



Together for Short Lives is a UK wide charity, for all children and young people who are expected to have short lives. Together with everyone who provides care and support to these children and families we are here to help them lead as fulfilling lives as possible. We can't change the diagnosis, but we can help children and families make the most of their time together.

The Families Together Facebook Group

The Families Together Facebook group is intended to provide a safe and supportive environment for families. The group is part of the support we offer to families of children with life-limiting conditions. There are many benefits for parents/carers in being a member of The Families Together Facebook Group. These include access to the group whenever is convenient to you, being able to share useful information or tips and having an opportunity to talk to others in similar caring roles. To ensure everybody's safety and wellbeing we have a few ground rules.

Principles of the Families Together Facebook group:

- This group is more than just a group, it is a community: All members treat each other with compassion and understanding.
- What is shared in the group stays in the group: all information shared in the group is confidential.
- When responding to a post please ensure your comments are positive, supportive and empathetic.

By joining the Families Together Facebook group you are agreeing to uphold these principles and stick to these guidelines. Failure to follow the principles/guidelines will result in an informal reminder. Persistent failure may result in removal from the group.

The group is managed through Facebook, and is what Facebook calls a 'secret' group. This means that new members have to be added by an administrator, and only members can see posts on the group, the group name and group members. The group will not be visible in a Facebook search.

To join the group, you must first be a member of the Together for Short Lives family community. Membership is at the discretion of Together for Short Lives. If you know someone who would like to join the group, please ask them to visit the Together for Short Lives website to sign up.



The Facebook group is associated with Together for Short Lives and we therefore reserve the right to remove any posts/members that violate the group guidelines or create an atmosphere contrary to the intended supportive environment.

Feedback from members is welcomed and encouraged through the appropriate channels. Any member with comments, complaints or concerns should email families@togetherforshortlives.org.uk. Please do not post them directly on the group wall; they will be removed as they do not contribute to a supportive environment.

Posting Guidelines

Information in the group

Members of the Families Together group provide most of the information in the group. The person who posts

the material remains solely responsible for it. Please note that views shared on the group do not necessarily reflect those of Together for Short Lives, and Together for Short Lives takes no responsibility for what is posted. Information presented on the group should be for general use only - please refrain from providing personal medical advice to other group members - you should always seek the opinion of a health professional. If you have an urgent medical enquiry we recommend that you contact your GP, call 111 or in the event of an emergency call 999 or attend A&E.

Please also note, the Families Together Facebook group is not a place to advertise your business, so please refrain from attempting to sell anything on our page, or promote your business or other commercial organisations on this page.

We also ask that you please refrain from using the Facebook group to fundraise. Please note that posts of this nature will be removed.

Posts

The group is for families to share information, access mutual support and to keep up to date with Together for Short Lives activities.

This group is provided by Together for Short Lives to create a safe and supportive environment for families. You may want to post for a variety of reasons: to share information you think will be of interest to the community, to share your own daily experiences, or to reach out for support and reassurance when you need it.

We encourage group members to post to the group as they see fit, but please do so in a spirit of respect for other members. The guidelines below give more information on this.

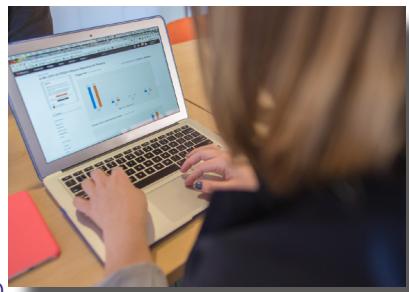
Maintaining a positive group atmosphere

The Families Together group has a zero tolerance policy to any form of negative, critical, jealous, bullying or argumentative comments or posts.

Respectful Posting

Things posted on Facebook can easily be taken the wrong way. With a large group of members, it is likely that you will not always agree with everyone. In order to maintain a supportive environment in this group we encourage all members of this group to self-moderate and to be conscious of their posts, replies and feelings of others. By joining the Families Together Facebook group you are agreeing to only make supportive, positive and understanding comments on other people's posts.

We acknowledge that sometimes you may want to post about an experience that is difficult for you or that you are having a bad day. The Families Together Facebook group is a safe space for you to do that. The group is a secret group and so only other parents in a similar situation to yourself can read your message.



