Huntington's
Disease
Association

Huntington's disease:

Branch pack

A guide for branches

Introduction

Thank you for establishing your branch and for those who are new to the association thank you for your interest in setting up a local branch to support people affected by Huntington's disease in your area.

A branch can offer excellent local support to people affected by Huntington's disease and we hope you will find the information contained in the pack useful.

In this pack you will find hints and tips on finding suitable venues, how to run your meetings, support available from the Huntington's Disease Association, running effective committee meetings and much more!

We are extremely proud of the work our local branches carry out and we want to encourage a network where you can discuss activities you might want to introduce for your branch members - you may want to introduce exercise classes, organise days out or just offer some company and a cuppa - whatever you want to do, we are here to guide you.

If you have any questions about setting up your branch please do not hesitate to get in touch with us - **branch@hda.org.uk.**

About the Huntington’s Disease Association

Who are we?

The Association was founded in 1971, as a result of a family being given a diagnosis of Huntington’s. They were told they were one of a few families in the country. They put an advert in the local paper asking if anyone knew of any other families in a similar situation and as a result the Association was formed. It was initially a self-help group with 76 members and was known as the Association to Combat Huntington’s Chorea. In 1993, as a result of a consultation with the Huntington’s Disease Association membership, a project known as the CASE (Care, Advice, Support and Education was implemented. This was a result of feedback that suggested families would benefit from professionals with knowledge and understanding of the illness supporting them in accessing information, care and support.

The project is now known as the Specialist Huntington’s Disease Advisory Service and continues to be a valued resource and focus for expansion and development. The Huntington’s Disease Association covers England and Wales and supports anyone affected by or working with people with Huntington’s. In addition we work closely with other organisations with similar interests. We employ 38 staff members from a wide range of backgrounds from nursing and social care to fundraising and administration all united in their dedication to supporting those impacted by Huntington’s.

What is Huntington’s disease?

Huntington‘s disease is a degenerative neurological disorder that causes progressive mental deterioration, significant behavioural changes and severe physical incapacity. It is a hereditary condition affecting generations of families. Each child of a parent with Huntington‘s has a 50% chance of inheriting the faulty gene. It is estimated that there are around 8,000 people living with Huntington‘s in the United Kingdom.

Our vision, mission and values

Our Vision

Together we will build a better life for anyone affected by Huntington’s disease

Our mission

To enable everyone affected by Huntington's disease to live life to their full potential by:

- Improving care and support
- Educating families and the professionals who work with them
- Championing the needs of the Huntington's community by working together
- Influencing decision makers to tackle discrimination and secure equity of access to services

Our Vision

We are:

- Tenacious
- Experienced
- Compassionate
- Inclusive
- Inspirational

North Staffordshire branch

We talked to Sue and Glenys about the North Staffordshire Branch. Sue is the Chair of the Branch and Glenys is the Secretary; both have held these roles for over 20 years! Both Sue and Glenys cared for their husbands with Huntington's and, by coincidence, they knew each other through work!

The branch has been fortunate with venues; for many years they used a free community room at a fire station. When this changed use, they had a short spell at a different station but are now moving to a Tesco community room. The room is free of charge, accessible and they even provide free tea and coffee. They meet on the third Wednesday of every month from 7.30 – 9.30 pm and continued this, via Zoom, through Covid. Their local Specialist Huntington's Disease Adviser, Lindsey Hughes, joins some of their meetings.

The group has around 20 members, and people come and go as their situations change. Sue and Glenys are really aware that people have times when the group is right for them and times when they want to step away. They have a WhatsApp group which has worked really well in keeping members of the group connected as well as providing personal advice and support at critical times.

> *"The moment I stepped through the door it was friendly and welcoming"*
> *- Glenys*

They have raised funds through tabletop sales, car boot sales and coffee mornings, and these events are also an opportunity to get together and to raise awareness. They take the banner along and people often stop and ask questions or say that they know someone with Huntington's.

The branch is ever grateful to Marj who is an absolute knitting star, and keeps the branch funds coming in with a range of different knitted goodies for all occasions – Christmas decorations and Easter bunnies are knitted at a great pace!

“You get more out of it than you put in - I’ve met really lovely people”

- Sue

John has been a member of the branch for several years and he, too, cared for his wife who had Huntington’s. He is often called upon to give talks to history and family history groups, Rotary and Probus clubs and other organisations and asks for a donation for Huntington’s in lieu of a fee.

Sue also volunteers at the local clinic for people with Huntington’s. She is a friendly, welcoming face at clinic and will make people a cup of tea, have a chat and signpost them. Alongside this Sue sits on the local ‘Service Users and Carers Council’ sharing her experience of caring, neuropsychiatry and of Huntington’s disease to support the local strategy in these areas.

Hull and East Riding branch

Christina, Liz, Peter, Julie and Graham form the Committee of the Hull and East Riding Branch. They chatted to us about their branch and how it runs.

The committee all have a family link to Huntington's and this was why they became involved - some since the branch started whilst others have joined more recently. The branch is fortunate to have a good number on the committee, with lots of different skills! There are currently 28 families registered with the branch and this number has increased rapidly since the branch developed publicity materials.

