



Best interests

Support resources



Since Together for Short Lives became aware that Best Interests was to be broadcast, we have been speaking to the producers of the programme to help prepare the children's palliative care sector and our partner organisations for any impact on services or on audiences and families with children who have life limiting or life-threatening conditions.

We have produced this list of resources to support you in your work and/or when working with families who may need extra support or wish to read further. The resources are separated by theme and audience.

Media support

During the run of the series, the Together for Short Lives media team will be on hand to support you with any media enquiries you

would like help with. Please do contact Alex Holdaway, Head of Brand and PR:

alex.holdaway@togetherforshortlives.org.uk
07463239350

Support from Together for Short Lives

Family Support Hub

Together for Short Lives' Family Support Hub provides support and information for families who are caring for the most seriously ill children across the UK. Through our helpline, we provide information, a listening ear and can assist in finding support locally.



0808 8088 100



togetherforshortlives.org.uk



helpline@togetherforshortlives.org.uk

Withdrawing life support

For families	For professionals
For emotional support – the Together for Short Lives helpline	Caring for a child at end of life – a guide for professionals on the care of children and young people
Peer to peer support – Facebook community	RCPCH - The second opinion process - external second opinions in paediatrics RCPCH
End of Life Guide for Families	RCPCH - Making decisions to limit treatment in life-limiting and life-threatening conditions in children
Medical Mediation Foundation	NHS England - Conflict Management
NHS – Withdrawing treatment	GMC - Neonates, children and young people
Ombudsman	GMC - Ethical guidance
NHS - How to raise a concern or complaint	

Siblings

For families	For professionals
Together for Short Lives – Sibling Factsheet	Sibs - supporting siblings for professionals
Sibs charity – for brothers and sisters of disabled children and adults	
CBUK - Telling a child somebody has died	
Sibling Support	
Being a young carer - Your rights (NHS)	

Ethics committees and complaints

For families	For professionals
Complaints/ raising concerns with the NHS	Practical guide to clinical ethics support
Healthwatch - Support for families when making a complaint about an NHS service from Healthwatch	Towards developing an ethical framework for decision making in long-term ventilation in children
CQC – making a complaint E-mail: enquiries@cqc.org.uk Website: www.cqc.org.uk	Treatment and care towards the end of life: good practice in decision making
	Making decisions to limit treatment in life-limiting and life-threatening conditions in children: a framework for practice

Impact on families/maternal health

For families	For professionals
For emotional support – the Together for Short Lives helpline	Talk to us about how to support a family you are caring for
Together for Short Lives' peer-to-peer support - Facebook community	Caring for a child at end of life – a guide for professionals on the care of children and young people
End of Life Guide for Families	
When a child dies	
Winston's Wish	
Child Bereavement UK	

Financial support for families

[The Together for Short Lives Family Support Hub can support families with the financial implications of caring for a seriously ill child](#)

[Debt advice](#)

[Benefits support](#)

[Citizen's advice](#)

[Family Fund](#)

Some additional reading:

[Together for Short Lives' submission to the Nuffield Council on Bioethics \(NCoB\) government-commissioned review into disagreements between professionals and parents of critically ill children.](#)

[Nuffield-Literature-Review-FINAL-Disagreements-in-the-Care-of-Critically-Ill-Children-Causes-Impact-and-Possible-Resolution-Mechanisms.pdf \(nuffieldbioethics.org\)](#)

[Child and Young Person's Advance Care Plan Collaborative \(CYPACP\)](#)