

Forum Use (ADSHG_FU_v1-11-25)

Context and Scope

All of our members are given access to the ADSHG Forum: this is in fact a selection of forums, hosted on a platform called Invision Community. ADSHG members are given an account on the platform when they join. The forum is a safe space for our members to support each other and share information. It is very important it is a positive and encouraging community that keeps people accurately informed.

The ADSHG monitors and moderates messages on the forum, but it is primarily a place for our members to connect, and have supportive conversations with each other.

Forum 'House Rules'

By using the forum you agree to follow our Forum House Rules. You also acknowledge that ADSHG cannot be held responsible for content posted on the forum or in personal messages, however, through our rules and moderation, we do our best to keep the forum as pleasant (and safe) as possible.

1. Posting

Things that make our forum a better place to be:

- **Writing in a friendly style, as you would talk face-to-face.** Letting off steam can be understandable, but be careful about how it might make others feel. Post carefully and listen and show support for others.
- **Sharing your own stories** is a good way to show that you understand. Being honest about the reasons you are sharing a story helps others get to know and trust you.
- **Helping others find the conversations they want to join** by posting your topic in the appropriate area. If it is already being talked about somewhere on the forum, post there rather than starting a new thread.
- **Waiting a while before replying to something that makes you angry.** If you feel strongly about a comment, please think through your response before posting. Always consider how someone else may read or interpret your post. If you think someone is being aggressive or contentious, please use the report button to let the moderators know and then ignore the post.

- **Avoiding posting copyrighted material.** Please do not post any material onto the forum that you don't have the rights to. Providing a link or other helpful directions to the content is much safer.

Things that make the forum less supportive and break forum rules:

- **Cross posting** - copying a post across different threads or forum sections to push it back to the top of the 'most recent posts' list.
- **Bumping** - adding to a thread just to push it back to the top of the 'most recent posts' list.
- **Spamming** - promotions and links that add nothing of value.
- **Shouting** - over-using CAPITALS and exclamation marks (!) is very annoying in posts and post titles. Please use bold, italics or underline to stress words in your posts instead.

2. Keeping everyone safe

We do not tolerate abuse of any kind on the forum.

If you think someone on the forum might not be safe, please email us on safeguarding@addisons.org.uk so that our designated Safeguarding Lead can investigate your concerns.

We will listen to the views of anyone who is at risk in deciding what to do, following our [Safeguarding Policy](#) at all times.

Please note that the following types of posts break forum rules:

- **Personal attacks** - Posts that insult, belittle, discredit or are rude to other members, moderators, volunteers, staff, medics or indeed anyone else. It's not helpful and it doesn't make the forum a friendly place.
- **Swearing** - Offensive language (including disguised words) or attempts to avoid filters.
- **Commenting on someone's appearance or other features** - Please keep the forum for discussing life with AD. Even well-intended compliments can be misconstrued or seen as patronising and may be removed.
- **Racism, sexism and other discrimination** - Being unfair or unkind to someone because of their origins, ability, gender, mental health or other factors (it's usually illegal).
- **Content not suitable for family viewing** in posts and personal messages will be removed. Please report any such posts and we will act immediately.



- **Politics and radicalism** – This forum is for chats about life with AD and not political opinions and debates.
- **Inappropriate profile pictures**–Photos that are deemed inappropriate by a moderator will be removed.
- **Use by children** - You must be 16 or over to use the forum (parents of an AD patient may join of course).You can visit [Rare Youth Revolution](#) for young people with rare conditions.

Please visit [Mind's Urgent Help Page](#) or contact [The Samaritans](#) if you feel unsafe or need support with your mental health.

3. Medical matters

ADSHG is proud of the high-quality information it provides around Addison's Disease and adrenal insufficiency and it is important to us that we avoid spreading any misinformation or inaccuracies.

Therefore, please bear in mind that Forum users are not medics.

Some people may write convincingly and even appear to be qualified, but please be wary of “medical advice” in posts or messages and remember that lived experience is personal and individual experience. Always consult your own qualified healthcare professionals to get medical advice.