"We are like an extended family - and the branch is a lifeline to those involved"

As a committee, they are very aware that different people need different things and they work flexibly to give the support they can. Some members come to on-line meetings, others prefer the walks - some people just want to be on the mailing list – to know the support is there if they need it in the future. They send a regular newsletter to keep people in the group up to date.

The key thing that the group offer is peer support; people who understand what members are going through and can share experiences and help each other through difficult times. They also have a lot of fun; they have quiz nights, dress up and lots of laughs are shared!
They have established links with the local Carers Services and posters and leaflets are on display in their premises as well as being available electronically.
They have a good relationship with Justine, their local Specialist Huntington's Disease Adviser.

Justine attends many of the online meetings and they are able to refer people to her when they need more than peer support. They have a poster up at the local HD Enroll Clinic and give them leaflets about the branch to hand out to people too. These were created on RightMarket with Justine's support and the committee is happy to share them if anyone would like to see the designs!

"The Hull and East Riding group are amazing, they go above and beyond for their members and have grown a lot over the last year.
They are committed to the Huntington's community and have made several steps to raise awareness of both their group, and the support they offer and Huntington's disease in general. They are creative, dedicated and fun to be around. They show care and compassion to everyone they support and have even supported me at difficult times. The area is very lucky to have this group, I couldn't imagine being without them."

Justine
Local Specialist Huntington's Disease Adviser

Starting your branch

Raising awareness of your branch

Huntington's disease can be an isolating condition and many people tell us how they struggle to find local activities to support them. This is where a local branch may be able to offer friendship and support to local people and families affected by Huntington's disease.

When you are thinking of setting up a branch ask your local Huntington's Disease Association Specialist Adviser if they are aware of any other local people affected by Huntington's disease and ask them to publicise your meetings to them.

The Huntington's Disease Association can also provide posters and leaflets for you to put up in various places to let people know about your branch. Some suggestions of places to put posters and leaflets include:
- Local Huntington's disease clinics
- GP surgeries/walk in centres
- Libraries
- Day centres and care homes
- Carers groups
- Supermarket notice boards
- Chemists
- Local cafes
- Community centres

You can also ask your local newspaper if they will publish a press release for you with information on your meetings.

Finding a venue for your meeting

A number of groups meet virtually by using software such as zoom. If you would like help with this please contact us at branch@hda.org.uk. Your safety and the safety of attendees is important and you should choose to hold your meetings in a local coffee shop, community centre or some other public space. It is important that your meetings are held in easily accessible, bright, welcoming spaces. You cannot use your homes for meetings. When choosing a place for your branch to meet we recommend considering the following:

Venue checklist

- Can the venue be reached by public transport?
- Is there car parking close by?
- Is the venue warm and safe?
- Is the venue in a public place?
- If the venue is in a public place - cafe or pub, will it be quiet enough for people to hear discussions? Will people feel comfortable talking in a public area?
- If you aren't meeting in a café will you provide refreshments? How will you do that?
- Make sure there is clear signage at the venue so people can easily find you; see if you can reserve a table in a café, etc

List of community venues

There may be some meeting rooms in your local communities which offer free spaces or rooms for local charities. Supermarket and garden center chains usually offer rooms free of charge including:

- John Lewis
- Sainsburys
- Asda
- Tesco
- Dobbie's Garden Centers or other garden centers chains

Ask the Community/Charity Champion at any of these stores to see if this is something they are able to offer your branch.

You may also wish to consider other venues such as care homes, local hospices, church halls, community centers, fire stations or local councils.

Funding

We are able to provide funding for the first two meetings of any branches - up to the value of £100 per meeting. After the second meeting, you are expected to either find a room/venue free of charge or fund your own meetings spaces through collections or fundraising.

Awareness and fundraising materials

There are a number of ways to raise awareness of your branch across your local area by developing and using leaflets and posters in advertising the branch. The first step is to let people in your local area know about you and the work you do to support people affected by Huntington's disease. You can do this in a number of ways.

Branch Leaflet

A branch leaflet can help raise the profile of the work you carry out. It can be a handy reference to hand out at events. Make sure your local SHDA has a supply of your leaflets to hand out to families they come into contact with. The Huntington's Disease Association is on hand to help you design your branch poster. An example of a branch leaflet can be found in this pack.

Branch Poster

An eye-catching poster can help you find new members and volunteers. You can put these up in local supermarkets, libraries, volunteers centers, health centers, clinics and hospitals, etc. The Huntington's Disease Association is on hand to help you design your branch poster. An example of a branch poster can be found in this pack.

Hand-held Banners

We have two hand-held banners available for branches -one which says #TeamHDA and is more for fundraising types of activities and one which says #LetsTalkHuntingtons which is more useful for awareness raising or information days. They are available free of charge,

Banners and pop up banners

These can be very useful if your branch is planning on attending awareness days or collections in supermarkets, etc. Huntington's Disease Association can provide artwork for banners and pop-up banners if you wish to contact printers locally who can produce them for you at a reduced cost.

