

## **Cancer Plan Priorities for children, teenagers and young adults**

### **A joint submission from Together for Short Lives and Rainbow Trust Children's Charity to the children, teenagers and young adults' cancer sector**

**18 August 2016**

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Together for Short Lives and Rainbow Trust Children's Charity welcome the opportunity to contribute to the planned joint submission to the National Cancer Transformation Board on behalf of the organisations which represent children, teenagers and young adults with cancer. We ask for the following points to be reflected in the joint submission:

#### **About Together for Short Lives**

Together for Short Lives is the leading UK charity that speaks out for all children and young people who are expected to have short lives. Together with everyone who provides care and support to these children and families, we are here to help them have as fulfilling lives as possible and the very best care at the end of life. We can't change the diagnosis, but we can help children and families make the most of their time together.

#### **About Rainbow Trust Children's Charity**

Rainbow Trust Children's Charity provide emotional and practical support for families who have a seriously ill child. We offer the whole family support 24/7 regardless of diagnosis and for as long as it is needed.

Our vision is for all families who have a child with a life threatening or terminal illness to have access to a Rainbow Trust carer at this time of great need.

#### **Summary of our proposals to make sure that the Cancer Plan reflects the care and support needed by children and young people with cancer who need palliative care**

1. Cancer is a life-threatening condition for which curative treatment can fail. Despite improving survival rates, cancer is the leading cause of death in children, teenagers and young adults. **Children and young people with cancer may need palliative care if their treatment fails.** They may also need it **alongside curative treatment**, and/or if they experience a **temporary, acute crisis**, irrespective of how long the threat to their life lasts.
2. **At whatever point a poor prognosis is recognised for a child or young person with cancer, it is crucial that the family is made aware.** This should be the first milestone in the child or young person's palliative care pathway. **Children's palliative care referral pathways should be commissioned and implemented** to make sure that children and young people with cancer are referred to these services as soon as possible.

3. **All children and young people with cancer should be offered an advance care plan (ACP)** which includes planning with their families for the end of their life. They should be supported to collaborate with their care providers to develop these plans. This should be done at a pace which suits the family and in a way which reflects their understanding of the situation.
4. Children and young people with cancer, and who need palliative care, require support from a range of professionals and organisations from health, social care and other agencies. Every family of a child with cancer should receive a child and family centred **multi-disciplinary and multi-agency assessment** of their needs as soon as possible after their child is recognised as likely to die prematurely. As a result of this assessment, every child and family should have a **multi-disciplinary multi-agency care plan**, developed in partnership with them.
5. Children and young people with cancer should be **supported to have conversations about dying**.
6. Children and young people with cancer and their families **should be offered the choice of how and where they receive palliative care**, including at the end of their lives. Professionals should support children and families to make these choices.
7. Where a child who has had cancer has died, or is expected to die, **bereavement support** should be available for the child and family.
8. Young people with cancer should experience **smooth transitions** from children's to adults' services - and receive palliative care which is appropriate to their age.
9. There are barriers to **research** into children's palliative care. The Cancer Strategy recommended that, by September 2016, a proposal should be developed to ensure that all children, teenagers and young adults diagnosed with cancer are asked at diagnosis for consent for their data and a tissue sample to be collected for use in future research studies. The strategy also states that NHS England should work with research funders to make best use of these resources in the future. **We ask that the joint submission emphasises the need for this proposal and joint work with funders to be realised.**
10. **Kinder treatments** are needed for children and young people with cancer to reduce the risk of those who survive having to live with long-term conditions resulting from the treatments they are given. Children and young people who survive cancer may need palliative care later in life.

A more detailed submission is offered in Annex A.

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## **Annex A: Our detailed submission**

### **Children with cancer may need palliative care**

1. Cancer is a life-threatening condition for which curative treatment can fail. Children and young people with cancer may need palliative care if their treatment fails. They may also need it alongside curative treatment, and/or if they experience a temporary, acute crisis, irrespective of how long the threat to their life lasts.
2. Palliative care for children and young people should<sup>1</sup>:
  - i. meet their physical, emotional, social and spiritual needs
  - ii. aim to enhance their quality of life and support their family in coming to terms with their condition and the care they will need
  - iii. help families understand how the young person's condition and their needs may change over time
  - iv. include managing distressing symptoms, providing short breaks and care through death and bereavement
  - v. be provided in ways which are appropriate to their age and stage of development; this means care provided in age and developmentally appropriate settings by professionals who are skilled in working with them.
3. Despite improving survival rates, cancer is the leading cause of death in children, teenagers and young adults. Survival is significantly lower in teenagers and young adults than in children for several cancer types, including bone tumours and soft tissue sarcomas.
4. Around 250 children, aged 0 to 14 years, lose their lives to cancer every year in the UK. In children aged 1 to 14 years, this is around one fifth of deaths in this age group. In teenagers and young adults, cancer accounts for around 310 deaths per year in the UK.<sup>2</sup>

