How we may use your information

Information for people with or affected by motor neurone disease and Kennedy’s disease

The MND Association aims to provide you with the highest level of support. To do this, we must keep records about you and the support we provide to you.

This sheet explains why we ask for information and how it is used. It also explains how we protect confidentiality and your rights.

The information is split into the following sections:

1: What information is collected?
2: How will the MND Association use my information?
3: What are my rights?
4: How do I find out more?

This symbol is used to highlight our other publications. To find out how to access these, see Further information at the end of this sheet.

This symbol is used to highlight quotes from other people with or affected by MND.

The MND Association has been certified as a producer of reliable health and social care information.

www.england.nhs.uk/tis
1: What information is collected?

We need to collect and use certain types of information about the people we support, so that we can carry out our work effectively. Only relevant, factual information should be collected.

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

- personal details such as your name, address, date of birth, and preferred method of contact, such as telephone or email
- details about your main carer, and if we can contact them
- simple notes about any contact we have with you, such as with our Support Services team or Association visitors, and any support provided to you.

Information and records are stored securely and only accessible to authorised staff and volunteers who have had appropriate training. If any member of staff becomes aware of changes to your details, they will inform our Care Admin team, who will update your record.

If you are a member of an MND Association branch or group, they may contact you as a member, but your personal details will be kept confidential and will not be discussed at branch meetings or on paper 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.

We also record feedback that you send to 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. Your feedback is recorded and stored anonymously and your personal identity is not disclosed. You can ask not to be included in surveys if you wish and this will not affect the support the MND Association is able to offer you.

2: How will the MND Association use my information?

We will use your notes to:

- make decisions about applications for grants or equipment loans
- make sure any support we provide is safe and effective
- work effectively with others in the MND Association who provide support to you
- check the quality of the support we provide to you.
Your information may also be used to help us to:

- make payments to you, such as support grants, and keep track of spending
- manage and plan our services
- investigate concerns or complaints
- keep our membership up to date about events and conferences.

Whether you apply for funding or support from the MND Association, through our head office, branches and groups, or through a volunteer, your information will be dealt with securely.

**Co-ordinating care and support**

At times, we may need to share information with others who support you, such as our local volunteers, or health and social care professionals. This helps to co-ordinate your care and support with local services or benefits that you might need.

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

> “Due to the combination of the complexities of the disease and the way the health and social care system is set up, people will almost certainly benefit from the support the MND Association can give.”

**Research**

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

At times we may be approached by healthcare organisations asking if people with MND, 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 explicit consent. You will not be identified in any published results without your agreement.

> “I am optimistic there will be a cure one day. It’s a challenge for the 21st century and I think science will find a way.”
**Personal stories**

We use personal stories from people with or affected by MND in a range of ways:

- highlighting the work we do
- supporting one of our campaigns
- raising awareness
- encouraging support
- raising funds, helping us to get closer to our vision of a world free from MND.

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.

> “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.”

We collect personal stories by speaking to people living with and affected by MND. We share the transcript and give people the opportunity to make amends 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 avoid using stock photos, and routinely 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 the parent or guardian.

Images may be used at any time, normally within a five year period from the date of capture. All images and consent forms are stored securely. You can withdraw your permission at any time.
Publications

In our care publications, we use quotes from people living with MND and their carers to share ideas and experiences. People have told us that this helps to reduce the sense of isolation that MND can bring.

We collect quotes from surveys, studies and feedback. We will always ensure that your quotes are used anonymously and remove any identifying information, unless you have given us permission to use your name.

“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.”

Online Forum

Our forum is a safe place to share experiences, advice and 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.

We recommend that, although the forum is intended to be used for open discussion, you should not include any private or confidential information that you would not be happy to share publicly.

You can access the forum by visiting: http://forum.mndassociation.org

Social Media

We use social media to share information about care, research, campaigns and fundraising. It is an extremely effective tool for people living with and affected by MND to engage with us.

We may share, like and retweet any social media content that you publish. 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 exercise caution when direct messaging another user. Although these features enable private conversation, the contents could be copied and shared publicly by the other user.

You can connect with us on social media by visiting:
Facebook:  www.facebook.com/mndassociation
Twitter:  www.twitter.com/mndassoc

3: What are my rights?

Will my records be kept confidential?

You have the right to confidentiality under the Data Protection Act 1998, 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, then discuss this with the member of staff or volunteer you are in contact with, or contact our Data Protection Officer on 01604 611835.

There are some situations where we may share information about you without your consent. These are:

- if there are reasonable grounds to believe that you are at risk of harm
- if there are reasonable grounds to believe that not disclosing the information could put someone else at risk of harm
- if the MND Association has a legal duty to disclose information, e.g. as a result of a Court Order.

Can I access my records?

Under the Data Protection Act 1998, 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 supporting you, or contact our Data Protection Officer on 01604 611835.
How does the MND Association ensure it complies with legislation?

We are bound by the laws regarding data protection, and work hard to ensure we meet the standards. We have a number of things in place to ensure we are treating your personal information as we should:

- We have a named data protection officer, who is a trained member of the National Association of Data Protection Officers (NADPO) and regularly attends external workshops to ensure their knowledge is updated.
- MND Association responsibility for data protection is governed by our Board of Trustees and discussed by them annually at Governance Committee.
- In addition, an Information Governance Steering Group meets quarterly and records are kept of any breach, with details of the learning put in place. These records are only visible to senior executives.
- We have only reported a breach to the Information Commissioners Office on one occasion, due to concern, but were told that our solutions and management of this were above expectation.
- We asked for a representative from the Information Commissioners Office to visit in 2014, to assess our data protection process. They commented on the robust nature of our systems and this was publicised on their website for over a year.
- We are now working to be compliant with the more robust rules that will be introduced on 25 May 2018 in light of the EU General Data protection Regulation, which all organizations will be expected to adhere to. This means we may well contact people in the coming year about this.

4: How do I find out more?

Useful organisations

We do not necessarily endorse any of the following organisations, but have included them to help you begin your search for further information.

The contact details are correct at the time of print, but may change between revisions. If you need help to find an organisation or have any questions, contact our MND Connect helpline (see Further information at the end of this sheet for details).

Gov.uk
Online government information about data protection.

Website:  www.gov.uk/data-protection
Information Commissioner’s Office
The independent body set up to uphold information rights.

Helpline: 0303 123 1113
Email: casework@ico.org.uk
Website: https://ico.org.uk

References

References used to support this information are available on request from

Email: infofeedback@mndassociation.org

or write to:

Care Information feedback, MND Association, PO Box 246, Northampton NN1 2PR

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Further information

We have an extensive range of information sheets, providing guidance on specific aspects of MND. The following information sheets may be helpful:

1A – NICE guideline on motor neurone disease

We also provide the following guides:

Living with motor neurone disease – our main guide to help you manage the impact of the disease

Caring and MND: support for you – comprehensive information for unpaid or family carers, who support someone living with MND

You can download most of our publications from our website at www.mndassociation.org/publications or order in print from the MND Connect helpline, who can provide further information and support.

MND Connect can also help locate external services and providers, and introduce you to our services as available, including your local branch, group, Association visitor or regional care development adviser.
We welcome your views

Your feedback is really important to us, as it helps improve our information for the benefit of people living with MND and those who care for them.

If you would like to provide feedback on any of our information sheets, you can access an online form at: www.surveymonkey.com/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, MND Association, PO Box 246 Northampton NN1 2PR