

together for short lives

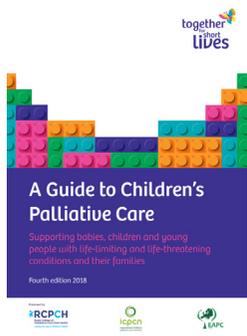


"It saves me time that I could have spent searching research databases which means I have more time to actually read the articles or spend with families."

"Being able to access this guidance and support easily via the website and regular bulletins is invaluable and provides a refreshing alternative to the sea of complex information that surrounds our sector."

Publications catalogue

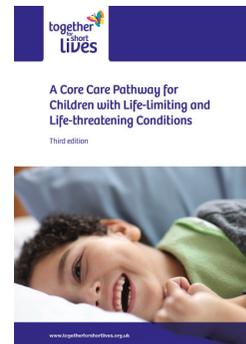
Resources for professionals - available to download or order



A Guide to the Development of Children's Palliative Care Services (4th edition 2018)

The Guide sets out the Together for Short Lives vision for the future sustainable development of children's palliative care, ensuring that the best quality care and support is available to all the children, young people and families that need it.

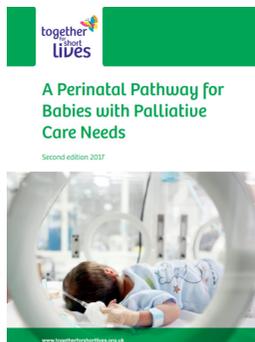
www.togetherforshortlives.org.uk/theguide



A Core Care Pathway for Children with Life-limiting and Life-threatening Conditions (2013)

The Care Pathway is the children's palliative care sector's 'gold-standard' guide for professionals planning and delivering care to a child with a life-limiting or life-threatening condition and their family.

www.togetherforshortlives.org.uk/corecarepathway



Perinatal Pathway for Babies with Palliative Care Needs (2017)

The Perinatal Pathway for Babies with Palliative Care Needs is to support professionals to help families with seriously ill babies have more choice in their child's care and the best experience and memories of their baby, no matter how short their life may be.

www.togetherforshortlives.org.uk/perinatalpathway



Stepping Up (2015)

A guide to enabling a good transition to adulthood for young people with life-limiting and life-threatening conditions is our care pathway for teenagers and young adults with life-threatening, life-limiting or complex medical conditions.

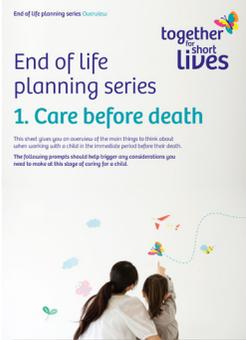
www.togetherforshortlives.org.uk/steppingup

Terms and conditions apply:
Together for Short Lives
reserve the right to charge
a discretionary amount on
postage and packaging for
large orders.



Basic Symptom Control in Paediatric Palliative Care (2013)
 A key clinical tool used by children's palliative care doctors and nurses across the world. It is the only resource of its kind that provides comprehensive guidelines for treating a wide range of symptoms experienced by children with life-limiting or complex health conditions.

www.togetherforshortlives.org.uk/symptomcontrol



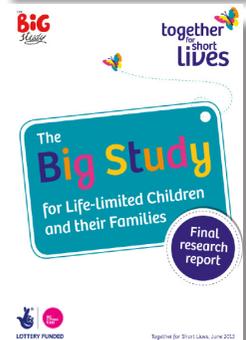
End of life planning prompt sheets (2012)
 These End of life prompts pull out the key elements from each chapter of A Guide to End of Life Care. The prompts are designed to be used in practice for easy reference to help practitioners make sure they have covered every aspect of care, with the more detailed guide being intended for more in-depth study.

www.togetherforshortlives.org.uk/promptsheets



Making a difference for young adult patients (STAPP resources 2013)
 A research briefing and set of practice prompts present key findings from a national study on health care transitions for young adults with significant, and potentially life-limiting conditions. For professionals and those with responsibility for transition from paediatric to adult care.

