



Huntington's  
Disease  
Association

# Confidentiality policy

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# Confidentiality policy



## Introduction

The Huntington's Disease Association recognises that employees, volunteers, trustees and others who work within the charity handle a great deal of information in both paper and electronic formats about individuals and organisations during the course of their work or activities. Some of this information could include personal data of beneficiaries, suppliers, staff, volunteers, supporters, donors and trustees, the processing and handling of which is undertaken safely and securely in line with our Data Protection Policy. It could also be information about the Huntington's Disease Association and its work which, if sensitive and confidential in nature, could have adverse implications for the charity if disclosed.

The Huntington's Disease Association takes the privacy of our beneficiaries, supporters, members, volunteers and employees very seriously and is committed to openness, avoiding unnecessary secrecy and bureaucracy, and ensuring individual privacy is respected. This confidentiality policy and other policies such as the data protection policy, determine the process the charity has in place to ensure personal and any other potentially sensitive information is collected, stored, handled and disclosed in line with General Data Protection Regulation (GDPR) and confidentiality best practice.

Confidentiality is ensuring that no information is given directly or indirectly to any unauthorised person, without the individual's prior consent preferably given in writing to disclose such information. That is unless we are obliged to disclose data by law, or the disclosure is 'necessary' for purposes of national security, taxation and criminal investigation. We will only disclose personal information in other circumstances where there is a significant risk to either the person or other persons should the information not be shared.

Most breaches of confidentiality happen through lack of thought or consideration of the possible consequences, inadequate storage or sharing information in a place that lacks privacy. The best protection against breaches of confidentiality is to keep the number of people who have access to sensitive information to a minimum. It should also be restricted to those who are required to process the information for the purpose in which it was given.

## Scope

This policy applies to all people working for the Huntington's Disease Association or on behalf of the Huntington's Disease Association in any capacity, including employees, trustees, agency workers, seconded workers, volunteers, contractors and suppliers.

This policy is intended to work with and support the work undertaken by the charity as well as to support guidance used by the charity on safeguarding children and vulnerable adults, data protection, and use of information technology. It should be read in conjunction with the Data Protection and Safeguarding policies.

## Our commitment

The Huntington's Disease Association is committed to the principles of confidentiality and must be integrated across all aspects of our work. We will:

- Treat all personal data and sensitive organisational information as confidential to the Huntington's Disease Association
- Comply with the law regarding the protection and disclosure of information (including the Data Protection Legislation) and our policies, including our Data Protection Policy.
- Treat any breach of this policy as a serious disciplinary matter, recognising that it could have very serious consequences for an individual or for the charity.

## Confidential information

All personal data and confidential information about the Huntington's Disease Association, those who work for us, those who use our services, those who donate money and fundraise for us and other organisations we work with must be kept and handled confidentially, whether the information has been received formally, informally or discovered by accident. Staff and volunteers will treat any such information in a confidential manner unless there is a perceived threat or danger to the individual or others. Anything seen or overheard accidentally is still personal data. This includes:

- Any information which relates to or is about an identified or identifiable individual.
- Anything else provided to us in confidence by third parties and that is not a matter of public record.
- Sensitive organisational information that could be used to damage the charity.

People using our services are provided with a link to our privacy policy, relevant privacy statement or are provided with a leaflet explaining how their data will be used and the confidentiality measures in place.

## Handling confidential information

All personal data should be treated in the strictest confidence and in accordance with our Data Protection Policy.