### ***How this should be reflected in the Cancer Plan***

5. The plan should acknowledge that some children and young people with cancer need palliative care.

### **Identifying children and young people who need palliative care as early as possible**

6. For children with cancer, the point at which they are recognised as being likely to die prematurely - or at which they have an acute crisis - may come considerably later than the point at which they are diagnosed. For others, it may be the point at which curative treatment has failed.
7. If the child or young person's condition has deteriorated to the extent that it has become evident that their long-term prognosis is poor, it may be that child or family has needs that could be best met by children's palliative care services.

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<sup>1</sup> Together for Short Lives (2013). Definitions. Available to download from: [bit.ly/Z34i5s](http://bit.ly/Z34i5s).

<sup>2</sup> Cancer Research UK. 2016. Children's cancers mortality statistics. Available to download from: <http://bit.ly/2bAIOxy>

8. It may be that the health professional(s) caring for the child has identified a shortened life-expectancy but feels reluctant to discuss this with the family. At the point when professionals recognise that the prognosis is poor for a child with cancer, this should be communicated to the family with the same degree of care and sensitivity as with children for whom the prognosis was clear from the start.
9. At whatever point this poor prognosis is recognised, it is crucial that the family is aware that their child has a life-limiting condition. Sharing this news marks the first important milestone along the children's palliative care pathway. Some children will have a very short life expectancy and will move to the final stage of the pathway quickly, while others will require many years of support.

### ***How this should be reflected in the Cancer Plan***

The plan should recommend:

10. that clinical commissioning groups and local authorities jointly commission services for children and young people with cancer that include referral pathways to palliative care; Together for Short Lives has produced a core care pathway for children's palliative care, which is available download without charge at: [http://www.togetherforshortlives.org.uk/assets/0000/4121/TfSL\\_A\\_Core\\_Care\\_Pathway\\_ONLINE .pdf](http://www.togetherforshortlives.org.uk/assets/0000/4121/TfSL_A_Core_Care_Pathway_ONLINE.pdf)
11. that commissioners and providers of cancer and palliative care services for children and young people should also work to implement:
  - the new National Institute for Health and Clinical Excellence (NICE) clinical guideline 'End of Life Care for Infants, Children and Young People: Planning and Management', which will be published before the end of 2016: <http://bit.ly/NICEeolcyp>
  - Together for Short Lives' guide to jointly commissioning palliative care for children and young people aged 0-25, which is available to download without charge at [www.togetherforshortlives.org.uk/jointcommissioning](http://www.togetherforshortlives.org.uk/jointcommissioning)
12. that sustainability and transformation plan (STP) footprint areas include care and support for children and young people with cancer who need palliative care in their strategies
13. that NHS England should work with the Local Government Association, the Association of Directors of Children's Services and voluntary sector organisations to produce joint guidance for CCGs and local authorities on how to fund palliative care for children and young people, including those with cancer.

### **Advance care planning and parallel planning**

14. All children and young people with cancer should be offered an advance care plan (ACP) which includes planning with their families for the end of their life. They should be supported to develop these plans.
15. Advance care planning is a process of discussion between an individual and their care provider. It can also often include those close to them. ACP and clarity about resuscitation decisions are essential to quality care. This is as important for children

and families as it is for adults receiving end of life care. ACP may lead to actions such as advance statements about:

- i. wishes and preferences
  - ii. preferred place of care
  - iii. withdrawing treatment
  - iv. whether or not to attempt resuscitation.
16. For children and families this will include decisions relating to care in the case of acute deterioration; it may also address preferences for organ and tissue donation.
17. ACP should also include a parallel plan which sets out what will happen if the child or young person does not die. A parallel plan approach can reassure the child, young person and their family that a range of outcomes are planned for. It also means that the range of professionals who will provide the planned care are introduced to the child, young person and family in a timely, early and proactive way. It is vital that parallel planning is begun as early as possible following the child or young person's diagnosis.

***How this should be reflected in the Cancer Plan***

18. The plan should recommend that all children and young people with cancer should be offered an advance care plan (ACP) which includes planning with their families for the end of their life. The ACP should also include a parallel plan for range of different potential outcomes. Children and young people should be supported to develop these plans.

