

## Parent Support Groups

At Together for Short Lives, we know families often appreciate support from professionals and other families who understand their situation. This factsheet provides information and contact details for some helpful charities and support groups for families with experience of looking after a seriously ill child. We've grouped them into general support groups and those supporting families with specific conditions.

### General support groups

These are groups that support families regardless of their condition.

#### Together for Short Lives - Online support group

The Together for Short Lives family Facebook group is a supportive community where people with experience of caring for a seriously ill child can connect with other families.

WEB: [www.togetherforshortlives.org.uk/familyfacebook](http://www.togetherforshortlives.org.uk/familyfacebook)

#### Camp Simcha - Parent support

Camp Simcha is a Jewish charity that offers counselling for parents and siblings who are struggling to cope emotionally with their child or sibling being seriously ill. To find out more about what they offer, email their team or head to their website.

EMAIL: [office@campsimcha.org.uk](mailto:office@campsimcha.org.uk)  
WEB: [www.campsimcha.org.uk/our-services/support-groups-and-therapy](http://www.campsimcha.org.uk/our-services/support-groups-and-therapy)

#### Children of Jannah - for bereaved parents of Muslim faith

**Private online groups:** Children of Jannah runs private Facebook groups, allowing bereaved parents to share their feelings and fears in a safe, online environment.

**Life after Loss meetings:** Facilitated by specially trained Life After Loss staff, ring bereaved parents together through mutual support. The facilitators work through five areas of bereavement over the course of five two-hour sessions in a safe, secure environment.

EMAIL: [info@ChildrenofJannah.com](mailto:info@ChildrenofJannah.com)  
WEB: <https://childrenofjannah.com/how-we-can-help/>

#### Children's Hospice Services across the UK

Children's Hospices across the UK offer support for families looking after a seriously ill child, and for those who are bereaved. Find your local children's hospice in the Together for Short Lives service directory.

WEB: [www.togetherforshortlives.org.uk/findaservice](http://www.togetherforshortlives.org.uk/findaservice)

## Contact - Local and national groups

Contact, a charity for families with disabled children, runs a number of local and national support groups. Some professionals and organisations, particularly children centres, run their own groups. Find your nearest one on their website.

WEB: [www.contact.org.uk/advice-and-support/parent-support-groups](http://www.contact.org.uk/advice-and-support/parent-support-groups)

## Family Lives - Local groups

Family Lives' vision is that all families should have access to active support and understanding. They offer parenting and relationship support groups across the UK.

WEB: <https://www.familylives.org.uk/how-we-can-help/in-your-area/>

## Grandparents Plus - Local groups

Grandparents Plus is the national charity working for all families where grandparents play a vital role in the development of their grandchildren. They run local support groups for kinship carers - relatives or friends who look after a child when their parents aren't able to.

WEB: [www.grandparentsplus.org.uk/Pages/Category/support-groups](http://www.grandparentsplus.org.uk/Pages/Category/support-groups)

## Rare Connect - Online platform

A safe, easy to use platform where individuals, families and patient organisations can develop online communities and have conversations across continents and languages. RareConnect partners with the world's leading rare disease patient groups to offer global online communities.

WEB: [www.rareconnect.org/en](http://www.rareconnect.org/en)

## SWAN - Support network

SWAN (Syndromes Without A Name) is the only dedicated support network available for families of children and young adults with undiagnosed genetic conditions in the UK. Find out more about becoming a member by emailing SWAN on the address below.

EMAIL: [joinus@undiagnosed.org.uk](mailto:joinus@undiagnosed.org.uk)  
WEB: [www.undiagnosed.org.uk](http://www.undiagnosed.org.uk)

## Condition-specific support groups

**These are groups that support families whose child has a specific condition.**

## Batten Disease Family Association - online support group

The Batten Disease Family Association (BDFFA) is a national charity supporting families affected by Batten Disease. They run a private online support group for families, which can be accessed by calling their support line.

