GP FACTSHEET

Grace Kelly
Ladybird Trust

Children's
Cancer and
Leukaemia
Group

Childhood cancer: End of life care

Information for general practitioners (GPs)

Childhood cancer affects approximately 1,800 children with around 230 children dying as a result of cancer every year in the UK[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 of quality of life for the infant, child or young person. Technically, 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 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 and specific wishes and the practicalities of how this could be done
  - Organ or tissue donation wishes as appropriate
- Distribution list for advance care plan

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. It is important to be aware that the child or young person may not be able to communicate their needs effectively so pain indicators may need to be used.

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 after a child dies. 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 special cold room in which the child can remain after death right up until their funeral. This can provide great comfort to families as they are more like a bedroom than a mortuary and allow 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 very 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 that worked with 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 specific child and family situation, other services available and the wishes of the family. Following the death of a child, a family may need increased support. Their GP is often their first port of call for this.

Further information

The CLIC Sargent Outreach Information Resource has further information about caring for a child with cancer in the community: **www.cclg.org.uk/outreach**

Information for parents and families

CCLG produces booklets for parents and families on palliative care ('Managing symptoms at home') and bereavement, which can be downloaded or ordered free of charge from **www.cclg.org.uk/publications**

References

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

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 and young people 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. **For more information, visit www.cclg.org.uk**

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Grace Kelly Ladybird Trust

The Grace Kelly Ladybird Trust is a children's cancer charity working to raise awareness of the signs and symptoms of childhood cancer and how it may present. We fund solid tumour research in children and young people and provide support to families as well. Our evidence based publications help raise awareness and provide information both to parents, carers and clinicians. The GKLT was set up in memory of 4-year-old Grace Kelly who passed away in 2014 to help Grace fulfil her wish of helping other children. Registered charity number 1167783

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