

Richmond, Kingston & West London



ME Group

PRIVACY POLICY

Database

The group membership database is maintained on the computer of the group membership secretary. It is never disclosed or sent to third parties, nor are third parties allowed to access it. Only the Chair, Treasurer, Membership Secretary and 2 other Committee members (Social Secretary responsible for sending cards and Committee member responsible for the activity schedule and reminding members of forthcoming events) are allowed to access it/keep copies on their computers and access is encrypted for extra security. The Group follows the new general data protection regulation (GDPR) implemented on 25th May 2018 and therefore no personal information from any member is stored in our database or given to a third party without his/her consent.

Email Network

New members are asked if they would like to join our Google email group. This is administered by our membership secretary and access is restricted to those members who have chosen to join it. There are Group email network guidelines on using the group which are posted on the website. There is no public access to this group.

Other Email Contact

At regular intervals between newsletters, an email bulletin is sent to all members who have given us an email address with items of general ME interest. Any member who prefers not to access the email bulletin by screen may receive it by post. In addition a schedule of events is emailed monthly and reminders of upcoming events are emailed to members unless they

decide they do not want these. These emails are all sent as blind copies so that email addresses are not revealed.

WhatsApp Group (everyone)

New members are asked if they would like to join our WhatsApp (everyone) group. This is administered by our Membership Secretary and at least one other member and access is restricted to those members who have chosen to join it. There are WhatsApp group guidelines on using the group which are posted on the website. There is no public access to this group.

WhatsApp Group young people

New members under the age of 30 on joining are asked if they would like to join our younger members WhatsApp group. This is administered by our Membership Secretary and at least one other member and access is restricted to those members who have chosen to join it. There are WhatsApp group guidelines on using the group which are posted on the website. There is no public access to this group.

Newsletter

Our newsletter is published up to four times a year and sent to members by email (as blind copies) or by post if the member is not online or specifically requests this. It is the main means of contact with the Group for many members who are not well enough to attend meetings or participate in the email network, etc. An edited version of the newsletter, with members' names and contact details redacted, is also distributed by email to other ME support groups in exchange for their newsletters to pool material with the proviso that nothing is reused without permission and that the newsletter is not forwarded or posted by them online. Nevertheless any member who contributes to the newsletter is specifically asked whether they are happy for their name, contact details or photo to be included or would prefer to write anonymously, as the redacted version is published on our website.

Website

Our entire group website (www.richmondandkingstonmegroup.org.uk) is accessible to anyone who visits it, with no member-only section. Its main function is to allow someone who has ME or thinks they have ME, plus their friends and family to find us, find out about us and ME and to contact us. It also contains information about ME for health, education and social care professionals who may have clients with ME. No members' photos, names or contact details are given on the website without their express permission.

Facebook

Our Facebook page:

www.facebook.com/RichmondandKingstonMEGroup?ref=hl is similarly open to everyone in the UK. There may be up to three administrators who can, if necessary, remove posts or shut down the page. The main function of the Facebook page is to provide information about ME to members and to other interested people who may not have joined the Group.

X

Our X account: @randkmegroup is used to raise awareness about ME and publicise the Group.

Instagram

Our Instagram page: @me_group_richmondandkingston is a public page and open to anyone to view and comment on. Its purpose is to raise awareness about ME and similar chronic illnesses, and to publicise the Group.

Amended 11/1/25