TEL: 0800 046 9832  
WEB: [www.bdfa-uk.org.uk](http://www.bdfa-uk.org.uk)

## CLIC Sargent - Online support group

CLIC Sargent is the UK's leading cancer charity for children, young people and their families. Their Facebook group "CLIC Sargent parents and carers" helps families:

- Connect with other parents and carers
- Share information and tips
- Find out about opportunities to get involved with CLIC Sargent
- Share views on different topics

FB: <https://www.facebook.com/groups/1449201121810524/>  
WEB: [www.clicsargent.org.uk](http://www.clicsargent.org.uk)

## CLIC Sargent - Online support group for dads

CLIC Sargent also runs a Facebook support group aimed at dads whose children are facing cancer. Dads can use the group to:

- Share experiences and offer peer support
- Ask questions and give tips on practical issues
- Share views and experiences to feed into the wider work of CLIC Sargent
- Find out about what's going on and how you can get involved

FB: <https://www.facebook.com/groups/1723917634285056/>  
WEB: [www.clicsargent.org.uk](http://www.clicsargent.org.uk)

## Cystic Fibrosis Trust - Peer to peer support

The Cystic Fibrosis Trust is the UK's only national charity dealing with all aspects of Cystic Fibrosis (CF). Their new service, CF Connect will put you in touch with a trained parent volunteer who you can talk to in confidence about having a child with Cystic Fibrosis. To connect with another parent call their helpline or send an email.

TEL: 0300 373 1000  
EMAIL: [helpline@cysticfibrosis.org.uk](mailto:helpline@cysticfibrosis.org.uk)  
WEB: [www.cysticfibrosis.org.uk](http://www.cysticfibrosis.org.uk)

## Epilepsy Action - Peer to peer support

Epilepsy Action is a charity supporting individuals and families impacted by epilepsy and seizures. They have a parents supporting parents programme where you can link up with other families affected by epilepsy. See also "West Syndrome support group" and "UK Infantile Spasms Trust" on this factsheet.

WEB: <https://www.epilepsy.com/living-epilepsy/parents-and-caregivers/parents-helping-parents>

## Kids Cancer Charity - Befriending service

Kids Cancer Charity is a national charity that supports children with cancer and their families. They run a befriending service and support groups. Call or email to enquire about support available in your area.

TEL: 01792 480500  
EMAIL: [enquiries@kidscancercharity.org](mailto:enquiries@kidscancercharity.org)

## Metabolic Support UK - Metabolic Connect

Metabolic Support UK is the leading umbrella patient organisation for all inherited metabolic disorders. Their service Metabolic Connect brings patients and families together to share experiences and provide support and friendship.

WEB: [www.metabolicsupportuk.org/metabolic-connect](http://www.metabolicsupportuk.org/metabolic-connect)

## Muscular Dystrophy UK - Local muscle groups

Muscular Dystrophy UK is the charity for the 70,000 people living with muscle-wasting conditions in the UK. Their Muscle Groups give young people and their families the opportunity to meet regularly to talk about the things that matter to them.

WEB: <https://www.muscular dystrophyuk.org/get-the-right-care-and-support/local-muscle-groups/>

## Spinal Muscular Atrophy UK - Online communities & sharing experiences

Spinal Muscular Atrophy UK gives support and information to those living with SMA and their families. Their website lists a series of support groups set up by people in the SMA Community.

WEB: <http://www.smasupportuk.org.uk/online-sma-communities>

- **Sharing Experiences:** The charity also has a Sharing Experiences page on their website, offering a range of ways to link up and share information, tips and experiences with other people affected by SMA

WEB: <https://smauk.org.uk/sharing-experiences-page>

## UK Infantile Spasms Trust - Online support group

The UK Infantile Spasms Trust (UKIST) provides a network of support to families with children affected by the rare seizure disorder infantile spasms, also known as West syndrome. They run a Facebook support group for affected families. See also “Epilepsy Action” and “West Syndrome Support Group” on this factsheet.

FB: <https://www.facebook.com/groups/1600888383553097>

Web: [www.ukinfantilespasmstrust.org](http://www.ukinfantilespasmstrust.org)

## West Syndrome - Support Group

The West Syndrome Support Group is run by parents and offers support and a sympathetic ear to families of children affected by West Syndrome. See also “Epilepsy Action” and “UK Infantile Spasms Trust” on this factsheet.

TEL: 01252 654 057

## Can't find what you're looking for?

If you can't find a support group that's right for you on this factsheet, we would recommend that you seek advice from the national charity Contact, which provides information on the many support groups around the country:

**[www.contact.org.uk](http://www.contact.org.uk)**  
**0808 808 3555**

## Get in touch

[www.togetherforshortlives.org.uk](http://www.togetherforshortlives.org.uk)

[info@togetherforshortlives.org.uk](mailto:info@togetherforshortlives.org.uk)

08088 088 100 (helpline)

0117 989 7820 (main phone number)

## Call our helpline

If your child has a life-threatening illness and you want support, we're here to help.



**0808 8088 100**

Our helpline provides information and listening support for families with experience of caring for a seriously ill child. We're open 10am-4pm Mon-Fri. Outside these hours, you can leave a message or email [info@togetherforshortlives.org.uk](mailto:info@togetherforshortlives.org.uk).