Collection Boxes

You can order cardboard collection boxes from our fundraising team to share with your branch or group members to help you raise funds.

Display board

Your branch may want to put together their own table top display board - these can be very useful at fundraising and awareness events or to have on display at your branch meetings. They can be a useful way to share a lot of information. They can contain local branch information along with displays of information about Huntington's disease, the local SHDA service, support the branch can offer, etc. Please contact the Ops team for further details on developing display boards.

Branch-made awareness items

We are aware that some of our branches wish to advertise your branch including meetings and events. Please complete the enclosed branch and support web page template form with your branch information and we will add your branch details to the Huntington's Disease Association website.

Deciding roles within your branch

To run as a Branch you will need to have at least a Chair, Secretary and Treasurer.

Chair

The Chair will have overall responsibility for running the Branch. They will chair any meetings and represent the Branch publicly.

Secretary

The Secretary is responsible for ensuring that meetings run smoothly - including finding suitable venues, preparing agendas, taking minutes, they ensure that they branch keeps up to date on all Huntington's Disease Association policies and that the branch maintains confidentiality and acts within GDPR guidelines.

Treasurer

The Treasurer is responsible for all matters relating to finance at the Branch. They will write cheques, make payments, count any monies collected and ensure that the Branch is following Huntington's Disease Association financial guidance. They will maintain financial records, submitting information to the Huntington's Disease Association as and when requested including year end accounts and financial returns.

You can find out more about the different roles your branch will need to appoint in the Declaration of Branch Commitment document.

You will find in this pack role descriptions for the Chair, Secretary and Treasurer roles. You should try and find someone from within your group to fill these roles, however, we can assist you with advertising as needed. We can put adverts onto our website, social media channels and also use external organisations such as the local Volunteer Bureau. Please contact us if you wish to advertise a role at branch@hda.org.uk.

Additional roles within a branch

Although they are not official roles to assist with the running of a branch, you may find it useful to have people within your branch to act as the following:

Meet and great

It is a good idea to have a meet and greet system in place. This will be someone at the door of the venue ready to meet and greet members as they arrive, make sure that any new attendees are looked after and made to feel comfortable.

Refreshments

If you hold your meetings in a venue where you are responsible for making your own refreshments, you can ask someone to take on the responsibility for ensuring that tea, coffee, biscuits etc. are available. Make sure you have people to assist with the washing up as well!

Buddy system

Your branch may wish to set up a buddy system for new attendees, linking them with more established members to check that they are keeping well - a quick phone call in-between meetings can make them feel more included.

Finances

As a branch, you will need to open a branch bank account. You are expected to be fully financially self-supporting and be able to pay for your meeting venues, refreshments, and any other activities you wish to offer. We expect you to use any income you raise to solely further the aims of the Huntington's Disease Association as per the guidance from the charity.

We expect the branch committee to agree on an annual budget for the year, including all anticipated fundraising activities. Your annual budget plans should be shared with the Huntington's Disease Association on an annual basis.

The branch committee will ensure the bank account is operated on a dual signatory basis. The following roles can be signatories: Chairperson, Secretary and/or Treasurer, and the two signatories should not be related. You can only spend branch funds in the ways described below:

- The branch will operate a branch welfare grant scheme for the financial support of individuals affected by Huntington's disease and their families. Your branch welfare grant scheme will meet the financial limits determined by the Executive Council. It is currently set at £350 per financial year per individual. If you wish to award more than £350 to any one individual during the financial year you will need to seek prior approval from the Executive Council.
- The branch will pay for any reasonable and necessary out-of-pocket expenses incurred by branch members on branch business. All expenses will be recorded in the year-end branch return by the branch treasurer.
- The branch will transfer any money above the sum of £2000 that remains in the branch account at the end of the financial year (31 March) to the Huntington's Disease Association.
- The branch will need to request special permission from the Executive Council if you wish to hold over £2000. If granted, it will apply only for the financial year in which it was granted.
- The branch will only support research officially authorised by the Huntington's Disease Association (e.g. research projects specifically authorised by the EC and Huntington's Disease Association Medical Advisory Board). These projects are selected based on their merit to obtain maximum benefit for the Huntington's community.
- All research projects are examined first by the charity Medical Advisory Board and their views and decisions are then passed to the Executive Council for relevant action.

Further Guidance

- For additional information on opening a branch account for the branch please refer to the Branch Declaration
- If you have any queries or concerns regarding opening a bank account please contact your Volunteer Manager by email branch@hda.org.uk

Huntington's Disease Association

* Welcome letter for new branch attendees – to be handed to new attendees by a branch officer *

Branch email address

Date

Dear ____________________

A very warm welcome from the __________ branch of the Huntington's Disease Association. This letter is to let you know that we are here to offer friendship and support for you and your family. We are delighted you have decided to join us.

The main purpose of our meetings is to offer friendship and support.

We will ensure all of the the personal information you share with us will be kept confidential in accordance to the latest General Data Protection Regulations. Please refer to How We Use Your Information leaflet that accompanies this letter for further information on how we keep your data.

Huntington's disease affects us all differently; you may not wish to, or be able to attend every meeting, but we'll be here for you should you need us.