### General principles

When handling personal data and other confidential information of the Huntington's Disease Association and any third parties we work with, ensure the following key principles are adhered to:

- Do not discuss any part of your work that could cause either an individual or the charity embarrassment or harm
- Be aware of your surroundings and who else may be listening, particularly in public or communal areas

- Clear your work area, ensuring all confidential information is locked away in desk drawers / filing cabinets before leaving at the end of each day.
- Lock your computer screen if you leave your desk unattended and log out completely when you finish for the day
- Never leave confidential information unattended or open to view by unauthorised people
- Do not take sensitive documents away from your office without seeking permission first
- Do not read confidential documents on public transport
- Do not leave confidential documents unattended in cars or public places

## Meetings

In discussions or meetings, ensure the following guidance is adhered to:

- Only disclose information that is relevant
- Do not discuss personal information about another person
- Consider referring to beneficiaries by their initials or record number in meetings

## Liaising with, collecting and recording information about a person

When liaising with someone, either in person or over the phone, ensure the following guidance is adhered to:

- If the conversation is over the telephone and someone else might hear, do not repeat aloud any personal information. If necessary, ask the person to say it again.
- Explain why any information collected / recorded is needed and how it will be used and obtain their consent if required. If we need to collect it for legal or other purposes, we must tell them that.
- We should give them a copy of our privacy notice or refer them to the privacy notice on the charity's website for more information.
- When collecting sensitive personal data (for example health information) for the purposes of advice and support as part of the Specialist Huntington's disease advisory service, this may be done without explicit consent as the processing of this special category data is part of the charity's legitimate activities.
- When collecting sensitive personal data (for example, health information) outside of the advisory service, in many cases we will need to have explicit consent. This can be an oral recorded agreement or a written statement. We should also explain, who will have access to it, the implications of not giving the information, any special procedures for protecting particularly sensitive information. If the individual does not agree, do not record or pass on the information.
- 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.
- Ensure any personal data recorded is factual, accurate and relevant and that expression of opinion is kept to a minimum and clearly recorded as an opinion.
- Where appropriate, ask for and examine supporting documents and record this on the file
- Ensure information is comprehensive and clear. Another staff member might have to form a judgement from the information and the person concerned may wish to read it
- Establish if the individual is happy to receive information in relation to their enquiry or contact to their home address, or another specified address or means of contact and update records with this information accordingly

## **Handling incoming information**

When handling incoming information received by post, the following guidance should be adhered to:

- All external post should be opened and checked by the appropriate person before being passed on to the addressee.
- Post marked confidential should be passed to the addressee unopened, unless prior instruction has been given.
- If anything of a confidential nature is not in an envelope, put it in a sealed and appropriately marked envelope before passing it to the addressee
- If you open confidential correspondence by mistake, reseal it or use a new envelope and write your name and 'opened in error' on the outside before forwarding it to the addressee

## **Administration**

The administration, typing, printing, photocopying, scanning and filing of confidential information must only be carried out by employees or volunteers who are familiar with the Huntington's Disease Association's confidentiality procedures. The following guidance should be adhered to:

- Securely destroy all unused rough work and any spare copies.
- When photocopying or printing ensure the correct printer setting is enabled and do not let anyone else read the documents, make only the required number of copies and check that nothing is left in the machine afterwards.
- When scanning move the scanned document from the scan drive to a secure place of storage immediately
- File all paper and electronic files in secure folders with access limited to those who require the information only.

- When taking notes in a meeting in which confidential information is discussed, ensure the information is not disclosed to anyone outside of the meeting and that notes are kept securely and circulated only to those who require them. If any individual is discussed during the meeting, their initials should be used in any meeting minutes.

## **Computers and emails**

When working with computers and emails, the following guidance should be adhered to in order to maintain confidentiality:

- No disks, CDs or other portable storage media should be used to store personal data unless encrypted and unless authorised by the charity
- Any personal data stored on laptops should be securely stored on the relevant database or folder within the charity's secure remote server.
- Computers should be locked or users should log out to prevent access if computers are left unattended for any length of time.
- When using e-mail addresses, external recipients should not be grouped in a manner where they can see each other's email addresses, unless permission has been obtained
- The Bcc facility on e-mail should be used when emailing multiple people so as not to disclose personal contact information

## **Keys**

When handling keys for charity premises and secure filing systems, the following precautions should be adhered to:

- All keys to the Huntington's Disease Association's premises must be kept securely
- Spare keys should be kept in a key cabinet or drawer that is kept locked.
- Do not keep keys in unlocked drawers.
- Filing cabinets and desk drawers with confidential information should be kept locked and keys kept securely with spare keys kept in a locked key cabinet. Do not keep keys in unlocked drawers.

