Children's Cancer and Leukaemia Group | the EXPERTS in CHILDHOOD CANCER

Childhood cancer:

End of life care

Healthcare information for general practitioners (GPs) who are involved in the care of a child or teenager with cancer

In partnership with

Grace Kelly Childhood Cancer Trust

About childhood cancer mortality

Around 260 children die as a result of cancer every year in the UK, accounting for 7% of all childhood deaths (0-14 year olds).[1,2] Some of these children die in hospital or a hospice, but often end of life care at home is favoured by parents and children. Where end of life care is at home, there may need to be more involvement from the general practitioner. Usually, the child's oncology team or the palliative care team will lead the care.

Paediatric palliative care is an approach that focuses on the improvement in quality of life for the infant, child or young person. It also includes supportive care of children with life-threatening or life-limiting conditions, so ideally it should be introduced to help symptom management whilst the child is still undergoing active treatment.[3]

In practice, however, often the hospice does not become involved until a decision is made by the MDT and family that there is a movement towards non-curative treatment or end of life care.

Advance care plans

When curative treatment is no longer an option for a child or young person, their oncology team or another specialist team should build an advance care plan (not to be confused with a 'do not attempt resuscitation' order). Ideally, these should be drawn up as part of a multidisciplinary team including the paediatric oncologist and palliative care teams. At times, a GP may be involved in this process.

The contents of an advance care plan for children deemed palliative may include:

- up-to-date contact details and demographic information
- a list of professionals involved in care, and the person responsible for giving consent
- a distribution list for advance care plan
- a short summary of their condition
- social factors, religious beliefs and wishes of the child (if appropriate) and their carers
- a record of significant discussions
- agreed treatment plans, including management of life-threatening events
- plans for resuscitation or life support
- end of life care, including:
  - preferred place of care and death, specific wishes and the practicalities of how this could be done
  - organ or tissue donation wishes, as appropriate

The advance care plan should be reviewed regularly and kept up to date. It may be good practice to review the care plan of these children, in a similar way to reviewing adults on the palliative care register.[3,4]

End of life care

Symptom management in children is approached in a stepwise manner in a similar way to adults. Pain indicators may need to be used if the child or young person is not able to communicate their needs effectively.

Medication doses need to be calculated using the body weight of the child instead of age-weight estimates, which may differ markedly from the norm in children with cancer.[3]

Pain

Pain needs to be managed in a simple stepwise approach making sure to rule out conditions such as constipation or infection that may be aggravating pain.[4] Use the minimal effective dose that relieves and prevents pain, titrating up with breakthrough pain relief as needed.[4] When prescribing, be aware of multiple morbidities in children with cancer. For example renal impairment can greatly affect prescribing practices. Seek specialist advice as needed.[3,5]

Agitation

Rule out a correctable cause first such as urinary retention or pain. Manage agitation through correcting the cause if possible, environmental changes (such as a calming environment) and pharmacological methods as needed.[3]

Respiratory distress

Pay attention to discussing the worries and concerns of the child or their parents and provide anxiolytic agents, if needed. Oxygen can be used if this makes the child or young person more comfortable.[3,5]

Managing hydration and nutrition

Encourage oral intake if the child wants to and is still able to eat/drink. Provide lip and mouth care in all cases as needed irrespective of oral intake.[5]

Care and support for parents, family and carers

Following the death of a child at home, a GP may be asked to certify the death or discuss with parents or carers the practical arrangements that need to be made. This ideally should be provided in writing, and should include involvement of the coroner as required, care of the child after death, registration of the death and funeral arrangements as needed.[3] Completing necessary paperwork as soon as possible may also avoid the child being unnecessarily moved (e.g. if the child is being kept at home or the hospice until the funeral), minimising distress to the family.

