Together for Short Lives is the leading UK charity for the 49,000 babies, children and young people with life-shortening conditions and all those who support, love and care for them. We support families, professionals and services, including children’s hospices. Our work helps to ensure that children can get the best possible care, wherever and whenever they need it.

The number of children and young people with life shortening conditions is increasing but this is not being reflected in budget setting nor in the better coordination of services that they need. For example, a 2015 report showed a 25% increase in children with life-shortening conditions in Scotland in just 4 years – from 12,039 in 2009/10 to 15,404 in 2013/14.¹

Children’s palliative care is different to palliative care for adults. Whereas the majority of adults only need palliative care at the end of their lives, children with life-shortening conditions require palliative care over a much longer period, often from birth as they live with the instability of their condition. It is common for their conditions to fluctuate and, as such, it is often much more difficult to identify when a child is moving into their end of life phase. Children with life-shortening conditions often have complex disabilities, while the range of health conditions which results in children requiring children’s palliative care is more diverse. Children’s palliative care is an approach to care in conjunction with curative treatments.

We estimate that palliative care costs for children and young people in the UK amount to £110 million per year. Yet the only figure committed from statutory sources in England is a hospice grant of a £11 million a year and this is only committed to on a year-on-year basis.

**Together for Short Lives Summary Points**

- The Spending Review did much to address the needs of adults, for example, ring-fencing additional council tax for adult social care but the same consideration was not made to children.

- We are concerned that the voices of these children and young people are not being heard and as a result their increasing need is being ignored – they do not vote in elections, they do not influence policy

- The Spending Review did not set out how children’s palliative care services will be funded in the long-term in a fair and sustainable way. Statutory funding for children’s palliative care services remains patchy and inconsistent.

- Concerns over the proposed new per-patient funding system for children’s palliative care have not been addressed. This approach focusses on adult care and wrongly assumes one size fits all. It also fails to consider full support for short breaks, vital for family resilience or bereavement care.

- Cuts to local authorities’ budgets, coupled with the decision to ring-fence the optional 2% council tax precept to adult social care only, will reduce the funding that commissioners provide to children’s palliative care services – including children’s hospices.

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Many children and their families are already unable to access the short breaks that they are entitled to and this problem may be exacerbated by the failure to commit funding specifically for this purpose.

While the removal of the cap on nursing training places is welcome, it is unclear what affect removing nursing bursaries will have on the number of nurses in training and consequently the children’s palliative care workforce.

Our submission

Funding

1. Together for Short Lives remains concerned that the Spending Review did not set out how the government plans to make sure that children’s palliative care services receive fair and sustainable funding in the long-term. The 2011 Palliative Care Funding Review found that the lack of a clearly defined funding model has led to a wide variation in the level of state funding to services and made a series of recommendations on how palliative care should be funded. However, the government is yet to formally respond to these recommendations.

2. In our representation to the review, we highlighted the wide disparity in state funding for services. Our own surveys found that funding from CCGs is patchy and inconsistent – particularly when compared to adult hospices. CCGs contribute an average of 10% of children’s hospices’ care costs compared to 30% for adult hospices.

3. NHS England is currently testing a new per-patient funding currency for children’s palliative care; a non-mandated currency will be available for commissioners to use from April 2017. We are very concerned that it is limited to the medical elements of care and omits crucial non-clinical elements such as short breaks and bereavement support. Short breaks are essential to relieve some of the pressures on families of children with life-shortening conditions - most relationships will suffer, with 36% experiencing a breakdown of the family.

4. Our representation to the Spending Review set out the criteria for the new funding system to be a success. However, it is not yet possible to say whether the new per-patient system will meet these criteria. We call on the government and NHS England to clarify a number of key issues as soon as possible. The criteria that we set out were:

   a. Every baby, child and young person with a life-shortening or life-shortening condition - and their family - has access to palliative care services, which are sustainable and fairly funded.
   b. The new system reimburses providers of children’s palliative care according to the activity they undertake.
   c. CCG commissioning of the general clinical aspects of children’s palliative care through an NHS currency - and subsequently any tariff - complements NHS England’s commissioning of specialised children’s palliative care and local

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2 Hughes-Hallett T, Craft A and Davies C (2011). Palliative care funding review - creating a fair and transparent funding system; the final report of the palliative care funding review. Available to download from: bit.ly/XQBlE7


authorities’ commissioning of the social elements of children’s palliative care; together, this should create an overarching system whereby providers are commissioned for providing all of the elements of children’s palliative care - including the clinical and non-clinical aspects of short breaks (respite) and bereavement care.

d. The system provides a clear incentive for both commissioners and providers to make sure that palliative care is provided in a child’s home, in the community or in children’s hospice settings - if this is consistent with the child or their family’s preferences and is clinically appropriate.

