MND Association

1D

How we use your information

Guidance for people with or affected by Motor Neurone Disease (MND) or Kennedy's disease who receive support from the MND Association

We aim to provide you with the best possible support. To do this, we need to keep records about you and the support we provide you with. This sheet explains why we ask for your information and how we use it. It also explains how we protect confidentiality and your rights. The content includes:

1. **What information is collected?**
2. **How will the MND Association use my information?**
3. **What are my rights?**
4. **How does the MND Association ensure it complies with legislation?**
5. **How do I find out more?**

Trusted Information Creator
Patient Information Forum

This content has been evidenced, user tested and reviewed by experts. See: piftick.org.uk

💬 This symbol highlights quotes from people living with or affected by MND or Kennedy's disease.

ℹ This symbol highlights our information resources to help you explore further. Find out how to download or order printed copies in section 5: **How do I find out more?**

If you have any questions about how we use your information, please contact the Data Protection Lead at:

Telephone:	**01604 250505**
Email	**dataprotection@mndassociation.org**

1. What information is collected?

We need to collect and use certain types of information about the people we support, to carry out our work effectively. Only factual and necessary information should be collected to help with this.

As standard, we collect the following basic information about you:

- personal details such as your name, address, date of birth, information about your diagnosis (if you are living with MND or Kennedy's disease), and preferred method of contact, such as telephone or email
- details about your main carer and if we can contact them
- details about the health and social care professionals supporting you
- simple notes about any contact we have with you, such as with our Support Services team, and any support we provide to you.

Information and records are stored securely and only accessible to authorised staff and volunteers, who:

- have had appropriate training
- need to access these records in order to support you.

Your details will be shared with branch and group volunteers, who may contact you directly. They will only do this if you have given consent to be contacted about our services, membership or fundraising.

However, your personal details will be stored securely and not discussed on paper or by email between staff and volunteers.

Your information will only be stored for as long as it is needed or required by law and will then be disposed of securely.

Your general record with us will be stored while we are in contact with you or while your membership lasts. Once inactive, we keep that record for six years, after which the data will be reviewed and disposed of securely if necessary or appropriate.

We will keep some basic identifiable information about you and the support we have given, to assist our business needs and development of the support we provide.

Your information will be stored in secure systems where access can be monitored. In most cases, we will ensure your data is held within the UK or European Economic Area (EEA), where your rights are protected.

Occasionally information is held outside the EEA, but where this is the case, we have contracts in place that give you the same safeguards and rights that apply to data held within the UK.

If you wish to query how long your data will be stored, or ask for it to be deleted, please contact **dataprotection@mndassociation.org** You can also read our privacy policy at: **mndassociation.org/privacy-policy**

We also record feedback that you send us through surveys and other media. This is used to inform our work, so that we can continue improving our support for people living with or affected by MND or Kennedy's disease. You can ask not to be included in surveys if you wish, and this will not affect the support we can offer you.

2. How will the MND Association use my information?

The MND Association will always deal with your information securely.

Our services

The MND Association provides a range of services, including our:

- MND Connect helpline
- support grants and equipment loan
- wheelchairs and communication aids services
- regional staff and volunteers.

Your information will be shared between the members of staff or volunteers in these teams to co-ordinate the service we provide.

As part of this, we will use your information to:

- make sure any support we provide is safe and effective
- make decisions about applications for support grants or equipment loan, make payments if these decisions are approved, and keep a track of spending
- check the quality of the support we provide to you
- manage and plan our services
- investigate concerns or complaints
- keep you up to date about events and conferences.

Co-ordinating care and support

To help co-ordinate your care and support with local services or benefits you might need, we will share your information with others who support you, including information about your health.

This is only done with your consent and is subject to strict rules about how your information will be used and kept confidential.

Research

Research has a vital role to play in the development of healthcare and health service delivery for those we support.

At times we may be approached by healthcare organisations asking if people with MND, Kennedy’s disease, their carers or families would like to be involved in research or surveys. We are keen to support you, if you wish to be involved in this type of research. However, we will only share your contact details with your clear consent. You will not be identified in any published results without your agreement.

Direct marketing

It is essential that we can communicate with our supporters and keep you up to date about the work we are doing. We want to tell you about the amazing difference you make. This includes information about volunteering opportunities, and ways of helping our campaigns or MND Association funding.

We do this by sending letters and emails to you, which are known as direct marketing.

We may use direct marketing to ask you for help with:

- fundraising
- volunteering
- campaigning.

However, we will only send you direct marketing requests if either:

- you have given us your consent to do so
- we have told you we will contact you in this way and, when given the option, you haven't opted out of this form of contact.