Often, children's hospices have a cold room in which the child can remain after death right up until their funeral. This can provide great comfort to families as it feels more like a bedroom than a mortuary, and allows the child to be visited. Some may provide this even if the child passed away at home. Some hospices may also loan 'cooling blankets' to allow families to keep their child at home a little longer.

In the immediate aftermath, there may be a lot of support for bereaved parents from friends and family. However, after the funeral, this tends to dissipate and this may be when the support of a GP is valuable.

The type of bereavement support available varies greatly by region, so make sure to check what is available in your area. In addition, the death of a child from any cause is likely to have an impact on all the professionals who cared for the child as well, so there should be arrangements made for professionals to talk about their thoughts and feelings with colleagues after the child's death.

The involvement of the GP will depend on the child and family situation, other services available and the wishes of the family. After the death of a child, a family may need increased support. Their GP is often their first port of call for this.

References

1. Public Health England. Children, teenagers and young adults UK cancer statistics report 2021. Published February 2021.

2. Royal College of Paediatrics and Child Health. Why children die: death in infants, children and young people in the UK, 2014. Retrieved on 10.11.22 from www.rcpch.ac.uk/resources/why-children-die-research-recommendations

3. NICE. End of life care for infants, children and young people with life-limiting conditions: planning and management NG61. Updated July 2019. Retrieved on 10.11.22 from www.nice.org.uk/guidance/ng61

4. Together for Short Lives. End of life planning prompt sheets. 2012. Retrieved on 10.11.22 from www.togetherforshortlives.org.uk/resource/end-life-planning-prompt-sheets/

5. Together for Short Lives. Basic symptom control in paediatric palliative care. New edition May 2022. Retrieved on 10.11.22 from www.togetherforshortlives.org.uk/resource/basic-symptom-control-paediatric-palliative-care/

FURTHER INFORMATION

Childhood cancer information for healthcare professionals is available from CCLG, including further information for GPs and those who are supporting a child with cancer in the community
www.cclg.org.uk/professionals
www.cclg.org.uk/outreach-information

Resources for healthcare professionals are available from the Grace Kelly Childhood Cancer Trust, including further information for GPs on early diagnosis and care of children with cancer in the community
www.gkcct.org/clinicians

CCLG booklets for parents and families about palliative care can be downloaded or ordered FREE of charge
www.cclg.org.uk/publications

Grace Kelly Childhood Cancer Trust information for bereaved families and booklets for children to order or download
www.gkcct.org/information-and-support/bereavement

Children's Cancer and Leukaemia Group (CCLG) is a leading national charity and expert voice for all childhood cancers.

Each week in the UK and Ireland, more than 30 children are diagnosed with cancer. Our network of dedicated professional members work together in treatment, care and research to help shape a future where all children with cancer survive and live happy, healthy and independent lives.

We fund and support innovative world-class research and collaborate, both nationally and internationally, to drive forward improvements in childhood cancer. Our award-winning information resources help lessen the anxiety, stress and loneliness commonly felt by families, giving support throughout the cancer journey.

CCLG publications on a variety of topics related to children's cancer are available to order or download free of charge from our website. If you have any comments on this booklet, please email us at publications@cclg.org.uk.

We are grateful to all those who have contributed to this publication. We make every effort to ensure that information provided is accurate and up-to-date at time of printing. We do not accept responsibility for information provided by third parties, including those referred to or signposted to.

The Grace Kelly Childhood Cancer Trust is a national charity based in Worcestershire which provides vital support to families affected by childhood cancer.

The Trust was set up in memory of four-year-old Grace Kelly who passed away in 2014 from a rare form of childhood cancer.

We fund research into rare childhood cancers, work to educate families and clinicians about the signs and symptoms of childhood cancer and produce information booklets that are written by medics to explain to parents and children about the treatments they are facing.

We provide financial, practical, and emotional support to local families through our family support service at the charity, giving families a listening ear at the time when they need it most.

Our information booklets and further information can be downloaded or ordered free of charge from our website.

Because the children of today all deserve a tomorrow.

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