We also invite you to get more involved with the association by becoming a member of the charity,

We hope to see you at our meetings, but don't hesitate to contact the Huntington's Disease Association on 0151 331 5444 or ourselves if you have any questions.

Yours sincerely

Name
branch officer

Running effective meetings

It is important to encourage regular communication between all those involved in the running of a branch. This will help your group to grow and develop.

Why meet?

As branches play an important role in supporting local people affected by Huntington's disease, meeting is important to offer support to each other, plan fundraising activities, raising awareness, planning support meeting and to catch up with each other on what is happening locally.

Branch committee meeting

We recommend the Committee of a branch should meet at least four times in each calendar year. Any two branch committee members have the right to call a meeting. Some branches prefer to set the dates for committee meetings a year in advance, as this helps with planning and booking venues. However, if new volunteers join the committee during the year, a review of meeting dates may need to take place.

Meeting agenda

Some branches have standard agenda items such as secretary report, chair report, treasurers' report, welfare grants issued and fundraising update. We recommend circulating the agenda and reports before the meetings so attendees know what is going to be discussed at the meeting.

Taking minutes

Minutes are a record of the branch committee's decisions and who has agreed to carry them out. They should be brief and to the point but may include important comments in support of the decisions taken. The minutes should be taken to the Branch Secretary.

Following the meeting, write up your minutes and circulate to all committee members as quickly as possible. Please also send a copy of the minutes to the Huntington's Disease Association **branch@hda.org.uk** to keep us informed and highlight to us the ways we might be able to provide further information or support to your branch. Branch minutes must be kept securely for 6 years. After 6 years, the minutes can be shredded.

Data protection

Please ensure that when discussing details regarding financial support to be aware of how much detail is being shared about the person making the application - in local communities the applicant may be known to many people and they may not wish to be identified. Discussing the person's life story and personal details is not appropriate - keep any discussion as anonymous as possible.

General branch meetings

Branch meetings are open to anyone affected by Huntington's disease in your local area. They can run on the same day of your branch committee meeting but there should be a clear break between the committee meeting fishing and branch meeting starting.

Keeping touch with your local Huntington's community

For many people with Huntington's disease attending a local branch meeting may not be possible or may not be something they want to do every month. For some people attending a local branch meeting when newly diagnosed or non-symptomatic can be quite challenging. They may be afraid to be around others whose disease have progressed when they themselves are coming to terms with what it means to have the Huntington's gene.

For others, there may be issues in trying to physically attend meetings, transport issues or carer issues may stop them from attending. Others in the Huntington's disease community may have been moved into care homes or a local hospice.

Local branches are encouraged to continue communicating with your local community about all things branch, Huntington's Disease Association or Huntington's disease related - even those people who may have attended only one meeting. Make sure you have permission from them to stay in touch and think about the different ways your branch or support group can share relevant information to people who may not be able to attend your meetings.

Key points to consider

Invitation letters

Ask your local Specialist Huntington's Disease Adviser to share an invitation to your meeting. Or maybe ask your adviser to share the letter at each family or professional meeting they have. These letters help to let the local Huntington's disease community know about you.

The venue

Make your meetings as welcoming and friendly as you can. Consider whether the venue is accessible, easy to reach and clearly signposted.

Meet and greet

Do you have someone acting as a meet and great person to welcome old and new members? This doesn't have to be the Chair or Secretary - there are specific skills around meeting and greeting and someone in your wider membership may be ideal for this role.

Welcome letters for new members

Consider giving each new member a welcome letter, accompanied with the How We use Your Information leaflet when they attend their first meeting - you can find a templates in this pack.

Information and support meeting topics

Do your meetings cover a wide-range of topics? Have you thought about inviting different speakers along to meetings? You could have local Specialist Huntington's Disease Adviser, local health and social care professionals, a researcher from a local university, someone to talk about the benefits system - all practical information and support.

Social and leisure meeting topics

You may even want to consider topics which are not related to Huntington's disease at all - local history experts, gardening or wildlife professionals - local groups would be happy to come out and give talks about their subject to groups of people. This gives your member an opportunity to get together in a more social setting.

Social activities

You could organise a social night once every few months - a bingo night or quiz or hotpot supper. Again, these events offer your members an opportunity to get together and socialise, something that can help dispel feelings of isolation a lot of people in the Huntington's community can feel.

Webpage

Make sure your branch or support group webpage on the Huntington's Disease Association website is up to date. Use our template to ensure we have the right information about your branch or group.

Social Media

Social Media offers a great way to share information about your branch and support group - you will need someone in your group who can keep it up to date and share things regularly. Please contact us for advice on setting up social media accounts for your branch and support group.

