



Yorkshire and Humber
Children's Palliative
Care Network



Recognising children and young people with palliative care needs

Childhood?

ASSESS current care needs

- Consider introducing local palliative care team and hospice services
- Begin discussions with family about their wishes for their child, both during life and in an emergency
- Consider introducing and completing a Child and Young Person's Advance Care Plan (CYPACP) document
- Ensure CYPACP distributed amongst all involved professionals and Yorkshire Ambulance Service

**Would you like
to hear this
died with**

The next 12 months?

ASSESS end of life care needs

- Ensure CYPACP documentation is completed and up-to-date, including what family and professionals should do in an emergency
- Discuss choices including preferred place of care and preferred place of death
- Allocate keyworker
- Ensure multi-disciplinary team (MDT) around the child is regularly updated, including education
- Check whether respite care is needed
- Liaise with commissioners on funding of continuing care package

Consider plans following death

- Tissue/organ donation?
- Consider ongoing place of care; offer home/hospice cooling
- Ensure bereavement support offered
- Coroner's referral required?

The next three months?

PLAN for end of life care

- Review CYPACP/ReSPECT documents and place of care choices
- Ensure GP up-to-date and consider review meeting, plus check whether regular GP review is required to aid certification of death
- Ensure wider MDT is up-to-date and clarify roles
- Introduce end of life care teams as appropriate
- Ensure symptom management plans are in place, with anticipatory medications available
- Ensure family have contact details, including out of hours
- Emergency referral/review of funding for continuing care package

be surprised
s child had
within...

The next few days?

IMPLEMENT end of life care

- Do the family know?
- Are child and family in their preferred place of care? Use regional rapid discharge paperwork if appropriate
- Ensure robust symptom management plan and anticipatory medications are available
- Update team, including GP
- Ensure 24-hour support in place with regular review
- Ensure ReSPECT documentation is in place and up-to-date

- Complete MCCD (+/- cremation form)
- MBRRACE form for infants <28 days
- Inform Child Death Review Team and all professionals involved

Things to watch out for

Flags to help identification of children where advance care planning/ parallel planning for life and death may be appropriate.

- Diagnosis of a condition which is highly likely to be life-limiting or life-threatening
- Lack of response to treatment
- Frequency of admissions with life threatening events is high or increasing
- Rapid progression of disease
- Multi organ failure
- Agreed consensus that the child's quality of life is so poor that further invasive treatments are no longer appropriate
- Cachexia despite nutritional support

Useful resources

- Child and Young Person's Advance Care Plan Collaborative: cypacp.uk
- Together for Short Lives: basic symptom control in palliative care: tinyurl.com/TfSLsymptomcontrol
- Association of Paediatric Palliative Medicine: Master Formulary: tinyurl.com/masterformulary
- Plus you can find more useful resources on the YHCPCN website: tinyurl.com/YH-cypacp

Hospice contact details

Andy's at St Andrew's Hospice

Call 01472 350908

Email hello@standrewshospice.com
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Forget Me Not

Call 01484 411040

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