

*“Thank you for your support”*

**Only together, can we beat brain tumours!**

**We rely 100% on voluntary donations**

Blue Skye Thinking is a charity supporting research so that all children diagnosed with brain tumours will have a better chance of survival and a better quality of life post-treatment.

Although research is our primary area of support, we also plan to take a touring Musical Puppet and Magic Show to all Children's Oncology and Surgical Wards in the hope to provide some entertainment and smiles.

If you know someone who is keen to support you or the vital work we do, please give them a copy of this leaflet.

For inspiration on fundraising ideas please visit our website.

You can donate online at [blueskyethinking.org/donate](http://blueskyethinking.org/donate)

If you have any questions please do get in touch:

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Find us on



BLUE SKYE THINKING

*“If there is anything I can do just ask...”*

A practical guide for friends & family wanting to offer support to parents of sick children

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**SUPPORTING RESEARCH & TREATMENT OF CHILDHOOD BRAIN TUMOURS**

Registered Charity No. 1158021



[www.blueskyethinking.org](http://www.blueskyethinking.org)

“If there is anything I can do, just ask...”

It's what friends and family say to each other in times of crisis, right? So why is an offer of help, generally not met with a long list of what can actually be done?

In the case of the parent of a child with a serious illness, like a brain tumour, it's probably because you are asking the overwhelmed, embarrassed and exhausted to think further than what will immediately help their child.

Here's a practical list to support those you care about in times of need

- ★ **Text or email often.** Let us know you care; we do read messages and they mean a lot but we don't always have the ability to reply so please don't expect or feel hurt if you don't get a response.
  - ★ **Be specific with offers of help.** Think of three things you could do i.e. take care of a sibling for the afternoon, clean the house, cook a meal, so all we need to do is answer "yes please".
  - ★ **Offer to be a point of contact among friends / family.** To pass on the current situation and progress, it is helpful to know one phone call or email can reach everyone concerned.
  - ★ **Visit.** It may be daunting and you may feel like you don't know what to say but visits from the outside world are sometimes what get us and our children through each day. Not only the visit itself and the practicalities of what you can bring in, but the anticipation can fill our child's mind and keep it from straying onto less pleasant things.
- When you come in, remember:**
- Only come if you are 100% well and have not been in contact with anyone with chicken pox or received a recent live flu vaccine.
  - Bring in fresh food, fruit and veg, a home made meal and homemade treats (all wards have microwaves). Bring in activities (if appropriate), as many children need even more entertaining than normal to keep them occupied. If possible, check if there is anything specific that is required from the outside world. Whims change rapidly and need to be fulfilled.
  - Stay for as long or as short a time as is needed. Short visits may sometimes be required (little and often) however medics may often interrupt visits. Don't take this as your green light to leave; offer to pop back in 10 minutes. Give us time. It is sometimes handy to visit in pairs so one person can stay with our child and the other can be there for us.
  - Visit often. Please don't feel like you have 'done your bit' by visiting once, we need your love and support over a long period of time, more so after the initial flurry of help.

- ★ **Arrange a food rota.** Among local friends/family take it in turns to prepare a home cooked meal either during hospital stays or even during stints at home. Delegate one person who organises everyone else (please don't expect us to). Doodle Cal is very useful for this. Remember to use disposable containers. [Find recipe ideas on our website!](#)
- ★ **Gifts.** We will almost always state we need nothing and of course all we really want is for our children to be better but well-thought-through, practical gifts that a group of people have chipped in to buy not only demonstrate how much you care, but can prove very useful. Here are some examples:
  - Portable DVD player and box sets – for our children during the day but us at night as the nights can be very long and escapism is sometimes required.
  - Masticating Juicer - more for use at home, but feeding becomes the hot topic of conversation amongst parents on the ward. We are all desperate to offer our children a healthy diet but sometimes encouraging them to eat 'anything' is considered a tremendous success. With the help of juicers, all sorts of food can be juiced and hidden in other foods or turned into lollies, which are sometimes more readily taken. They are a fun gadget for older children and provide an easy way of packing in the goodness for the whole family.
  - Small Coffee Machine - this is more useful for long periods of time in isolation rooms as it is not always possible to leave to grab a caffeine fix. Most wards also do not allow hot drinks to be carried across the ward in open mugs.
  - Hand cream or moisturiser - it is part of the process to neglect ourselves.
- ★ **Help your children to make video messages and drawings to send in.** Our children miss their friends and love to see familiar faces. They could perhaps record a joke or show themselves making something they then send in.
- ★ **Don't be needy or over-sensitive.** These are impossibly hard times. We need to give 100% of ourselves to our children and we don't have anything left for anyone else. We need you to be unwavering in your support.
- ★ **Try to empathise.** It is natural to say "I can't imagine what you are going through" and of course you can't but you can try. Listen and remember what we tell you about treatment plans and remember important procedural dates. Write them down if necessary or look up medical terms so we feel you want to be on the journey with us. If you choose to do your own investigations for other similar case studies / treatment options, be mindful that every case may appear the same but can be very different and while increased knowledge can prove exceptionally useful, ask first if we want you to share it and then ideally provide a list of links to a variety of different credible sources with no further personal comments or opinions.
- ★ **Fundraise.** There are many charities such as Blue Skye Thinking, which rely solely on fundraising, which sadly often comes as a reaction to someone close to us suffering. Some families might want you to fundraise directly for them and their child, but most just want to give something back and to be part of improving further, the support already in place. Either way, only good can come from funding further research and treatment. The very act of fundraising in honour of a particular child demonstrates good will and love. Ask first, but don't expect too much input. If you are given the green light then try to keep all the admin away from us as parents. Just tell us what you raised and know that even if we don't say so, we are grateful.

Do any of these things and we will be immensely grateful that you have made the lives of our children a little better and shown you care. Thank you!

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