Webpage form

Branch Name	
Contact details – we recommend putting the name of the secretary of the branch. If you have a contact mobile phone number that you are happy to be made public, please also add that. We will also add in the email (gmail) address for the branch / support group	
Information about the branch - who you are, why you exist, when you were founded, what you offer to attendees – remember this is the bit people will find out about what you do, so try to sell your branch as much as you can! (600 words max)	
When and where you meet (in general terms, eg: second Tuesday of each month at Church Hall at 7pm)	
Local HDA Adviser name	
Please list any photos you wish to appear on the website of your branch . Send photos to branch@hda.org.uk with names(Completed consent form to be returned)	
List of upcoming events – we will need dates, venue address, event name, details of events, photo	
List of upcoming meetings – we will need dates, venue address, event name, details of events, photo	

Webpage form example

Branch Name	
Contact details – we recommend putting the name of the secretary of the branch. If you have a contact mobile phone number that you are happy to be made public, please also add that. We will also add in the email (gmail) address for the branch / support group	Doris Murphy, Secretary of Garston HDA Branch 0778512 697520 garstonhdabranch@gmail.com
Information about the branch - who you are, why you exist, when you were founded, what you offer to attendees – remember this is the bit people will find out about what you do, so try to sell your branch as much as you can! (600 words max)	Welcome to the Garston Branch of the Huntington's Disease Association. We have been offering support and advice to local people affected by Huntington's disease for 10 years. We meet regularly and put on a variety of different activities from knitting club for carers to a hot pot supper night to day trips for our members. We also invite health and social care professionals to our meetings to give talks about various topics around Huntington's disease. We welcome the local Specialist Huntington's disease Advisor to our meetings. We are a volunteer-led group and we welcome anyone affected by Huntington's disease to our meetings.
When and where you meet (in general terms, eg: second Tuesday of each month at Church Hall at 7pm)	We meet the first Wednesday of each month at Garston Social Club, High Street, Garston, Liverpool, L19 8JH from 7pm - 9pm
Local HDA Adviser name	Anita Daley
Please list any photos you wish to appear on the website of your branch . Send photos to branch@hda.org.uk with names(Completed consent form to be returned)	A photo of our Branch Chair, Secretary and Treasurer is available. See completed consent forms

List of upcoming events – we will need dates, venue address, event name, details of events, photo (if you have one available, otherwise we will use a stock image)	10th January 2020 – a visit to Liverpool Empire to see the local pantomime – tickets are £20 per person. Please contact Doris Murphy for more details – garstonhdabranch@gmail.com. 20th March 2020 – a St Patrick's Night celebration – join us at the Liverpool Irish Centre for our annual celebration. Tickets are £10 – contact as above.
List of upcoming meetings – we will need dates, venue address, event name, details of events, photo (if you have one available, otherwise we will use a stock image)	6th November 2019, Garston Social Club, High Street, Garston, L19 8JH – we will be joined by the local HDA Advisor to answer your questions about Huntington's disease. 4th December 2019, Garston Social Club, High Street, Garston, L19 8JH – - including a Christmas Hot Pot Supper.

Group email address set up

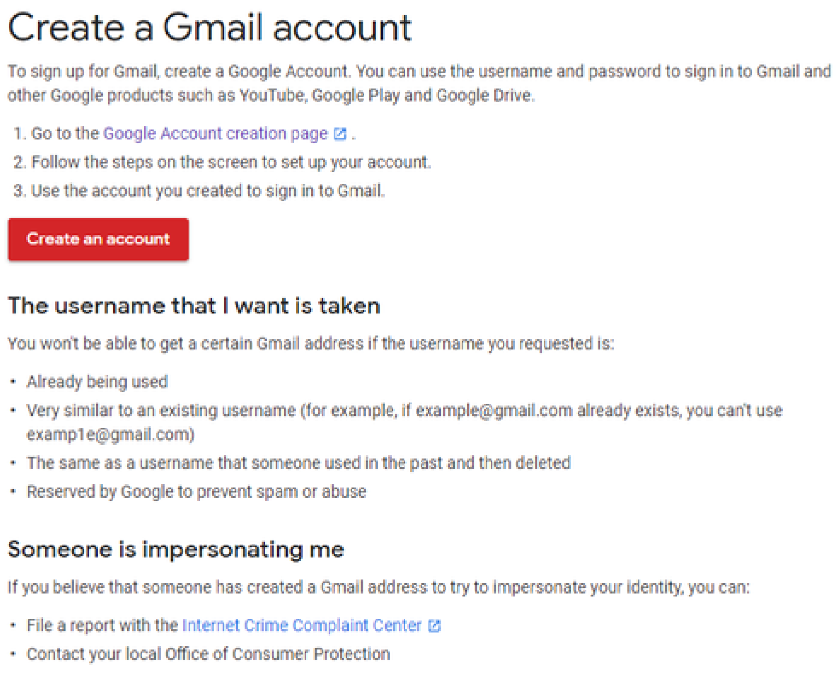
The Huntington's Disease Association asks all of our branches to set up "gmail" email addresses to offer a uniform approach to our communications. This makes it easier for potential branch or group attendees to remember the address and also moves our branch network towards using generic email addresses and away from using personal ones. Using one email address for all your branch business means that all communications are stored in one place and it makes us look more professional as an organisation.

You can assign as many people on your committee as you like to have access to the email inbox – but do be aware of GDPR guidelines around doing so. We recommend that the three main committee members – Chair, Treasurer and Secretary have access to the email inbox.