You can ask to stop receiving direct marketing from us at any time.

Personal stories and quotes

We use personal stories and quotes from people with or affected by MND in many ways, to:

- highlight the work we do
- support our campaigns
- raise awareness
- encourage support
- share ideas and experiences
- raise funds, helping us to get closer to our vision of a world free from MND.

> **"I'm so 'pleased', if you know what I mean, that our family's experience with MND could help towards raising funds and awareness. If only one good thing can come out of all this, then that is surely it."**

Sharing real life experiences also helps other people affected by MND feel that they are not alone and may also highlight a service or support they could access.

> **"The quotes are so useful. They re-engage me with the 'here and now' and allow me to compare what I am going through with the experience of others."**

We collect quotes from surveys, studies and feedback. These may appear as named if we have consent for this, but usually appear in care information publications anonymously, with any identifying information removed.

We collect personal stories by speaking to people living with and affected by MND. We then share the transcript with those people and give them the opportunity to make amendments before they sign a consent form.

We always ensure that the people who share their experiences are aware of how we use their story and images. In some circumstances, we will use anonymous stories.

Photography

We try to avoid using stock photos where possible, and instead use real images of people with and affected by MND in our publications and within our digital channels.

We gain permission to capture and use photos and videos of people by asking them to sign a consent form, or by making them aware we are taking photos or recording and providing an opportunity to opt out beforehand.

When capturing images of children and young people, a consent form is always signed by their parent or guardian.

Images are usually used for five years from the date of capture, unless otherwise agreed. All images and consent forms are stored securely. You can withdraw your permission at any time by emailing: **dataprotection@mndassociation.org**

Online forum

Our forum is a safe place to share experiences, and provides a wealth of information with other people living with or affected by MND.

> **"This can be such a help to those who may feel isolated in everyday life… This can really support those with MND and their families, as well as carers."**

We collect personal information when you register on the forum which is used to create your profile. We also ask for your date of birth to ensure you are eligible to use the forum. The information we capture will not be shared.

Although the forum is intended to be used for open discussion, we recommend that you don't include any private or confidential information that you would not be happy to share publicly.

You can access the forum by visiting: **forum.mndassociation.org**

Social media

We use social media to share news and information about care improvement, research, campaigns and fundraising. It is an extremely effective tool for people with MND, Kennedy's disease, their families and carers to engage with us.

We may share, like and retweet any social media content that you publish. This content may be seen worldwide. If you post something that we believe may be used to further promote the MND Association or awareness of MND, we may contact you via social media to ask for your permission to use it.

We will never ask you to share your personal information through social media, and we will never share any information we keep about you through this channel. We will always ask your permission before we share anything from social media on another channel, for example, our website.

We recommend you use caution when direct messaging another user. Although these features enable private conversation, the contents could be copied and shared publicly by the other user.

Find all our social media accounts at:
mndassociation.org/about-us/who-we-are/social-media

Social media sites themselves may use personal data. Check the privacy policy of the site you are using to find out how they use your information.

3. What are my rights?

You have various rights under the General Data Protection Regulation (GDPR).

One of these is the right to be informed of why personal data is collected and how it will be used. This information sheet is an example of how the MND Association aims to satisfy this right.

Will my records be kept confidential?

You have the right to confidentiality under the General Data Protection Regulation (GDPR), the Human Rights Act 1998 and common law duty of confidence. This applies to any organisation or institution that holds personal information about you.

Everyone working or volunteering for the MND Association has a legal duty to keep information about you confidential. Anyone who receives information from us is also under a legal duty to keep it confidential.

If you have any concerns or questions about the confidentiality of your information, discuss this with the member of staff or volunteer you are in contact with, or email:
dataprotection@mndassociation.org

There are some situations where we may share information about you without your consent, for example if:

- you or other people are, or may be, at risk of harm (including children)
- sharing the information could prevent a crime
- a serious crime has been committed
- a court order or other legal authority has requested the information.

Can I access my records?

You have a right to access any information we hold about you on our computer systems and in manual records.

You can request a copy of your record from the staff member or volunteer supporting you, or contact: **dataprotection@mndassociation.org**

Can I withdraw my consent?

If you have given us consent to use your information in order to carry out any of our services mentioned in section 2 **How will my information be used?**, you can withdraw this consent at any time.

You can do this by contacting the member of staff or volunteer providing the service, or emailing **dataprotection@mndassociation.org**

Can I ask for my data to be erased?

You have the right to ask for your personal details to be erased, if there is no legal need for us to be holding this data about you.