www.togetherforshortlives.org.uk/STAPPproject



The Big Study reports (2012/13)
 The Big Study involved collaboration with five academic institutions. Each academic partner pursued a different strand of enquiry to research how well the palliative care needs of children with life-limiting conditions and their families were being met by services in the West Midlands.

www.togetherforshortlives.org.uk/bigstudy



A Care Pathway to Support Extubation within a Children's Palliative Care Framework (2011)
 This resource aims to support extubation and to complement our three pathways for babies, children and young people. It can be drawn on at any time during the child's journey; once it has been recognised that continued invasive and aggressive treatment is not in their best interests.

www.togetherforshortlives.org.uk/extubationpathway



Guide to end of life care (2012)
 This resource provides information and recommendations for end of life care of the child across the sector regardless of setting. It focuses on principles of best practice in the care of the child and family before death, at the time of death, and after death.

www.togetherforshortlives.org.uk/endoflifecare



Medicines Management Toolkit (2014)
 The second edition of the Medicines Management Toolkit gives guidance for those working within children's palliative care services across the UK, with information on improving the safety and quality of medicines management.

This resource is under review and currently unavailable



Standards framework for children's palliative care (2013)
 This sets out the key standards that form the back bone of our four care pathways. It also includes self-assessment audit tools, so you can map how your service performs and think about how to develop the areas where the standards are not fully met.

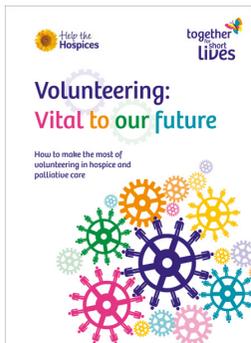
www.togetherforshortlives.org.uk/standardsframework



The Diversity Toolkit (2010)

This toolkit was developed to help children's hospice services to address the challenges and barriers faced in delivering services to children, young people and families from diverse communities.

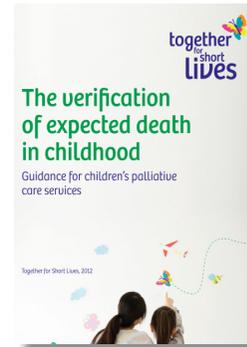
www.togetherforshortlives.org.uk/diversitytoolkit



Volunteering: Vital to our future (2014)

Designed to support organisations in the hospice and palliative care sector to develop their work with volunteers. It explores the role volunteers can play in enhancing and improving the care and support of children and adults with palliative care needs, as well as their families. It also provides a wealth of case studies, practical tools and templates.

www.togetherforshortlives.org.uk/volunteeringguide



The verification of expected death in childhood (2012)

Providing detailed information on the process and issues surrounding this subject, with the aim of building confidence and expertise of practitioners who may not have a great deal of experience with this procedure.

www.togetherforshortlives.org.uk/verification



Together We Can (2017)

Together We Can is a collection of resources for organisations developing a service where volunteers support families of a child with a life-limiting or life-threatening condition. The resources were developed and tested specifically for this purpose, but might be useful for any organisation developing volunteer services.

www.togetherforshortlives.org.uk/togetherwecan

We also produce regular newsletters for professionals - free and exclusively available to members of Together for Short Lives

e-bulletin

The Together for Short Lives e-bulletin is sent out monthly, and provides news about Together for Short Lives and the wider children's palliative care sector as well as links to job opportunities and upcoming events. It is aimed at professionals working in children's palliative care, and anyone can sign up for free www.togetherforshortlives.org.uk/ebulletin

e-xChange

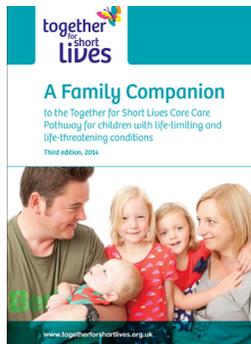
The monthly children's palliative care news roundup for Together for Short Lives members, sharing our members' news and good practice, policy updates and opportunities to contribute to consultations. Find out more about Membership at Together for Short Lives www.togetherforshortlives.org.uk/members