Please note that the following types of posts break forum rules:

- **Decrying,or advising anyone to ignore a medical professional’s expert advice**
- **Sharing false or misleading information about any matter that may lead to harm or fear.** The forum is not for conspiracy theories or misinformation; these will be removed.
- **Asserting that your experience will apply to everyone with adrenal insufficiency or Addison’s disease can be dangerous.** New patients in particular may not, for example, realise that advice for Primary Addison’s is not always the same for those with Secondary or Tertiary adrenal insufficiency.
- **Diagnosing, or giving the impression that you are medically qualified.** Stick to personal stories and experiences and be clear that you are not qualified to give individual clinical guidance.
- **Encouraging changes to medication,** regime, or health interventions on the basis of articles or research that has yet to be peer-reviewed, ratified by

governing bodies or reviewed by ADSHG medics. Please do share interesting news but we ask you not to advocate change without professional advice.

- **Naming individual healthcare professionals, hospitals or medical practices when being critical.** We understand that our members receive varied input from healthcare services, and we understand that by sharing your experiences, others can learn and support each other. However, please use non-identifying terms like 'my consultant' or 'my nurse' when you share your experience. It can be helpful to note how it might have been better, without getting personal. We should all be aware that we do not always have full context or all the details on the forum.

4. Keeping the forum private

Please be mindful that use of the forum is subject to our [Data Protection Policy](#).

The following actions break forum rules:

- **Revealing anyone else's personal information.**
- **Copying or circulating forum postings outside the forum, in any format, without the posting members express prior written permission.** What is said on the forum stays on the forum.
- **Sharing your log in details with anyone else, or posting on behalf of non-members.** If you are asked by anyone to post on their behalf please decline and contact us for support at enquiries@addisons.org.uk.
- **Using multiple forum accounts or throwaway email addresses** or accounts that impersonate another person. If you suspect a user is posing as someone else, please contact the moderators. We reserve the right to verify a member's identity if necessary.
- **The ADSHG does not allow researchers, journalists, pharma company representatives or clinicians** to register on the forum. Visit our [media centre](#) or [research application page](#) for further information and advice.
- **Direct Messaging:** Whilst our members have the opportunity to send direct messages (DMs) to each other on the forum, we provide clear instructions on how to change the settings on your Inbox to turn off Direct Messaging except from ADSHG Administrators.



ADSHG Moderation of the Forum

Our ADSHG Members' Forum is managed by a group of volunteers, supported by the Operations Team at the ADSHG.

As well as offering their extensive experience and support to forum members through their own posts and comments, they have a key task in ensuring that forum rules are followed, to keep our Forum a pleasant space. The moderating team are not able to edit the content of forum postings on the website so will ask for input from the ADSHG team if this is required.

Please be aware that if the ADSHG team consider that your post has broken the forum rules, it may be hidden.

Moderation is usually completed confidentially through private message with the relevant forum users. Where possible, we will let you know that your message is unacceptable and why. If you have been formally warned in this way more than twice, on the third occasion, your access to the forum may be removed. We may also, if appropriate post advice about the matter on the thread concerned.

Complaints & reporting procedure

We are committed to providing a high quality, accessible and responsive service to our members and the public. However, if you believe that things have gone wrong, or you are unhappy with our moderation actions, then rather than posting complaints on the discussion forums, we ask you to please send your comments in to us by email to opsmanager@addisons.org.uk.

Our team will inform those involved and where needed communicate more widely. We have a small team and we ask for your respect and patience while we investigate and address any rule-breaking. The ADSHG team's interpretation of the forum rules is final.

To protect the privacy of our forum members, we will only discuss moderation matters internally or with the individual(s) concerned and will not provide details to other forum members.

We will try to respond to any complaint within five working days. Please see our [Complaints Policy](#) for further information

Questions about this policy?

You can contact us by email on opsmanager@addisons.org.uk.

Our charity is registered with the Charity Commission in England and Wales (1179825)



Monitoring and Reviewing

This policy will be reviewed every 2 years by the Director, and any updates communicated to staff and volunteers.

Last reviewed Nov 2025