We recommend the following wording for email addresses:

Branch - namehdabranch@gmail.com
Eg: all our branch email addresses should read as follows.
Newcastlehdabranch@gmail.com
Cumbriahdabranch@gmail.com

To set up a new gmail account - go to gmail and put into the search box "Create a Gmail account" the next page should look like this.



Create a Gmail account

To sign up for Gmail, create a Google Account. You can use the username and password to sign in to Gmail and other Google products such as YouTube, Google Play and Google Drive.

1. Go to the Google Account creation page .
2. Follow the steps on the screen to set up your account.
3. Use the account you created to sign in to Gmail.

The username that I want is taken

You won't be able to get a certain Gmail address if the username you requested is:

- Already being used
- Very similar to an existing username (for example, if example@gmail.com already exists, you can't use examp1e@gmail.com)
- The same as a username that someone used in the past and then deleted
- Reserved by Google to prevent spam or abuse

Someone is impersonating me

If you believe that someone has created a Gmail address to try to impersonate your identity, you can:

- File a report with the Internet Crime Complaint Center
- Contact your local Office of Consumer Protection

There are easy to follow steps showing you how to go about setting up the account.

To set up the account you will have to register a first name/surname and date of birth and you will be asked to register a mobile number which will be used as a security feature. You will also be asked to set a password – remember this password as it is the one you will have to share with other members of your committee so they can gain access to the account. You will then be asked to choose a name for your email account – follow the guidelines above, eg: namehdabranch@gmail.com

Once your account is set up please email branch@hda.org.uk so we can register your email contact details. Please note that when the email address is set up this is the email the Huntington's Disease Association will use to communicate with you.

Resources and Information

It may be helpful to have a supply of leaflets and information readily available to share at your meetings. We recommend the following leaflets which you can order from the Huntington's Disease Association,

Huntington's Disease Association Leaflets

- Huntington's disease - what it is and who can help?
- Breaking down barriers - leaflet for South Asian families
- HDYES leaflet - Huntington's Disease Youth Organisation - offering support and advice to people aged up to 25 years old
- Contact information for the Huntington's Disease Association
- Membership to the Huntington's Disease Association forms

Creating your own resources

You may wish to develop the following leaflets or resources for your members.
hda.org.uk/create-your-own-posters

Local area

- Leaflets advertising local services and local organisations who can offer local support
- Information specifically for carers
- Print out latest branch and support group e-newsletter
- Print out of latest fundraising e-newsletter
- Selection of books and booklets relating to Huntington's disease - you may wish to loan these out to members.

Volunteer data protection

The Huntington's Disease Association takes privacy very seriously and we are committed to protecting and keeping personal information protected and stored safely.

Data protection

Some volunteers, such as Branch officers will need to hold personal information (for example names and addresses) in order to support people. Our Branches collect information about their members in order to keep them informed about Huntington's Disease Association activities. Our branches also collect information when an individual applies for a welfare grant from the branch funds. Our volunteers may also offer peer support to other families, and this can involve sensitive personal information about the individuals' health and their situation.

Where volunteers have access to personal information, the data must:

- only be collected for a specific purpose (normally this is keeping contact details to be able to tell people about upcoming events / activities)
- appropriate for the purpose for which it was collected and only the relevant information collected (normally a name and the contact details you will use)
- be accurate and up to date
- be kept secure and protected
- when held on computers, the computers will be password protected with up-to-date software to protect them from malware and viruses. The data will be stored in a secure document, such as a password-protected Excel spreadsheet. Passwords must be as a minimum eight characters long including at least one capital letter, one symbol and one number.
- personal information shared electronically will be password protected or encrypted. The passwords needed to access the personal information will be shared via an alternative delivery method as an added security measure. If you are unsure of how to password protect or encrypt your information please contact our data manager
- where information is stored on paper it will be filed securely, ideally in a locked drawer or cupboard
- only be shared if you have the individuals' consent to do so. For example, in a situation where you were keen to speak to an organisation and see if they could support the individual, you can only do this if the person says that they want you to do this (that they give their consent)

- Occasionally you may need to disclose personal information in other circumstances and you may not be able to gain consent, such as:

    - We believe that the person's life or someone else's life is in danger
    - We are informed that a person or someone else is at risk of harm
    - Where it is necessary to share personal information for the purposes of safeguarding the interests of children and adults at risk
    - It is necessary to share the personal information to prevent or detect a crime
    - We are required to share the information under a Court Order or other regulation or legislation
- Be reviewed annually to ensure that personal and confidential information is not stored and processed for longer than is required to fulfil the purpose for which it was collected. Data can be processed for as long as the individual is a member of the group. Information on welfare grants by branches, whether awarded or unsuccessful, should be held for six years from the end of the financial year in which the grant was awarded.
- Only processed when the appropriate privacy information has been provided
- Kept in once central list of contacts which one person looks after. In branches, this would normally be the Secretary.
- Only stored until it is no longer required or until such time as it has fulfilled the original purpose for which it was collected and processed. Where personal information is no longer required or it is out of date it will be destroyed at the earliest possible opportunity.
- Paper information will be treated as confidential waste and should be shredded by the data owner.
- Electronic records should be deleted and the recycle bin emptied where relevant.

