# **Publications - for professionals**

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#### A Guide to Children's Palliative Care

people with life-limiting and life-threatening conditions and their families

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Fourth edition 2018

lives

**RCPCH** 



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





#### • A Guide to Children's Palliative Care

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.



#### Core Care Pathway

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 lifethreatening condition and their family.



#### • Caring for a child at end of life

Caring for a child at end of life aims to provide a practical toolkit for all practitioners providing end of life care to babies, children and young people.





together lives

A Perinatal Pathway for Babies with Palliative Care Needs



• Perinatal Pathway for Babies with Palliative Care Needs 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.





Stepping Up A guide to enabling a good transition to adulthood for young people with life-limiting and life-threatening conditions



Stepping Up: Transition to Adult Services Pathway
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.



Scan the QR codes to read the resource or visit: www.togetherforshortlives.org.uk/re sources-and-research/



# **Publications - for professionals**



Making a Difference for Young Adult Patients - Practice
Prompts

These practice prompts present key findings from a national study (the STEPP project) on health care transitions for young adults with significant, and potentially life-limiting, conditions.



### To download



• Basic Symptom Control in Paediatric Palliative Care 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.



#### • Standards Framework for Children's Palliative Care

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.





Scan the QR codes to read the resource or visit: www.togetherforshortlives.org.uk/re sources-and-research/

> together lives

### Safe use of medicines

This third edition of the Safe use of medicines toolkit provides information and guidance to professionals working in children's hospice and palliative care settings about using medicines safely, and has been updated with the latest regulation and practice developments.



Developing volunteering services

Safe use of medicines



#### • Developing volunteering services

A collection of resources for organisations developing a family support volunteering service. The resources were developed and tested specifically in the context of children's palliative care, but might be useful for any organisation developing volunteer services.



## **Publications - for families**

### To download or order





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#### • A Family Companion

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.



Caring for your child at end of life – family guide
Caring for your child at end of life provides practical
information to support families at the most unbearable of
times. It answers questions and provides support.
Families might want to work through the Guide with their
care team one step at a time, when they are ready.



Scan the QR codes to read the resource or visit: www.togetherforshortlives.org.uk/re sources-and-research/

#### Making Critical Care Decisions 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.



#### Family Factsheets

together Lives

A parent's

king critical care

together Lives

choices for your child

#### Parent Support Groups

his factsheet provides key contact information for some of the main narities and support groups for families with children with an illness or isability. We have included a selection of some of the larger charities and support groups, many of which provide a wealth of information worker with generating department and department.

If you are unable to find a support group that you are looking for from this factsheet, we would recommend that you seek advice from the national charity Contact a Family, which provides information on the many support groups around the country: www.cafamily.org.uk

y.org.uk www.bdfa-uk.o. Support line: 080 aring Loss (formerly RNID) rring Loss provides a wide cesto individuals and about hearing loss and vides day-to-day care for e deaf and have additional as communication services no offers practical advice to rotect their hearing.

ormation line: 0808 808 0123 www.cerebra.org. hail: informationline@hearingloss.org.uk Tel: 0800 328 1159

### Family Factsheets

Together for Short Lives has developed a series of factsheets to support families and provide information on a range of issues.



#### • My Care Transfer

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.





#### **My Care Transfer**

A quick and easy care planning tool for young people and their families

Get started on your plan

## **Publications - for families To download**



#### • A checklist to a good transition

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.







The guide includes real life examples written in 2015 from three young people with personal budgets: Heidi, Leah and Chris.

Learn more about them in the 'How do personal budgets work in real life?' section.

#### • Moving to Adult Services: What to Expect

This guide is for any young person with a life-threatening condition who is thinking about their future as an adult and wanting to consider their options and plan ahead in terms of education, employment and living arrangements, as well as what's important to them in other areas of their life.



• Young Person's Guide to Personal Budgets in England This e-resource is written for young people with a lifelimiting or life-threatening condition and may be considering a personal budget. The easy to use guide aims to help young people decide if a personal budget is right for them.





#### • Together for Families: Family newsletter

Our Together for families newsletter gives you the latest information on resources and services that can support you and your family, and shares stories of other families caring for seriously ill children. Register using the QR below. Just scan it on your phone!



Scan the QR codes to read the resource or visit: www.togetherforshortlives.org.uk/re sources-and-research/

