an application form.

How often will I be asked to get involved?

We will ask each ambassador to create some content for us (blog/video/soundbites etc) a minimum of twice a year*. This could be to do with projects or themes such as awareness month, mental health, caring for someone, or it could be a little bio about yourself or even a blog post. In regards to press and speaker requests, we have little control over these requests but we usually get something through every couple of months.

*After one year if you have not come forward for a request, will will contact you to check in and make sure the programme is right for you or see if there is a different volunteering opportunity that might be better suited.

How long will I have to respond?

Each request will have its own timescale but requests will be assigned on a first come first served basis so long as you are the right fit for the request.

How do I take part?

We will announce most requests through our ambassador WhatsApp which has been set up for this group. If we have a very specific request that you fit, we will contact you directly. Most often we will speak to you over WhatsApp or email and introduce you to external people via email. There will be times when you are asked to speak with a writer/journalist/researcher over the phone or on zoom. If you don't have WhatsApp, we will share requests with you via email.

Will I get any help if I need to speak on camera?

Yes, we have a media sheet that we will provide to you and we can talk you through this and support you through the process.

Do you have a Huntington's disease factsheet in case there is something I don't know the answer to?

Yes, we have a factsheet about Huntington's disease and the charity.

Will I have to respond to all the requests that are sent out?

Unless it is something that we are asking everyone for, you do not need to respond to every request only ones that are relevant to your experience or circumstances.

Will I get paid?

Our ambassadors are volunteers. If you are required to travel, we would organise for your travel costs to be reimbursed.

What if I decide I don't want to be involved anymore?

If you join but later decide you don't want to take part please just let us know.

How will you protect my data?

You can view our privacy policy here. Any personal information you provide us via your application form will not be shared without your consent. This information will be stored securely and will only be used if we need to identify someone for a request in a particular area or with a particular status. You will be invited to join our ambassador WhatsApp group - if you choose to join, your number will be visible to the rest of the group. You can hide your name and picture on WhatsApp, find out how to do this here.

Contact us

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Registered charity No. 296453 Company No. 2021975