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.\(^2\) 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.\(^6\)

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

Contact
contact@gracekellyladybird.co.uk  |  www.gracekellyladybird.co.uk

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 2011 to help Grace fulfill her wish of helping other children. Registered charity number 1167783

Publication of this factsheet was written by Dr Jennifer Kelly, General Practitioner, in conjunction with the CCLG Publications Committee, comprising multiprofessional experts in the field of children’s cancer. Produced in partnership with Grace Kelly Ladybird Trust. CCLG makes 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 in this publication. Information in this publication should be used to supplement appropriate professional or other advice specific to your circumstances.