Please note:

- Email address will only be recorded where the individual consents to be contacted by email. The email address should only be used for the stated purpose/s (in line with the Huntington's Disease Association privacy policy and data protection legislation), and the individual has the right to revoke or change their consent at any time
- Specialist Huntington's Disease Advisors, or other members of the Huntington's Disease Association Staff can only share data with Branch Officers if the individual concerned has given their consent to do so
- Public wi-fi must not be used, as unsecure wi-fi connections make it easier for hackers to access private files and information, and it allows strangers to use your internet connection
- You must not use your personal email address in your volunteer role. Branches should have a specific email address for the group (the data manager can support volunteers to set this up if one isn't already in existence)

- Data held for the purposes of mailing about Huntington's Disease Association activities should be held for as long as the individual is a member of the group (delete if the individual dies or asks to be removed from the mailing list).
- For welfare grants, data should be retained for six years from the end of the financial year in which the grant was processed
- When an individual has died or there has been no contact for three years and there is a paper file in existence (for example where a volunteer has kept notes of conversations which have taken place), the paper file will be sent to the Operations Team for archiving (clearly marked to say the date of the last contact with the individual or the date of death). The file will be archived and marked for destruction in six years from date of last contact. When an individual has died or there has been no contact for six years and there is an electronic file in existence, this should be deleted.

Training

Mandatory data protection training will be provided by the Huntington's Disease Association.

Confidentiality

All employed staff, temporary workers and volunteers must sign a confidentiality agreement before being given access to any information held by the charity. For Branches it is covered by the charity's confidentiality form or by the Branch Declaration. All volunteers must comply with the charity's data protection policies.

In meetings

- Only disclose information that is relevant and where there is consent to do so.
- At the beginning of the meeting inform everyone that the information shared in the meeting remains confidential, however if there are issues which are deemed as a safeguarding concerns you are duty bound to share the information with a member of staff from the Huntington's Disease Association.
- Do not discuss personal information about another person.
- Give individuals a copy of the 'How we use your information' leaflet alongside the welcome letter.
- Do not ask questions that are not relevant.
- When leaving a message for an individual, do not make reference to the Huntington's Disease Association, unless it is appropriate or it has been agreed beforehand that you may do so.
- When using your email address, recipients should not be grouped unless permission has been obtained.
- The BCC facility on email must be used when emailing multiple people so as not to disclose personal contact information.
- No memory sticks, CDs or other portable storage media should be used to store personal data unless encrypted and unless you have had written authorisation from the charity.

Data breaches

A data breach can include unlawful or unauthorised disclosure or use of personal information, the recording or sharing of inaccurate personal information and the unlawful processing of personal information. Breaches can be the result of both accidental and deliberate causes. Examples of data breaches include:

- access by an unauthorised third party
- sending personal data to an incorrect recipient
- computing devices containing personal data being lost or stolen
- sharing information without consent

Data breaches should be reported immediately to the charity's Data Protection Lead, who will then decide if it needs to be reported to the Information Commissioner's Office (ICO). If this is required it will be reported by the Data Protection Lead within 72 hours of discovery.

Other data

- Where branches hold minutes of meetings and similar documents, these must be destroyed after 6 years.

Key Contact

Data Manager (for all volunteer enquiries relating to data) and Data Protection Lead (to report a data breach) John Gandy
Phone: 0151 332 2765 Email: john.gandy@hda.org.uk

Personal safety for volunteers

Health and Safety

The Huntington’s Disease Association recognises and accepts that it is responsible for the health, safety and welfare of its volunteers, when they are volunteering for the charity.

We are committed to ensuring, as far as is reasonably practicable, that we minimise volunteering related injuries, ill-health, fatalities, and we reduce health and safety risks.

What does this mean for Branch and Support Group volunteers?

The Huntington‘s Disease Association has specific expectations of our volunteers to ensure they adhere to and follow our policies and procedures including health and safety.

All volunteers are responsible for taking care of their own health and safety and others who may be affected by their actions while volunteering and complying with any duty or requirement under the Health and Safety Act.

Volunteers should not visit people at home, nor transport individuals in their cars. Whilst this can be frustrating for volunteers the resources are not in place to ensure volunteers safety and therefore it is not safe to carry out these activities.

These are all measurements that our Specialist Advisers have so they are safe in the community. Due to this the Huntington‘s Disease Association can not ensure you, nor the individual‘s personal safety.

Boundaries when supporting individuals

Requests for support via a professional

Professionals should not be signposting individuals to the Branch for anything other than peer support or welfare grants.

If this does happen, volunteers should pass on the referral to their local advisor, and respond to the initial referrer stating you do not accept referrals of this nature and give them to your local advisor's contact details. Please send back or delete any personal information which has been shared with you.

Request for support via an individual/family member

If you receive requests from **individuals** for support (over and above peer support), again you should refer them to their local advisor.

If these requests are received out of hours, volunteers should give individuals the contact details for the local crisis team, or social care and health emergency numbers (101 or 999). Please ask your local advisor for these numbers if you do not have them.