**Making sure that children and young people with cancer - and who need palliative care - can access a range of care and support, which includes health and social care**

19. Children and young people with cancer, and who need palliative care, require support from a range of professionals and organisations from health, social care and other agencies. This will often include practical social care and support on a day-to-day basis at home, in hospital and in the community.

***How this should be reflected in the Cancer Plan***

The plan should recommend that:

20. Every family of a child with cancer should receive a child and family centred multi-disciplinary and multi-agency assessment of their needs as soon as possible after their child is recognised as likely to die prematurely. They should also have their needs reviewed at appropriate intervals.
21. The needs assessment should provide the opportunity for the child and family's hopes, wishes and concerns to be heard and for their full range of needs to be explored. It should empower the family and ensure that they can take control of their lives. It should reframe the relationship between professionals and families from professionally-led care to family-led care, where families are enabled to deliver the care their child needs to make the very most of the opportunities and time they have with their child. The ultimate goal should be for the family to have the very best life possible.

22. As a result of this assessment, every child and family should have a multi-disciplinary multi-agency care plan, developed in partnership with them. It should help to make sure that they can access co-ordinated care to enhance family strengths and meet need. A multidisciplinary and multiagency team, identified in agreement with the family, should provide care using key working principles. Wherever possible this should involve all agencies involved in supporting the child and family, including the child's community nursing team, allied health professionals, hospice, local acute and tertiary hospital services, education, social care and short break services.
23. If the child or young person has a special educational need (SEN), the multi-disciplinary multi-agency care plan should form part of their education, health and care (EHC) plan. Professionals should be particularly mindful of children and young people with cancer who would benefit from such an integrated plan, but who may not be eligible for an EHC plan because they do not have a SEN.

### **Support to talk about dying**

24. Children and young people with cancer need to be supported to have difficult conversations about dying, even if they ultimately go on to be cured. Each person is unique and will have unique wishes.
25. Peers of children and young people with cancer, as well as professionals who work with them (teachers, for example), may also need support to have conversations about dying.

### ***How this should be reflected in the Cancer Plan***

26. The plan should recommend that cancer and palliative care professionals should support children and young people with cancer to have these conversations - and get to know them before embarking on these conversations. Training and support should be available to professionals to make sure that they have the skills needed to hold these conversations.
27. We suggest that the scope of the secondary school cancer education programme recommended in the joint submission also includes work to support well children and young people to talk about situations in which a peer who has cancer.

### **Choice**

28. Children and young people with cancer and their families should be offered the choice of how and where they receive palliative care, including at the end of their lives. Professionals should support children and families to make these choices.
29. In July 2016, the Department of Health published its response<sup>3</sup> to a review of choice in end of life care which was commissioned by ministers and carried out by the National Council for Palliative Care between 2014 and 2015. Crucially, the government stated that:
  - to support high quality personalised care for children and young people, commissioners and providers of services must prioritise children's palliative care

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<sup>3</sup> Department for Health. 2016. What's important to me. A Review of Choice in End of Life Care. Available to download at: <http://bit.ly/2aXWynp>

in their strategic planning; this is so that services can work together seamlessly and advance care planning can be shared and acted upon.

- children and young people with complex needs should enjoy the same independence and choice which we all expect.
- it is essential that the voices of children and young people are heard so that they are involved in their care, able to express their needs and preferences and make informed choices about their care.

30. The National Institute for Health and Care Excellence (NICE) has published a draft of its clinical guideline 'End of Life Care for Infants, Children and Young People: Planning and Management'<sup>4</sup>. It recommends that children, young people and families should be supported to choose where they die.

### ***How this should be reflected in the Cancer Plan***

31. The plan should recommend that commissioners and providers of services implement the government's response to the review of choice in end of life care.

### **Bereavement support**

32. Where a child who has had cancer has died, or is expected to die, pre-bereavement and bereavement support should be available for the child and family. The death of the child is not the end of the care pathway for the family. They may experience grief for many years to come and may need support along the way. The family's bereavement support needs should be assessed, planned, commissioned and delivered through their care team.

33. According to NICE<sup>5</sup>, services should be coordinated across all relevant agencies encompassing the whole care pathway for cancer in children and young people.

### ***How this should be reflected in the Cancer Plan***

34. The plan should recommend that CCGs and local authorities include bereavement care as part of a commissioned children's palliative care pathway.

### **Transition to adulthood and age-appropriate services**

35. In July 2015, the independent Cancer Taskforce published a strategy<sup>6</sup> which set out how England could achieve the very best cancer outcomes by 2020. This document includes a commitment that, by March 2017, it will develop proposals to improve the transition of patients between children's and adult services.

