Collecting and entering data

Introduction

This article explains how data is collected and recorded and why it is important that the Association has good quality data. It is divided into two main sections.

Collecting data
Submitting and entering data

It is not intended to be fully comprehensive but to provide an overview and should be read in conjunction with data protection guidance.

It is designed primarily for use by the **care development** and **volunteering** teams, including support volunteers, but may also be of interest and relevant to **fundraising, campaigns** and other teams.

It will be updated on a regular basis and we are particularly interested in your comments, ideas and thoughts for improvement. Please contact john.gillies-wilkes@mndassociation.org

Section one
Collecting data

Data and the law
Essential data
It can be difficult but……
Case notes

Data and the law

Data is a collection of **accurate** and **objective** facts, figures, statistics and notes, which individually are of value but collectively are immensely powerful and hugely valuable. The data the MND Association collects and records allows it to ensure that it can:

- Provide the best possible support to people with or affected by MND
- Demonstrate the difference that it makes
- Influence decision makers, improve services and change policies
- Support volunteers according to their needs

The collection, recording and storage of data is governed by data protection legislation, including the **Data Protection Act 2018** and the **General Data Protection Regulation (GDPR)**, which seeks to ensure that any information held about an individual is only collected and stored fairly and lawfully and is properly protected. All data held by the MND Association about people with, living with or affected by MND is recorded and stored on its **MrC** and **Raiser's Edge (RE)** databases.

Essential data

The **enhanced data set** is completed for everyone with or affected by MND who is being or has been supported or helped by the Association. This includes people who:

- Contact MND Connect
- Are being supported by a member of staff or a volunteer
- Attend branch or group support meetings
- Apply for grants
- Use support services

Don't forget!

The person's permission to collect and store data must always be obtained

First name Last name	Gender Title
Address	Ethnicity (see appendix one)
E-mail	Free Association membership
Telephone (land line)	Referrer
Mobile	Lives alone
Preferred method of contact	Date of birth
Consent to store & share data and receive information -Verbal -Written	**Care centre, network or other specialist service** Name Contact details
Authority to contact third party -Verbal -Written	**GP** Name & practice Contact details
Authority to liaise with main carer -Verbal -Written	**Main carer (family, partner or friend)** Name & relationship Contact details
Other people in household (names)	**Other people in household (relationship & DOB)**

The **Minimum Data Set (MDS)** is completed for other people and a copy is available on request.

It can be difficult but……

…….it is important that the enhanced data set is always completed for people with or affected by MND. Although much of the information may be provided during the course of a conversation there will be times when specific questions will need to be asked.

"There are a couple more things I will need to ask you if I may"

"We use this kind of information anonymously to show the impact of MND on different groups of people and the difference we can make"

For the most part people are quite happy to provide information about ethnicity, age etc providing they are not asked to do so before a conversation gets started and the reason(s) for collecting data can be clearly explained.

"Good quality data is really helpful in making a case for funding MND services and for undertaking research".

Case notes

What makes a good case note?
Additional information
Using contact forms

What makes a good case note?

Case notes are used to keep a record of what is going on for a person with or affected by MND and may reflect a conversation that has taken place between an individual and a Support Volunteer or member of staff. They may also be used to summarise a conversation with a third party. Case notes should always be:

- Objective
- Factual
- Relevant

Case notes are **not the same** as clinical or medical notes. Ideally they should be broken down into three distinct sections:

- Problems, issues or events
- The way in which problems, issues or events might be addressed
- How and when things will be taken forward and by whom

An example of a good, a reasonable, an indifferent and a poor case note are shown below.

A good case note	**A reasonable case note**
Mr M telephoned to say that he had not heard back from the OT who had promised to call him about his wheelchair. Talked with Mr M about the situation generally and timescales in particular. It was noted that initial contact had been made with the OT two days ago. With Mr M's permission I called the OT who said that she was due to call tomorrow to arrange a visit. A visit for the following day was arranged. It was left that Mr M would call MND Connect if the visit did not take place or if he was dissatisfied with its outcome.	Spoke to Mr M. He has not heard from the OT. Turned out that initial contact had been made with the OT two days ago. Phoned the OT and arranged a visit for the following day. Mr M will get back in touch if there are further problems.
An indifferent case note	**A poor case note**
Following contact with Mr M, phoned the OT and arranged for them to visit the next day. He will get back in touch as needed.	Mr M was really angry and clearly feels that life is being very unfair to him. No one has followed up on his request for a wheelchair. Once again xx Hospital has failed to deliver as promised. Arranged for an OT to visit the next day and will make sure that they have done so.