If you want your details to be removed from our system, please contact: **dataprotection@mndassociation.org**

Can I ask to stop receiving marketing materials from the MND Association?

Direct marketing is any fundraising, volunteering or campaigning letters or emails you may receive from us.

You have the right to ask to stop receiving these at any time.

You can do this by selecting the ‘unsubscribe’ option on emails from us, emailing **dataprotection@mndassociation.org** or calling 01604 250505.

What if the information you have stored about me is incorrect?

If we have any incorrect personal information about you on our system, you have the right to ask for it to be corrected or removed. We will then correct or remove this information within a month of your request.

4. How does the MND Association ensure it complies with legislation?

We are bound by laws regarding data protection, and work hard to ensure we meet these standards. To ensure we are treating your personal information as we should, we have:

- a member of staff who is the Senior Information Risk Officer (SIRO)
- a member of staff who is the Data Protection Lead
- responsibility for data protection governed by our Board of Trustees, with an annual report to the Governance Committee
- an Information Governance Steering Group, who meet every three months and keep records of any breach, with details of learning put in place (these records are only visible to senior executives)
- ensured we are compliant with the robust principles of the General Data Protection Regulation (GDPR), which all organisations in the UK are expected to follow.

5. How do I find out more?

Other organisations

We cannot endorse organisations, but the following may help your search for further information. Our MND Connect helpline can help you find organisations. See contact details later in this section, under the heading: Our support.

GOV.UK
Online government information about data protection.
Website: **gov.uk/data-protection**

Information Commissioner's Office (ICO)
Independent body set up to uphold information rights.
Tel: 0303 123 1113 (can also be used to raise a concern)
Email: casework@ico.org.uk
Website: **ico.org.uk**
ico.org.uk/concerns (to raise a concern)

NIDirect
Online government information about data protection for Northern Ireland.
Website: **nidirect.gov.uk/articles/freedom-information-and-data-protection**

Acknowledgements

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Lindsay Gibson	Data Protection Specialist from a data protection advice company and an MND Association volunteer, Worcestershire Branch.

References

References used to support this resource are available on request:
Email: **infofeedback@mndassociation.org**

Or write to:
Information feedback,
Motor Neurone Disease Association,
Francis Crick House,
6 Summerhouse Road,
Moulton Park,
Northampton, NN3 6BJ

Further information

We offer a wide range of information about MND and Kennedy's disease. You may find the following resources helpful, relating to this sheet.

Information sheets

1A NICE guideline on Motor Neurone Disease

Large guides

Living with MND
Caring and MND: support for you

Search for information by need at: **mndassociation.org/careinfofinder**

Find information for professionals at: **mndassociation.org/professionals**

Download our information at: **mndassociation.org/publications**

Find information in other languages at: **mndassociation.org/languages**

Order printed copies from our MND Connect helpline (see Our support next).

Our support

Every day we support people affected by motor neurone disease, campaign for better care and fund ground-breaking research. Because with MND, every day matters.

We also support people affected by Kennedy's disease.

MND Connect
Our helpline offers practical and emotional support, information and signposting to people with MND, carers, family and professionals. Find out more and current opening times at: **mndassociation.org/mndconnect**

Tel:	0808 802 6262
Email:	mndconnect@mndassociation.org

Support services
Find out about our support services at: **mndassociation.org/our-services**

Local and regional support
Find out about our branches and groups at: **mndassociation.org/local-support**

MND Association Benefits Advice Service
For help to identify claims and how to apply, visit: **mndassociation.org/benefitsadvice** or call our MND Connect helpline.

Tel:	0808 802 6262

MND Association website and online forum

Website:	**mndassociation.org**
Online forum:	**forum.mndassociation.org**

We welcome your views

We'd love to know what you think we're doing well and where we can improve our information for people with MND or Kennedy's disease, their families and carers.

Your anonymous comments may also be used to help raise awareness and influence within our resources, campaigns, and applications for funding.

To give feedback on any of our information sheets, access our online form at:
smartsurvey.co.uk/s/infosheets_1-25

You can request a paper version of the form or provide direct feedback by email:
infofeedback@mndassociation.org

Or write to:
Information feedback
Motor Neurone Disease Association
Francis Crick House,
6 Summerhouse Road,
Moulton Park
Northampton, NN3 6BJ

Would you like to help with user review of our information?

If you are living with MND or Kennedy's disease, or a carer, contact us at
infofeedback@mndassociation.org

Motor Neurone Disease Association
Francis Crick House,
6 Summerhouse Road,
Moulton Park
Northampton, NN3 6BJ

Tel: 01604 250505
Email: enquiries@mndassociation.org
Website: mndassociation.org

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