

Family Factsheets

Factsheet 1

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

There are groups that support families regardless of their child's condition.

Together for Short Lives' Facebook 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.

<https://www.facebook.com/groups/1270199326332286>

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.

<https://contact.org.uk/help-for-families/information-advice-services/local-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.

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

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.

<https://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.

joinus@undiagnosed.org.uk
www.undiagnosed.org.uk

Kinship

Kinship provides support for all kinship carers. In addition to their peer support groups they also have a scheme called "Someone Like Me" – a volunteer delivered peer support service.

www.kinship.org.uk/peer-support-for-kinship-carers/

Camp Simcha - parent support

Camp Simcha exists to make a difference to all Jewish children and their families across the spectrum of Jewish observance. They offer 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.

office@campsimcha.org.uk

<https://www.campsimcha.org.uk/get-support/how-we-support/groups/parents/>

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, bringing 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.

info@ChildrenofJannah.com

<https://www.childrenofjannah.com/>

Children's Hospice Services and other charities

Children's Hospices and other children's palliative care charities across the UK offer support groups for families looking after a seriously ill child, and for those who are bereaved. Find details of these in the Together for Short Lives service directory.

https://www2.togetherforshortlives.org.uk/_portal/public/volunteer/

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 (BDFA) 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.

0800 046 9832

www.bdfa-uk.org.uk

Young Lives vs Cancer- online support group

Young Lives vs Cancer have different groups for young adults, parents and carers, bereaved families and dads:

<https://www.younglivesvscancer.org.uk/what-we-do/day-to-day-support/join-our-facebook-groups/>

They also have a helpline and live chat if you have a question about support groups in your area:

You can either message on Live Chat, call on 0300 303 5220 or email at getsupport@younglivesvscancer.org.uk.

Cystic Fibrosis Trust - Peer to peer support

The Cystic Fibrosis Trust is a national charity dealing with all aspects of Cystic Fibrosis (CF). Their 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.

0300 373 1000
helpline@cysticfibrosis.org.uk
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.

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

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, provide support and friendship.

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.

<https://www.muscular dystrophyuk.org/get-support/muscle-groups>

Sands

Sands is the leading stillbirth and neonatal death charity in the UK. They have a countrywide network of over 104 local support Groups, usually run by bereaved parents and family members, offering parents the chance to meet others, gain support and share experiences.

<https://www.sands.org.uk/support-you/how-we-offer-support/sands-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.

<https://smauk.org.uk/connect-with-others>

UK Infantile Spasms Trust - Online support group (UKIST)

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 which you can access via the link below. See also "Epilepsy Action" and "West Syndrome Support Group" on this factsheet.

<https://ukinfantilespasmstrust.org/contact/>


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.

01252 654 057

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 Like Together for Short Lives on Facebook at www.facebook.com/togetherforshortlives

 Follow Together for Short Lives on Instagram @togetherforshortlives

Call our helpline or chat via live chat

www.togetherforshortlives.org.uk

helpline@togetherforshortlives.org.uk

Helpline: 0808 8088 100

Live chat:

www.togetherforshortlives.org.uk

Our helpline and live chat 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 helpline@togetherforshortlives.org.uk.

**Helplines**
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