The **good** case note is objective and factual, provides enough background information and shows what is to happen next. The **reasonable** case note contains the bare minimum but lacks background information. The **indifferent** case note is far too brief and simply describes events. The **poor** case note makes assumptions and is for the most part subjective.

NB. Everyone has the right to see all of the information held by us about them.

It's worth considering……..

- **How you might feel if your case note was read out in court, or needed to be provided as part of a Subject Access Request.**
- **How the person with or affected by MND might feel if they read your case note**
- **If someone could pick up where you left off after reading your case note.**

Background and other information

There are a number of other things that it can be helpful to know, including:

- The name(s) and role(s) of Health & Social Care Professionals (HSCPs) that are involved
- Where treatment or care is being provided
- Whether other family members or friends are involved
- The names and ages of children
- Whether there is financial hardship and if benefits have been claimed
- The facilities and equipment being used and whether benefits are being paid
- If there are other major but not health related issues

Using contact forms

Some staff and volunteers (MND Connect team members, RCDAs, Support Volunteers etc) will enter their case notes directly onto MrC or via the portal whilst others will submit the information using a **contact form** to a third party, such as an RCDA or member of the care admin team, who will enter the information on their behalf. There are two types of contact form the **full** version and the **short** version.

The full contact form is very comprehensive. It contains prompts to ensure that all of the elements of the Enhanced Data Set (EDS) are collected and a section for case notes. Generally it is used when the Association has previously had little or no contact with the individual.

Q. Do I really have to complete a form if I run into someone with or affected by MND in the street.

A. No you don't. This is not a significant contact.

The short contact form is much simpler and is used where all of the elements of the EDS have already been recorded. Regardless of whether the full or the short contact form is completed every single **significant contact** does need to be recorded.

A **significant contact** is one where some form of support is provided. It **does not** include ad hoc social conversations in informal settings or at more formal events but it **does** include such things as telephone calls, emails or visits to:

- See how someone is
- Check on the progress of something
- Provide emotional or practical support

Section two
Submitting and entering data

Hard copy submission
Electronic submission
Additional notes

Hard copy submission

Contact forms and other documents should be sent recorded delivery, marked **private & confidential** to the care admin team at:

David Niven House
10-15 Notre Dame Mews
Northampton
NN1 2BG

They may also be sent or handed to an RCDA or other member of Association staff.

Electronic submission

Unless they are being sent from and to an MND Association e-mail address contact forms and other documents should be password protected and sent to the care admin team at:

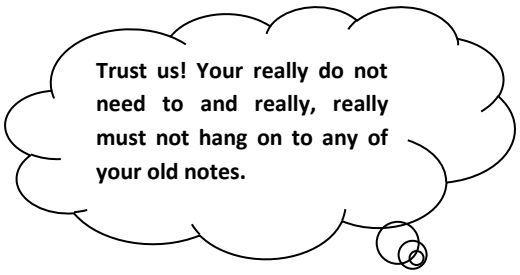
care.admin@mndassociation.org

They may also be sent in the same format to an RCDA or another member of Association staff. The password should be sent in a separate e-mail.

Password protecting a document in Word

- **Click file**
- **Click information**
- **Click protect document**
- **Enter password**
- **Click OK**

Additional notes



Any additional notes that have been made must be kept in a secure place before they are submitted or entered on MrC. Once they have been submitted or entered they must be destroyed. Hard copy notes should be shredded and electronic notes should be deleted **and** the deleted items folder emptied.

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Appendix one

Ethnicity

Group	Sub-group	Code
A-White	English/Welsh/Scottish/N Irish/British Irish Gypsy or Irish Traveller Any other white background	A01 A02 A03 A04
B-Mixed/multiple	White & Black Caribbean White & Black African White & Asian Any other mixed/multiple background	B01 B02 B03 B04
C-Asian/Asian British	Indian Pakistani Bangladeshi Chinese Any other Asian background	C01 C02 C03 C04 C05
D-Black/African/Caribbean/Black British	African Caribbean Any other Black/African/Caribbean background	D01 D02 D03
E-Other	Arabian Other background	E01 E02
F-Prefer not to say		F01
U-Unknown		U01