Appropriate content

Please keep all your posts relevant and appropriate to your experience of raising a child with a life-limiting condition - this includes issues that relate to your role as a carer and wider family issues including siblings and relationships.

Confidentiality

This is a 'secret' group. This means only members can see what is posted in it. It is not acceptable to cut and paste, share any personal details, information or photos that other members have shared outside the group. Some of you may know each other outside of the group in the 'real world'. Please remember that information shared in the group still remains confidential and you should not share any information with mutual friends etc.

Failure to keep information shared in the group confidential may result in removal from the group.

Protect yourself on Facebook

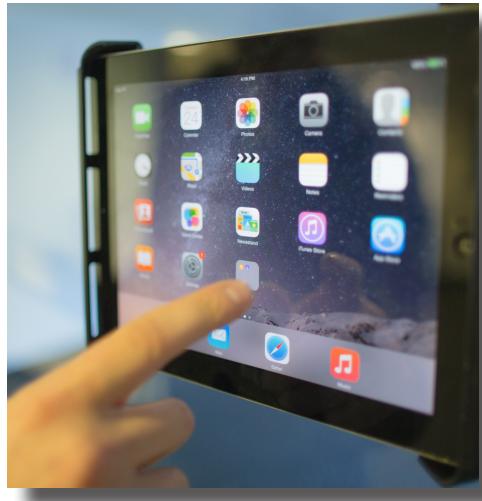
Please be aware of your privacy settings on Facebook and set them to a level you are comfortable with. Together for Short Lives has produced some guidance on this, please see attached.

Images/photographs

It is the responsibility of all group members to protect their own privacy and we would ask that you are mindful of this.

Under no circumstances are pictures of a pornographic or offensive nature to be posted.

Please note that it is an offence to make copies of an illegal image. Please report any concerns about images/videos to families@togetherforshortlives.org.uk and the administrators will deal with it appropriately.



Confidentiality and Safeguarding

Together for Short Lives will never share your personal details, or details about the subject of your posts, except where there is deemed to be a significant risk of harm to a child and we are required to share information according to our safeguarding and child protection policy.

Posts that violate the group guidelines

The group will be monitored and moderated by administrators, who are members of staff or volunteers for Together for Short Lives. This moderation is not available 24/7, however unsuitable posts will be removed in a timely manner.

At times issues may arise within the group. You may see a post you don't agree with, that concerns you or that you think is inappropriate. Should this occur, please contact Together for Short Lives directly and we will look in to it – if possible take a screen shot and email to families@togetherforshortlives.org.uk.

Please do not comment on the post, or post something that refers to it, as this is likely to inflame the situation further. You can help the situation by 'liking' or commenting on other posts so that the post causing concern moves down the wall and is less likely to have a negative impact on the group atmosphere.

- If a post concerns you, don't comment, report it
- If a post is inappropriate, don't comment, report it
- If a post is negative, critical or bullying, don't comment, report it

Members that violate the group guidelines

Members who violate the group guidelines will, in the first instance, be informally reminded of the guidelines by a member of Together for Short Lives staff.

Anyone who continues to/persistently violates the guidelines may be removed from the Families Together group.

If your post is removed and you wish to discuss this further, please email families@togetherforshortlives.org.uk. Please do not post it on the group wall - it will be deleted as Together for Short Lives will not enter into any discussions of this nature on the group wall. This is to ensure a positive environment is maintained and protect all members from animosity from other members.

Discussing services/professionals

All members will have different experiences of services and professionals they work with. All views are equally valid and whilst at times people may want to express their frustration, please remember to keep the tone of the group open and positive.

The Families Together group is not a space for general condemnation of professionals and services. Any such post will be removed. If you wish to share your experience with a particular professional, then please keep the professional's identity anonymous.

Moderators

The role of the moderators includes:

- Welcoming new members and encouraging them to introduce themselves and their family.
- Helping manage the group wall and bump up posts that haven't had a response yet/bring them to the attention of Together for Short Lives staff.
- Helping Together for Short Lives staff keep track of any important issues/themes arising on the group wall.
- Helping to maintain a positive group atmosphere by notifying staff of any posts that violate the group guidelines.
- Sharing information from Together for Short Lives across the group.

If you would like to become a moderator of the Families Together group, please email families@togetherforshortlives.org.uk.

We hope the group will provide a safe space in which you can share your experiences and connect with other families.