Whilst volunteers are often experts in Huntington's disease and have a huge amount of experience from their personal journeys, volunteers do not receive the in-dept and specialist training or are supervised by the charity to provide the support that extends beyond peer support.

Safeguarding adults

Safeguarding is a term used to describe activity aimed at ensuring adults who need care and support are not abused.

All volunteers who have contact with adults who could be at risk of abuse or neglect have a duty to act if they have any concerns that an adult is being abused, neglected or exploited.

Branch volunteers (Branch officers) must read the Huntington's Disease Association Safeguarding Adults Policy and attend Safeguarding training at least every three years as arranged by the Huntington's Disease Association.

Safeguarding practices apply to any adult at risk (18 years and over):

- who has needs for care and support, whether provided or not, and
- is experiencing, or at risk of, abuse or neglect, and
- as a result of those care and support needs is unable to protect themselves from either the risk of, or the experience of abuse or neglect

Abuse can be:

- Physical
- Neglect and acts of omission
- Self-neglect
- Sexual
- Emotional and psychological
- Financial or material Discriminatory
- Institutional abuse
- Domestic abuse
- Modern slavery

Prevent

The Prevent Strategy addresses all forms of terrorism. The aim of Prevent is to stop radicalisation or support of terrorism and operates in the 'pre-criminal space' i.e. before any criminal activity has taken place.

Safeguarding children

Protecting children from harm is everyone's responsibility no matter what your connection to the child is. If you only volunteer with adults, you need to be aware that those adults may at some point disclose important information about children or even their own childhood.

If you have any concerns at all you must report them to:

Within office hours: the children's safeguarding lead or a member of staff from the Huntington's Disease Association immediately.
Out of office hours or In circumstances where you are unable to contact a member of staff from the Huntington's Disease Association you can contact the NSPCC helpline for advice 0808 800 5000.

'Children' means children and young people from birth to their 18th birthday.

As a volunteer, you have:

- A duty of care. It is your duty to report any concerns to the children's safeguarding lead (contact details below) and not to take action or investigate further. Should you be unable to report directly to the children's safeguarding lead then you must report you concern to a member of staff, no matter how small it may seem.

- A responsibility to be aware of the Prevent strategy and the obligation to report any concerns to staff members of the Huntington's Disease Association

Branch and support group volunteers (Branch officers and Committee members and Support Group Leaders) must read the Huntington's Disease Association Safeguarding Children' Policy and attend Safeguarding training at least every three years as organised by the Huntington's Disease Association.

Child abuse is divided into four main categories:

- Physical abuse
- Neglect
- Emotional abuse
- Sexual abuse

Prevent

The Prevent Strategy addresses all forms of terrorism. The aim of Prevent is to stop people from radicalisation or supporting terrorism and operates in the 'pre-criminal space' i.e. before any criminal activity has taken place.

Key Contacts

Huntington's Disease Association Adult Safeguarding Lead (office Hours):

Ruth Sands
Phone: 0208 150 5980
Email: ruth.sands@hda.org.uk

Huntington's Disease Association Deputy Adult Safeguarding Leads (office hours)

Helen Santini
Phone: 01279 507656
Email: helen.santini@hda.org.uk

Anne Filson
Phone: 01535 281358
Email: anne.filson@hda.org.uk

Huntington's Disease Association Children's Safeguarding lead (office hours)

James O'Connor
Phone: 07718 424 905
Email: james.o'connor@hda.org.uk

Outside of office hours or if you are unable to contact a Safeguarding lead you should make contact with the Local Authority in your area and ask for the Safeguarding Team. Please follow up by reporting to the HDA Safeguarding Lead asap.

Membership

Branch Membership

As a committee, you will welcome everyone that is interested to join the branch. Anyone who attends the branch or maintains an interest in another way (e.g. by asking to be on a branch mailing list) will automatically be known as a 'member' of the branch.

Huntington's Disease Association Membership

We ask that committee members inform individuals about the benefits of becoming a member of the Huntington's Disease Association which is additional to branch membership,

Benefits of becoming a member of the Huntington's Disease Association

As a member, you will receive regular eNewsletters and other communications from the charity, meaning you will be among the first to hear about our work, news, events and opportunities to get involved.
You will automatically become eligible to vote at our Annual General Meeting.

Additional Benefits

- You have the ability to influence the direction of the charity's activities and priorities.
- You are at the heart of the charity having a say in how it is run, including voting for the board of trustees.
- You can attend the Annual General Meeting, and receive a copy of our Annual Report and Summary of Accounts.
- Being a voting member means you are playing an active role in making a positive impact in the lives of people affected by Huntington's disease.
- According to our Memorandum and Articles of Association, in the event of the charity being wound up, members are liable to contribute an amount not exceeding £1.00 for payment of debts and liabilities of the charity.

Membership forms are online, and it would be useful if you had paper copies to issue to individuals who may request them (please request these from branch@hda.org.uk).

Get in touch

There are many different ways for you to contact the Huntington’s Disease Association.

info@hda.org.uk

0151 331 5444

www.hda.org.uk

@hda_tweeting
@hdauk
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Huntington's Disease Association

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