36. Currently, many young people with life-limiting and life-threatening conditions experience a cliff-edge in their care and support when they reach adulthood. Some

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<sup>4</sup> The National Institute for Health and Care Excellence. 2016. End of Life Care for Infants, Children and Young People: Planning and Management. Available to download at: <http://bit.ly/NICEeolcyp>

<sup>5</sup> The National Institute for Health and Care Excellence. 2014. Support for commissioning for children and young people with cancer. Available to download at: <https://www.nice.org.uk/guidance/qs55/resources/support-for-commissioning-for-children-and-young-people-with-cancer-253724365>

<sup>6</sup> Independent Cancer Taskforce. 2016. Achieving world-class cancer outcomes: a strategy for England 2015-2020. Available to download at: <http://bit.ly/2aYdkmn>

children's services cease at 16, with some adult services not beginning until the age of 18. Transition pathways between specialist centres and shared care units are often difficult.

37. It is vital that professionals providing children's and adults' cancer and palliative care work with the young person and their family to develop a transition plan. This may incorporate support from health, social care, housing and education or work. Professionals should be particularly mindful of young people with cancer who would benefit from such an integrated plan, but who may not be eligible for an education, health and care (EHC) plan because they do not have a special educational need (SEN).
38. Children's cancer and palliative care professionals should identify as early as possible when a young person with cancer will transition from children's to adults' services. For young people with an EHC plan, planning for adulthood should start in Year 9, as specified in the SEND code of practice<sup>7</sup>. Under the Care Act 2015, local authorities also have a duty to assess young people's and their carer's social care needs ahead of their transition to adulthood (if the local authority believes that this will be of significant benefit).

#### ***How this should be reflected in the Cancer Plan***

39. The plan should recommend that every young person with cancer and their family is offered a transition plan by the professionals who care for them. Transition planning should start as soon as it becomes apparent that the young person is likely to need care and support in adulthood. It should happen in a co-ordinated way across education, health, social care and other agencies involved in caring and supporting the young person.

#### **Research**

40. We find that there are significant barriers to research into children's palliative care including clinician gatekeeping and research governance<sup>8</sup>.
41. The Cancer Strategy recommends that, by September 2016, a proposal should be developed to ensure that all children, teenagers and young adults diagnosed with cancer are asked at diagnosis for consent for their data and a tissue sample to be collected for use in future research studies. The strategy also states that NHS England should work with research funders to make best use of these resources in the future. We ask that the joint submission emphasises the need for this proposal and joint work with funders is now realised.

#### ***How this should be reflected in the Cancer Plan***

42. The plan should reiterate the need the research commitments in the existing cancer strategy to be realised.

#### **Kinder treatments and the potential need for palliative care again later in life**

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<sup>7</sup> Department for Education. 2014. Special educational needs and disability code of practice: 0 to 25 years. Available to download from: <http://bit.ly/1kOCi5i>

<sup>8</sup> Beecham, E., Hudson, B.F., Oostendorp, L., Candy, B., Jones, L., Vickerstaff, V., Lakhanpaul, M., Stone, P., Chambers, L., Hall, D., Hall, K., Ganeshamoorthy, T., Comac, M., Bluebond-Langner, M. (2016). A call for increased paediatric palliative care research: Identifying barriers. *Palliative Medicine*, pii: 0269216316648087).

43. Thankfully, many more children and young people are surviving cancer. While this is a reason to celebrate, the impact that treatments can have on survivors can result in long-term and possibly complex conditions<sup>9</sup>. The most common causes of death in childhood cancer survivors<sup>10</sup> are:

- i. The primary cancer comes back.
- ii. A second (different) primary cancer forms.
- iii. Heart and lung damage.

44. There are over 40,000 survivors of childhood cancer in the UK with 60% of childhood cancer survivors experiencing at least one adverse late effect of cancer treatment. Kinder treatments are needed to reduce the risk of these adverse effects. Children and young people who survive cancer may also need palliative care again later in life.

***How this should be reflected in the Cancer Plan***

45. The plan should recognise that children and young people who survive cancer may also need palliative care again later in life, and that kinder treatments need to be developed.

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<sup>9</sup> Cancer Research UK. 2016. 'We urgently need kinder treatments for children' – Noemi and Zofeya's story. Available to download at: <http://bit.ly/2aTJuz3>

<sup>10</sup> National Cancer Institute. 2016. Late Effects of Treatment for Childhood Cancer (PDQ®)–Patient Version. Available to download at: <http://bit.ly/2aYH8ek>