**HDA MESSAGE BOARD**

**TERMS OF SERVICE**

Please take a moment to review the Terms and Conditions detailed below. Remember, you cannot use the HDA Message Board unless you agree to these Terms and Conditions. Once you start using the HDA Message Board you are deemed to have accepted and agreed to be bound by these Terms and Conditions. The Huntington’s Disease Association reserves the right to prohibit you from using this site if it believes you have infringed these rules.

**1. Terms**

1. Children under the age of 16 are prohibited from creating an account and becoming a member of the HDA Message Board. In registering as a member you are acknowledging that you are aged 16 or above.
2. By registering you agree not to participate in mischievous or malicious behaviour which causes damage or may cause damage to the HDA or to any other individual or organisation.
3. Messages must not be obscene, vulgar, defamatory or libellous, sexually orientated, hateful, threatening or otherwise violate any laws or good morals and practice.
4. Messages containing contact details, phone numbers, fax numbers or postal addresses are not allowed except with the prior written permission of the HDA.
5. Messages must not contain advertisements or references to products or services.
6. We reserve the right to moderate messages that contain advice about intervention / lifestyle changes / treatment, or provide links to articles or research, that could be considered potentially harmful and do not reflect the advice given to the HD community in the UK by relevant professionals.
7. Messages which appear to impersonate someone else are not permitted.
8. Repeated posting of the same or similar messages (referred to as spam) will not be permitted.
9. You agree not to post any copyrighted material unless the copyright is owned by you or by this bulletin board.
10. Any user who feels that a posted message is objectionable is encouraged to contact the HDA immediately by e-mail.
11. By registering you acknowledge that the HDA is not under any obligation to monitor or review the discussion board and you agree that you are entirely responsible for all content that you make available on the board.
12. The HDA reserves the right from time to time to edit or remove posts that are contrary to the Terms and Conditions or not constructive to the overall purpose and mission of the HDA without prior contact with the author. Offenders may be banned from participating in the HDA Message Board without prior notice.
13. Posts to the message board must be in English

**2. Privacy and data protection**

1. Please read the [privacy notice](https://hdmessageboard.com/privacy) to understand how we use your data.

**3. Notice**

1. This agreement shall be governed in accordance with English law.
2. Please check the rules from time to time. The HDA reserves the right to modify these without notice, and your use of the HDA Message Board signifies your personal agreement.

**4. Warning**

1. This is a public forum and we encourage users to be welcoming and supportive - but remember your posts can be seen by thousands of people every day.

**5. Usernames and content**

1. When choosing your username you should ensure that this does not contain any personal information about you that may enable you or your family to be identified such as a photograph, your name or other personal information. We recommend that you therefore choose a user name that is more random and less personal.
2. Your privacy and personal safety is of the upmost importance to the HDA. The HDA Message Board is open to anyone and therefore you should not post personal information including name, address, email address and contact telephone number on the message board. Please at all times keep your personal safety in mind.
3. Any individual or organisation making use of information from this site does so at their own risk and the HDA takes no responsibility for any actions arising from this.
4. All views and information on the discussion board are those of individuals and do not necessarily reflect the views, policy or advice of the HDA. The content is the sole responsibility of the author.

**PRIVACY**

[Introduction](https://hdmessageboard.com/privacy#collect)

The Huntington’s Disease Association (HDA) takes your privacy very seriously and are committed to keeping the personal information you share with us protected and stored safely.

We collect the minimum information from you to enable you to complete registration and become a member of the Message Board. The personal information that you provide is not used for any other purposes than the completion of the registration process.

This document outlines exactly how we collect your personal information, what we will do with it, how we will use it and how we will store it.

Most importantly this notice will make clear your rights regarding the use of your personal information and what to do if you no longer wish your personal information to be held by the HDA.

So what has changed?

The 25 May 2018 marked the biggest change in data protection legislation in more than twenty years when the General Data Protection Regulation (GDPR) came into force. Much has changed since the Data Protection Act and the GDPR will give greater protection to your personal information in what is an increasingly digital world.

Amongst those key changes under the GDPR is that we are no longer able to collect and store your personal information unless we have identified a legal basis for processing your personal information.

GDPR also gives you increased rights to ask what we know about you and make changes to how we communicate with you in the future.

Legal basis for using your information

From 25 May 2018 the lawful reason we use to process your personal data is **CONSENT**.

This means that we only process your personal information where you have agreed and given the HDA permission to process your information as part of the registration process towards becoming a member of the HDA Message Board.

How do we collect information?

We will only collect information from you that is necessary for the completion of the message board registration process. The information that you give us shall only be used for the purposes of completing the registration process for the message board. If in the future, we would like to use the information for another purpose, or the reason for using your personal information has changed we will ask your permission before doing so.

Directly from you

We obtain personal information when you give it to us directly, for example when you complete the message board registration process.

What information we collect and how we use it

The personal information we collect and how we will use it is dependent on why you gave it to us in the first instance.

Support for developing the services provided by the HDA

At the HDA we use the information that you share to help inform us how we should deliver services in the future through looking at the nature of the information in your posts and threads on the message board and using these to inform future decisions.

Support for monitoring and evaluation

The HDA will use the information that you provide us with to regularly review the services we provide and ensure these services are being delivered to the highest standard and are contributing to the charities objectives of improving the lives of all those affected by HD.

The HDA will also use the personal information that you provide us with to help in increasing awareness about HD and promoting the work undertaken to improve the lives of all those affected by HD.

How we keep your personal information safe

We make sure that your information is accessed only by appropriately trained staff and approved contractors. We ensure that any external contractors we use are comprehensively checked and adhere to a formal agreement in which our expectations and requirements regarding the way in which they manage, collect and access any personal data, are met.

We make sure that there are relevant controls in place on our website and on our data networks to safeguard those personal details that you provided us with as part of the process of registering for the Message Board.

We take appropriate measures to ensure that any personal information you disclose to us is kept secure, accurate and up to date. We ensure that your personal information is kept only for as long as you have given the HDA permission to store this information. Information is securely destroyed within the relevant timescales in accordance with our data protection policies.

We will only disclose your personal information where we have your permission or when we are obliged to disclose personal data by law, or the disclosure is ‘necessary’ for purposes of national security, safeguarding, or where there is a risk of harm to self or others, taxation and criminal investigation.

Access to your information and contacting us.

It is your information so you have the right to ask us to stop contacting you or to stop using your personal data.

You have the right to request a copy of the information that we hold about you. If you would like a copy please contact us on [info@hda.org.,uk](mailto:info@hda.org.,uk) or write to us at Huntington’s Disease Association, Suite 24, Liverpool Science Park, IC1, 131 Mount Pleasant, Liverpool L3 5TF.

We want to make sure your information is up to date, so please contact us to ask us to correct it if it needs updating.

We make it clear and easy for you to tell us how you want us to communicate with you. We include information about how to stop receiving communication from us, or change your communication preferences with any mail out.

If you have any questions or concerns, you can call us on 0151 331 5444 or email us at [info@hda.org.uk](mailto:info@hda.org.uk)

Policy changes

Please note that the terms of this notice will be reviewed and updated and please visit our website for the latest privacy policy updates at:

[www.hda.org.uk](http://www.hda.org.uk/)

If you are unhappy about how we handle your personal information you can contact the Information Commissioners Office. For further information, please visit the Information Commissioners website:

[www.ico.org.uk](http://www.ico.org.uk/) or call 0303 123 1113