

Amputee support group - Information and privacy information

The Royal Free Charity

The Royal Free Charity works in partnership with the Royal Free London NHS Foundation Trust because together we can do what the NHS can't achieve alone.

The Support hub

The Support hub was set up in 2018 by the Royal Free Charity to support patients with long term health conditions, offering information and advice to patients to help them better manage living with their condition (e.g. a welfare advice service, peer support groups).

What is the amputee peer support group and what can I expect?

The amputee support group is a peer-led group arranged by the Royal Free Charity (RFC) Support hub, co-facilitated with the Limbless association (LA), as well as peer-led by those attending the group.

It provides an opportunity to meet and share experiences with other new and established amputees; sharing personal experiences of life after an amputation, with an opportunity to share learning of what they've found to be helpful or not helpful, with a shared understanding and shared support to each other.

Please note, the Support hub team and Limbless Association representative are not medical experts, physiotherapists or psychologists, however the majority of people in the group are fellow amputees with lived experience of life after an amputation.

We facilitate the group, listening to the expert that is you the attendee, and allow the conversation to flow as appropriate each week.

If you ever have any feedback, issues, or questions, please get in touch with Liz Fowler, the RFC Support hub lead, at elizabeth.fowler@royalfreecharity.org or call Liz on: 07932 719176

Privacy information

This leaflet lets you know about how we handle your personal information.

If you have any questions about this, wish to make a request to see your information, or exercise any of your other data protection rights, or have a complaint please contact the Support hub lead, Liz at:

elizabeth.fowler@royalfreecharity.org

Where is my information kept?

We record and hold your information in a secure database called Advice Pro.

We hold the information sent from you, or sent by the staff referrer at the Royal Free London. This includes your name, mobile number, address and email address. The reason for collecting this information is so that we can get in touch about upcoming groups, service changes, or if there are any emergencies during a group.

For some support groups, we may ask and record some special category information (e.g. health information), if it is relevant to being involved in the group.

We ask for some 'equality monitoring information' such as gender and ethnicity, although it is completely optional as to whether you give this.

Do you need my consent?

We are a support service, connecting patients with similar conditions to access social support via peer support groups. We cannot run these peer support groups or let you know about them without your information.

We believe both you and the Support hub have an interest in us collecting and using your personal information in this way. We have a "legitimate interest" and we consider that your interests do not override our interests.

We may also ask personal information about your health. Again, we need this sensitive personal information in order to run the support group to:

- support individuals with a particular disability or medical condition, or
- provide confidential advice or support.

We can do this because of the conditions outlined in the Data Protection Act 2018. For more information about the conditions we use, please see the Privacy Policy on our website.

Who can see my personal information?

It can only be accessed and used by:

- The Royal Free Charity Support hub administrator and Support hub lead (who co-chair the group)

The group is co-chaired with the Limbless Association (LA). Your personal data may be shared with Limbless Association only with your consent (asked in the registration form); please find their privacy notice here: <https://limbless-association.org/privacy-policy/>

Those attending the group will have access to personal stories and experiences of others; this is a confidential group, so we ask attendees not to share stories outside of the group. It is a safe space for all that attend.

Will my personal information always remain confidential?

We will not share your data with any third party unless we have your consent to do so.

We protect your confidentiality. However, we can share your personal information in the following circumstances:

- When there is a legal requirement – because of a law or a court order
- Where there is an overriding public interest (e.g. to prevent serious crime or serious harm to self or other person)
- To prevent a vulnerable adult from abuse (e.g. physical, sexual, psychological, financial)

How long will you keep my personal information?

The RFC Support hub retains personal information for the advice industry standard of 6 years. If you would like us to remove your information before this, please let us know.

How will you use my information?

We may contact you to remind you about upcoming support groups, via email or phone. If you would like us to remove you from our support group distribution list please let us know by emailing:

elizabeth.fowler@royalfreecharity.org

What if I want more detail?

Full details can be found on the Royal Free Charity Privacy Policy:

<https://royalfreecharity.org/about/privacy-policy/>