

Consent categories explained

Why capture consent?

We are required by data protection legislation to have a legal basis for processing data held on our systems.

We also need to be open and transparent with all our contacts on how we hold and process their information to show we are protecting and respecting the information they trust us with. We use consent as a legal basis for processing data for people with MND, as we capture health related information. This is classed as sensitive information which requires a more robust legal basis to process, this means obtaining explicit consent.

As part of the process, any new person with MND contacting/referred to our Care team, will be sent an introductory letter which introduces the Association and the help we can provide. It will also ask for their consent to actively contact them in the future or to share their information with Health and Social Care Professionals. They will also be asked if they want to become a member. As part of consent we should be specific and granular, so we also ask how they want to be contacted, either by post, email, phone or text.

This has led to the following Consent Categories being created

Consent categories	What it means	Examples
Services/Feedback - Email	Contact by us, to groups of people with or affected by MND, promoting services which we feel will be of benefit to them	Regular notifications on: Support Group meetings Events by third parties in their areas Improving MND Care Survey or anything similar Information on support in their area Regional conferences
Services/Feedback – Phone		
Services/Feedback – Post		
Services/Feedback – Text		

What we can do still do if they say no.

- You can still contact them about an existing relationship. For example, if they have an AV, the AV/Care can still initiate contact and visit
- Initiate contact if a concern is raised
- Respond to any request for information or assistance
- An initial individual contact with the person can be made to ascertain if any further support is required in relation to their referral or application.

Please remember, it is the persons choice about how much contact and information they want to receive, not ours. People also change their minds or circumstances change so at any contact you should check if their previous consents are still valid.

Additional Consents Captured

Consent categories	What it means	Examples
Share info with HSCP	We are asking if we can share personal identifiable details with a professional involved in their care or support	SLT referral Care Centre Multi-Disciplinary Team meetings
Marketing - Email	Where we are promoting the aims and ideals of the association and ask for support. There are strict rules on these types of communications.	Asking for funding Updates on the work of the Association Campaigning / awareness asks Volunteering Newsletters Conferences
Marketing – phone		
Marketing – post		
Marketing – text		
Free Membership	They will receive quarterly Thumb Print magazine and AGM notification, invites and voting rights	Free membership offered to people with MND and their carers

These consents are shared between our database systems in Head Office; MrC and Raiser’s Edge and communication consents with branches and groups, via the portal.

Additional information

There is an option to stop a branch and group contact. This is for people who expressly say they don’t want the branch or group to contact them. This will override any consents for the branch /group portal communication lists.

There are several other communication lists that may be joined.

Campaign network membership

Request to unsubscribe from the campaign network should be directed to the unsubscribe option on the email or contacting the Campaigns team. Requests to sign up should be directed to the website form sign-up or Campaigns Team.

Research Newsletter

Request to unsubscribe from the Research Newsletter should be directed to the unsubscribe option on the email or contacting the Research team. Requests to sign up should be directed to the website form sign-up or Research Team.

Research Participation List

Requests to sign up or unsubscribe should be directed to the website form sign-up or Research Team.

MND Register Newsletter

Request to unsubscribe from the MND Register Newsletter should be directed to the unsubscribe option on the email or contacting the Research team. Requests to sign up should be directed to the website form sign-up or Research Team.

Requests to be excluded from specific communications Marketing related requests can be sent to the volunteering team or relevant team managing the communications i.e. fundraising, campaigns, or conferences.