Synopsis

Synopsis contains hundreds of research abstracts drawn from as many medical, nursing and social care journals as possible. It captures the key research relevant to children and young people's palliative care. It is also available as a fully searchable abstract collection on the Together for Short Lives website www.togetherforshortlives.org.uk/synopsis

If you would like to know more about any of these newsletters and how you can make the most of your membership, email membership@togetherforshortlives.org.uk. Sign up for membership or find out more at www.togetherforshortlives.org.uk/join

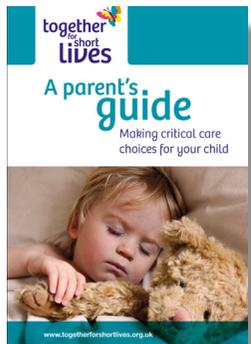
Resources for families - available to download or order



A Family Companion (2014)

This Companion is for family members of children and young people who have been diagnosed with a life-limiting or life-threatening condition and acts as a step by step guide through the complex and often confusing processes that take place following diagnosis.

www.togetherforshortlives.org.uk/companion



A Parent's Guide: Making critical care choices for your child

This leaflet has been developed for parents, carers or legal guardians who care for a child with a life-limiting or life-threatening health condition. It has been written to support you whilst you are thinking about the critical care options for your child.

www.togetherforshortlives.org.uk/parentsguide



Together for Short Lives Charter

The charter focuses on the types of information and support Together for Short Lives believes families should expect to receive. It emphasises the importance of choice for families, and encourages a joined up approach from all services and professionals involved.

www.togetherforshortlives.org.uk/charter



Family factsheets

We produce a wide range of family factsheets designed to provide key information in bitesize chunks. Factsheets range from Understanding Siblings' Needs to Emotional Support and Counselling.

www.togetherforshortlives.org.uk/familyresources

Family factsheets

A list of all family factsheets available to download and order for free

- A family guide to the SEND system in England
- A young person's guide to Personal Budgets
- Aids and equipment
- Assistive technology
- Benefits
- Care planning in advance
- Charities for children with cancer
- Children's palliative care definitions
- The child death review process (England)
- Children's hospice services
- Difficult conversations for young adults
- Emotional support and counselling
- End of life planning
- Grants and wishes
- Making a complaint (England, Scotland, Wales, Northern Ireland)
- Making critical care choices for your child
- The Mental Capacity Act
- Moving to adult services: what to expect
- Parent support groups
- Short breaks and holidays
- Spiritual religious and cultural wishes
- Talking with your child about their life-limiting condition
- Transport



My Care Transfer (2018)

My Care Transfer is a bespoke digital platform designed to help families looking after seriously ill children to communicate effectively with care professionals. It is particularly useful for those making the transition to adult services.

www.togetherforshortlives.org.uk/mycaretransfer



A checklist to a good transition (2018)

Generously supported by the Bupa UK Foundation, 'A checklist to a good transition' is designed for seriously ill young people to assess how well agencies involved in their education and care are working together to enable a smooth transition.

www.togetherforshortlives.org.uk/transitionchecklist



Subscribe to Together for Families to receive up to date information about support and services, government policy and other relevant charities that can help you.

The triannual newsletter also features real life stories from other parents who have children who may not reach adulthood.

If you would like to know more about our family newsletter or sign up to receive your copy for free, visit:

www.togetherforshortlives.org.uk/togetherforfamilies

To access our resource library, which includes external resources, visit: www.togetherforshortlives.org.uk/resources



Together for Short Lives

T: 0117 989 7820 | E: info@togetherforshortlives.org.uk

www.togetherforshortlives.org.uk

Registered charity in England and Wales (1144022) and Scotland (SC044139).
Co limited by guarantee 7783702.