5. Following its inquiry into end of life care in England, The House of Commons Health Select Committee recommended that the government ensure that future funding proposals fully recognise the importance of the voluntary sector and to specifically set out how it intends to ensure sustainable, long term funding for the hospice sector. We are disappointed that the government did not use the Spending Review to commit to continuing the children’s hospice grant during the transition to the new system. Our survey in 2015 found that 89% of children’s hospice organisations may be forced to reduce their services if this grant stops. The grant should be increased to reflect inflation and the increasing demand for children’s palliative care services from the growing number of children and young people with life-shortening conditions.

Integrating health, education and social care

6. We take a holistic, person centred view of children’s palliative care. This means that we are concerned about improving funding and connectivity across a range of health, education and social service which will improve cost efficiencies but importantly make the process of support easier for children, young people and their families. This means considering funding and support outside of a hospice building, at people’s homes, support by community nurses, volunteers and other community based support largely unfunded by statutory sources. We remain concerned that a government which is focussed on localism, 24/7 care and empowerment of patients is doing so little to address this for children with life shortening conditions.

7. We welcome the additional funding for the Better Care Fund and the pledge to integrate health and social care by 2020. This could have a positive impact for the families of children with life-shortening conditions, who currently have to co-ordinate and navigate all of the different services that they need, while also providing care around the clock for their child.

8. However, we are disappointed that the government’s new 2% Council Tax precept that local authorities can levy is to be limited to adult social care. The needs of children with life-shortening conditions are ignored in this formulation as the extra funding will not be extended to children’s services. With local authorities struggling to cope with rising demand, social care services that families rely on to keep going, including short breaks, will become much more scarce. Our 2015 survey found that over half (58%) of children’s hospices found it either difficult or very difficult to apply for short breaks services. This will become even more difficult amid the cuts that local authorities face.

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6 Ibid.
7 Ibid.
Supporting families through short breaks

9. In December 2010 the government committed £800m in funding for short breaks to ensure that local authorities could meet their legal duties under The Regulations for Breaks for Carers of Disabled Children 2011 over the course of the parliament. However, the Every Disabled Matters (EDCM) partnership found that 58% of local authorities who responded to their freedom of information requests had cut their short breaks spending during this period, by an average of 15%. This has a direct impact on families - the same survey found that only 9% of respondents to the survey of parent carers agreed or strongly agreed that families with disabled children can access the short breaks they need. The government has not committed to repeating the £800m funding and we are concerned that this will lead to a further reduction in short breaks provision by local authorities.

Transition from Children to Adult Services

10. Medical advances mean that more young people with a range of life-shortening conditions are living into adulthood. There are 56,000 young adults aged between 18 and 40 with life-shortening conditions and this figure continues to grow. Many young people and their families find the transition from the comprehensive care offered by children’s services to unfamiliar adults’ services daunting as they will have to forge relationships with new agencies and professionals. Furthermore, for many young people with life-shortening conditions, this transition coincides with a rapid decline of their condition and eventual death. As such, they have specific needs which differ from both younger children and older adults, yet there is a lack of age and developmentally-appropriate palliative care services for these young adults. We are disappointed that the Spending Review did not commit to provide seed-funding to stimulate voluntary sector organisations to provide these services.

Workforce

11. The removal of the cap on nursing training places and the goal of increasing these places by 10,000 may, in the long-term, have a positive impact on children’s palliative care. The current lack of community children’s nursing (CCN) teams across England prevents palliative care being provided at or closer to the home for children with long-term conditions. However, we are concerned that the removal of nursing bursaries and the introduction of student loans could have a negative impact on the number of students applying for nursing placements. Children’s palliative care services require more well-trained, highly-skilled nurses and the government should make sure that by removing these bursaries potential nurses are not deterred from pursuing nursing as a career.

12. A 2015 RCN survey found that nearly a third of children’s nurses did not feel that they had the resources to deliver adequate care at home. Furthermore, while it is recommended that a minimum of 20 full-time-equivalent CCNs are required for an average-sized district with a child population of 50,000, just 17 CCNs were due to qualify in 2014/15 in the UK. The shortage of nurses is particularly prevalent in children’s palliative care services. Our

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own survey showed that in 2015 more than 60% of nursing vacancies in the sector were defined as hard to fill.\textsuperscript{11}

22 January 2016