## **Access to confidential information**

### **Access to confidential and sensitive information**

Staff will have access to all information that they need to know to carry out their work and are under a duty to respect the confidentiality of all personal data held by the charity.

Staff should have explained or made privacy information available to the individual to explain the purpose of recording the personal data, how that information will be used and whether it will be shared with any third parties when they collect the information. If this causes concern, special arrangements for recording and access will be made where possible. If concerns cannot be allayed it may be impossible for the Huntington's Disease

Association to undertake a particular activity for a given individual. In these circumstances, this will be explained to the individual.

All employed staff, temporary workers and volunteers must sign a confidentiality agreement before being given access to any information held by the charity. For paid staff this agreement forms part of their contract of employment. For volunteers, it is covered by the charity's confidentiality form or by the Branch or support group agreement document.

### **Information obtained by peer support groups**

Those involved in group work/peer support activities are likely to be aware of personal data about others and should be made aware of the need to respect their right to privacy. People involved in group work/peers support activities will be asked to adhere to and confirm their agreement to the principles of confidentiality outlining their responsibilities and disclosure risks from other members. The Huntington's Disease Association will make beneficiaries aware of their responsibilities under these circumstances and they are responsible for ensuring they comply.

### **Sharing information with third parties**

External agents and contractors who process personal data and other confidential information on behalf of the Huntington's Disease Association must be made aware of the charity's information governance requirements; what they can and cannot do, and who they should contact if things go wrong prior to them being given any access to information.

All agents and contractors in receipt of confidential information should complete and sign a confidentiality agreement when the contract is established. Where third parties are processing personal data, as a data processor, for the Huntington's Disease Association, the contract should also set out that the Huntington's Disease Association is the data controller and the third party is a data processor and the obligations both parties must uphold under the relevant Data Protection Legislation.

## **Managing a breach of confidentiality**

If accidental disclosure of confidential information occurs, the relevant head of department should take swift action to minimise the damage. They should find out who knows about the incident, talk to them and remind them of their duty to maintain confidentiality.

The breach must be reported to the Data Protection Officer and recorded on the data breach log. An assessment will be undertaken by the Data Protection Officer to determine whether the severity of the breach requires it to be reported to the Information Commissioner's Office (ICO) or whether alternative action should be taken.

If there is the potential for adverse publicity then the Chief Executive must be alerted who will inform the Board of Trustees as required.

## **Disclosure**

Disclosure of personal data and other confidential information should only be made in accordance with the Huntington's Disease Association's Data Protection Policy.

## **Disposal**

All personal data and other confidential information will be securely shredded or destroyed in accordance with the charity's Information Management Policy and Retention and destruction schedule.

## **Responsibilities**

### **Executive Council**

Trustees shall ensure that:

- Confidentiality is managed appropriately within the charity and that adequate resources are made available to implement this policy

### **Chief Executive**

The Chief Executive shall ensure that:

- All confidential information processed by the charity is handled in line with the confidentiality policy and relevant data protection policies and for informing trustees on the measures in place.
- All staff, volunteers and third parties are aware of their responsibilities to adhere to this confidentiality policy, that the relevant contracts are signed and that training is provided where required.

### **Senior management team**

The Senior management team shall ensure that:

- All Huntington's Disease Association staff and volunteers have read the confidentiality policy and relevant data protection policies and are operating within the charity's agreed standards
- Training is provided to staff and volunteers to ensure confidentiality requirements are fully understood.

### **Employees and volunteers**

All employees and volunteers of the Huntington's Disease Association shall ensure that:

- They read, understand responsibilities and fully comply with the charity's confidentiality and relevant data protection policies when accessing confidential information.