

ME Friends Online forum user guide

This guide will help you navigate and participate in Action for ME's ME Friends Online.

You will learn how to register, create new topics, reply to discussions, and interact with other users.

Please note: after we move to a new forum platform on Wednesday 26 March 2025, all users need to re-register. This ensures that all Data Protection and permission measures are up to date, both for your privacy and for GDPR purposes. The new platform is easier to navigate and more accessible.

Everyone using ME Friends Online is affected by ME so our <u>Terms of Use</u>, which all users agree to comply with, have been developed with this in mind.

We hope you enjoy using the forum!

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Registering for the forum

Go to the **registration page** for the forum at <u>https://www.actionforme.org.uk/forum/</u>

Join u:	s today!
Flands Online has moved to a new platform slope with our new website. All usars	
ed to re-register to be able to access the forum again.	Username * Please don't use your real name or your email address, or any swear words. Length must be between characters and 15 characters.
tion for ME's ME Friends Online forum is a community offering peer-support and endly discussion. It is open to adults living with ME/CFS in the UK including carers.	L Username
you are under 18, please join our FREE Young People's Community instead, which fers a young people's forum, pen pals, monthly e-magazine and more.)	Email *
eryone using ME Friends Online is affected by ME so our Terms of Use have been veloped with this in mind	First Name *
welcome users of any age from 18 years onwards - we have users in their elabties! -	E First Name
th a wide range of topics being discussed, including a section for games. There's also area for users who want or need to go at a slower pace.	Last Name *
hile we endeavour to ensure that the information contained in our forums is accurate.	E Last Name
propriate and up to date, please note content is provided by users and not Action for	Date of Birth
hope you enjoy using the forum and find it helpful.	🖸 dd/mm/yyyyy
	Postcode
ining the forum	
Jisters one account only. u will need to provide your full name and email address when you register. Please oose an anonymous username to protect your privacy. then you register, your account needs to be approved by a moderator. This may take up five working days and is up to the moderator's discretion. Please check your spam ider for the confirmation email. registering with ME Friends Online you agree to accept and comply with our Terms of	
e along with any other legal notices and/or instructions which may appear in the 'um (including in any messages or attachments posted). tion for ME reserves the right, at our discretion and without notice, to remove or edit y messages and/or to restrict your access (either temporarily or permanently). To learn or e about how we collect, process and store your information, please see our privacy	
iicy. ter registration you will receive an email confirmation with a link to set a new ssword.	
e "Date of Birth" and "Postcode" fields are OPTIONAL. Sharing this information will help understand more about our users so we can seek funding to ensure the forum meets ur needs.	
I have read and agree to the Terms and Privacy Policy	
 I agree to receive an email confirmation with a link to set a password. After registration you will receive an email confirmation with a link to set a new password 	
	sider .
Rep	

Please read the page in full and follow the instructions to register.

Check your spam folder for the registration confirmation email. Please note this might take up to five working days.

Navigating the forum

Forums	Members Recent Posts My Profile Logout		C
Frien	ds Online forum	🕸 Unread Posts Forum:	s 🄊 Topi
Action f	or M.E		
2	Using the forum Terms of Use and other topics to help you get the best out of the forum	Forum is empty	
2	Action for ME announcements Key Action for ME updates, including signposting to our services and other support	Forum sempty	
2	Welcome new users A place to introduce yourself and welcome new members	Forum isempty	
2	Talking about ME Share your experience of ME, tips for managing symptoms and coping with challenges	Forum is ampty	
•	Social spot A place for more general chat about things like hobbies, interests, pets etc	Topics Pests Forum Participants 1 Knitting socks By Clare Ogden, 56 minutes ago	
2	Fun and games Jokes, word association, A-Z posts, this or that and other games played in the forum	Forum is empty	
2	Slower pace Short posts for users unable to post or read longer content	Forum is empty	
2	News and research Share current news and research items of interest	Forum is empty	
2	Caring for someone with ME	Forum is empty	

You can browse the **forum boards** and recent **topics** from the homepage:

Click on a board to view the topics being discussed.

Use the **search function** to find specific topics.

Forums Members Recent Posts	My Profile Logout	a
†		
ME Friends Online forum		Unread Posts Forums की Topics की
	There's a butto	n for Unread Posts which also
appears at the botto	m of the page, along w	ith a Recent Posts option.
III Forum Information		⊘ Mark all read ∷≣ Recent Posts 🔹 Unread Posts 🗣 Tags
8 Our newest member: Pink Penguin		
Forum Icons: 🎭 Forum contains no unread posts 🔩 Forum co	ontains unread posts	
Topic Icons: 📋 Not Replied 📄 Replied 🛅 Active ᠔ Hot 🐥	Sticky 😈 Unapproved 🥥 Solved 🍳 Private 🗎 Close	d

Adding a new topic (previously called a thread)

Set up a new topic by going into a board and clicking the **Add Topic** button.



You can then add a **Topic Title** and some content. To post, click the **Add Topic** button.

Social spot	
A place for more general mat about things like hobbies, interests, pets etc	
Subscribe for nur topics	
Topic Title *	
Knitting socks	
tipt B I U ≪ A - ⊟ ⊟ - ≣ Ξ Ξ Ξ ฮ ఔ (↔ ⊕ つ ் 🛱 (;)ⓒ 🗙	
I have started a new hobby of knitting socks, which I am finding really relaxing 🐸	
I also want to try this lovely pattern, which is free to download	
P	4
Ch. Topic Topic (formation any set)	λ
Topic tags (separate tags using a comma)	
Knitting, socks	
	Add topic
Preview 33 Revisions ✓ Saved	
You can add Topic Tags to help you categorise	your topic.
\backslash	

Use the **Preview** button if you'd like to see what your post looks like before you add it.

As you can see there's also the option:

Subscribe to this topic

This means that you will get an email alert every time someone adds a post. This is useful for users who start a topic asking a specific question and want to keep track of the answers.

Replying to an existing topic

You can do this by clicking on one of the Boards (eg. "Fun and games") then clicking on one of the topics.

	1 Topic starter	Ø
	I have started a new hobby of knitting socks, which I am finding really relaxing Ӱ	
	l also want to try this lovely pattern, which is free to download 🔮	
Clare Ogden		
(@co-personal)		55
Posts: 1		
Flower arranger	Posted : 19/03/2025 9:56 am	
Topic Tags	• Knitting • socks	
Leave a reply		
🌮 Title *		
RE: Knittingsocks		
H B T B M		
Tipt D 1 g ~~		
		Å
		Add Reply
		4
Scroll to the	I eave a reply how at the bottom	
and add you	r response.	
	Click the Add F	Reply
	button to post.	

Updating your profile

You need a minimum of three posts to be able edit your profile information.



You can see there are now lots of fields to complete if you would like to. Here's an example for the user Pink Penguin.

To update your cover image, clicking on the **little picture icon** in the bottom right-hand corner of the cover image, which is the one with the flowers on it in the picture below.

	Pink Penguin @pin Member	k-penguin	R Form Home (P Recent Post P Recen
0 Followers / 0 Followin	9		â 🏝 🏝
Profile	Activity	Favored a Subscriptions Messages	
Username		Pink Penguin	
Display Name *		2 Pink Penguin	
Nickname * URL Address Identifier		Ø pink-penguin	
Email *		S forum@actionforme.org.uk	
Title *		La Member	
Avatar		O Default avatar	
		O Specify avatar by URL:	
		Upload an avatar	
		Choose file No file chosen	

Here's what the fields in your profile refer to:

Username – this is the name you chose when you registered, and it cannot be changed.

Display Name – this is same as your username by default. If you like you can change it, please don't use your full real name or email address. This is to protect your privacy.

Nickname – this is your unique URL address identifier so you can link to your profile if you'd like to.

Email - your email address will already be there. Please note that when others view your profile they will NOT be able to see your email address.

Title – this is the description that appears under your profile pic when you post. It says "Member" by default. Feel free to change to anything APART FROM "Moderator" OR "Action for ME staff" as these are reserved for Action for ME colleagues only.

Avatar – this is where you can upload a profile picture. Please do not use an image that clearly shows your face, or anything that may cause offence.

You can also add your country of location and time zone if you like.

Your profile page is also where you can **reset your password** if you need to:

Location	United Kingdom	
Timezone	London ·	
Password * Must be minimum 6 characters.	Old password New password	
	Confirm password	
		Save Changes

Whatever you add, don't forget to click the **Save Changes** — button at the bottom!

This is what other users will see when they look at your profile:

	Pink Penguin (gpin Member	k-penguin		C Forum Hom	e * Recent Post
Sellow 0 Follow	vers / 0 Following				20 2/ 20 2 * X
Profile	Activity	Favored	ℬ Subscriptions		
B Forum Posts	Topics	? O Questions	 ✓ 0 Answers 	(a) Question Comments (b) Liked	
0 Received Likes	Received Dislikes	cc 0/10 Rating	0 Blog Posts	Q1 0 Blog Comments	
Display Name		Pink Penguir	1		

Unfortunately, we are not able to remove the categories that we aren't using – it's something of an all or nothing approach – so please ignore the following which are not live for any user:

- Questions
- Answers
- Question Comments
- Rating
- Blog Posts
- Blog Comments

Your profile WILL track the following:

- Forum Posts
- Topics
- Liked
- Received Likes
- Received Dislikes

Private messaging

You can send a private message to another user using the **Messages** button on your profile.

	Pink Penguin (e) Member	pink-penguin			Prorum Home Procent Post
0 Followers / 0 Follo	wing			1	≜ 2∘ ≛ ×
Profile	Activity	Favored	局 Subscriptions	Messages	
Username		Pink	Penguin		

This will open the following message box:

	Profile	Activity	Favored	奇 Subscriptions	Messages	
١	Create New Priv	ate Conversation				
	Conversation Title					
1	Conversation Memb	ers				
	Attach file: Choose f	Tile No file chosen			Maximum allowe	d file size is 10MB
Ado	d a Conve	rsation Tit	le			
		To use the	add Convers ername of the en choose fro	ation Member e user you wish m the dropdow	r s , start typing the I to send a message to, Vn list.	
						I

Add your message and click **Send**.

If you would like to turn off private messaging, please email <u>forum@actionforme.org.uk</u> The moderator will action for this for you so you will no longer be able to send or receive private messages.

Reporting posts

The **Report** button can be found in the top right-hand corner of each post. \mathbf{n}

	9 Topic starter		A Rep	ort Ø
	l have started a new hobby of knitting socks, which I am finding really relaxing 🔩			
	l also want to try this lovely pattern, which is free to download §			
Clare Ogden				
(@co-personal)	46	0	C	Ē
Flower arranger	Posted : 19/03/2025 9:56 am			
Topic Tags	• Knitting • socks			

Please use this button if you:

- think a forum user has contravened our forum Terms of Use. A moderator will review the post you have reported and get back to you with a response.
- are worried about the safety or wellbeing of a forum user. For confidentiality reasons, we often can't share how and what we follow up with other users but please assured we act to investigate all concerns.

If you need to repost a user in a private message, click on the people icon, and then the **little wheel** next to their name to bring up the **Report** button.

