



forget me not children's hospice

Forget Me Not Children's Hospice joins call on NHS England boss to make good his promise to properly fund children's hospices

NHS and local council cuts are hitting lifeline care for seriously ill children, a survey of 27 children's hospices in England carried out by charity Together for Short Lives has shown. The news comes as NHS England chief executive Simon Stevens' commitment to protect and increase children's hospice funding is not being met. With proposals already having been made to close Acorns Children's Hospice site in Walsall, Forget Me Not Children's Hospice is worried that this could be the tip of the iceberg. Forget Me Not is joining Together for Short Lives calling on NHS England to keep its promise to protect the Children's Hospice Grant – and go further by increasing it to £25million per year.

Together for Short Lives found that:

- In the two years between 2016/17 and 2018/19, the funding each children's hospice charity received from local NHS clinical commissioning groups (CCGs) reduced on average by more than £7,000 – a 2% cut from £371,303 to £364,076.
- In the last year, between 2017/18 and 2018/19, nearly three quarters (74%) of children's hospice charities experienced a real-terms cut (a cut, freeze or increase below 1.8%) in the money they received from CCGs. Over half (56%) of children's hospice charities experienced cuts or freezes in CCG funding in cash terms.
- Funding is also very patchy and varies widely across local areas: 15% of children's hospice charities receive nothing at all from their CCGs.
- The money that each children's hospice has to spend each year to meet the needs of seriously ill children and their families has grown to an average of £3,681,442 – a 4.5% increase between 2016/17 and 2018/19, faster than the rate of inflation.
- This combination of falling CCG funding and increasing costs is hitting our most vulnerable children and their families: a fifth (19%) of children's hospice charities are cutting vital short breaks for respite.

Acorns Children's Hospice has cited uncertainty over the future of the Children's Hospice Grant as a material factor in its recent decision to propose closing its Walsall hospice.

Simon Stevens had announced on 27 December that, over the next five years, up to £7million additional funding would be made available to children's hospices each year on top of the existing £11million Children's Hospice Grant, if CCGs also provide additional match funding [1]. However, NHS England subsequently rowed back on this promise in its Long Term Plan. This stated that the additional funding will also be available to other, non-hospice palliative care services.

This was later confirmed in Parliament by Care Minister Caroline Dinenage. While NHS England has increased the grant to £12million for 2019/20, she refused to commit to continuing it exclusively to children's hospices beyond this year [2] [3]. The minister said the Department of Health and Social Care would only “*expect* hospices to be significant beneficiaries of the additional funding” set out in the Long Term Plan – and that “*simply increasing the hospice grant is not a solution*”.

Andy Fletcher, Chief Executive of Together for Short Lives said:

“All children’s palliative care services, delivered in hospitals, children’s hospices and the community, need equitable and sustainable funding. However, children’s hospices in England are facing a dangerous cocktail of growing costs and declining, patchy NHS funding, which is putting their long-term future at risk. Acorns’ proposal to close one of its children’s hospices could be just the tip of the iceberg. It is simply not sustainable to expect specialist children’s palliative care services provided by children’s hospices to be funded by charity reserves and the generosity of the public. It is time for Simon Stevens to make good on the commitment he made at Christmas by protecting the grant and increase NHS funding for children’s hospices.”

Luen Thompson is Chief Executive of Forget Me Not Children’s Hospice which provides services to more than 600 families across West Yorkshire and North Manchester. She said:

“The lack of NHS and local council funding has a huge impact on the care and support we are able to provide to the families who need it. We have two hospices: we cannot fully open our Bury hospice yet despite having amazing facilities and families desperate to access them because it receives no funding from NHS England’s Children’s Hospice Grant. Our Huddersfield hospice receives less than 3% in statutory funding of the £4million it needs to run.

“Our offer to families shouldn’t depend on how much we raise at a bucket collection or how much bric-a-brac we sell in one of our shops. Increased NHS and local council funding would reassure families that the services they rely on at the most difficult times in their lives will be there when they need them. That there will be somewhere their child can stay overnight so mum and dad have time to rest and recuperate. That there will be support for brothers and sisters worried about their sibling. That when the time comes, their child will receive the end of life care they need – and the family will have the help they need to make precious memories and say their last goodbyes.”

Thea Walker from Hebden Bridge died in February this year aged two years and nine months as a result of Niemann-Pick disease type A, a rare life-limiting condition. She received palliative care at Forget Me Not Children’s Hospice. Thea’s condition meant she had to be fed through a tube, relied on a wheelchair and wouldn’t learn to talk. Her mother Gabriella Walker said:

“With the support of Forget Me Not we felt less alone, more empowered. Their help gave us the confidence and skills to pack as much fun and life into the few short years Thea had as we could, as well as maintain a ‘normal’ life, with work and school, birthday parties and holidays. I dread to think how different things could have been if Forget Me Not had not been there. And of course as Thea’s disease progressed we relied more on the medical support they provided, which was invaluable.”

“I was shocked when I learnt how little Forget Me Not and other hospices like them receive from the NHS and local councils. They made sure that my family spent those years living as best we possibly could, focussed on enjoying the time we had together. Surely every family deserves the same?”

Gabriella Walker has written an open letter to Health and Social Care Secretary Matt Hancock, calling on him to make sure Simon Stevens honours his commitment to protect and increase children’s hospice funding. This Children’s Hospice Week, Forget Me Not is joining Together for Short Lives in calling on the public to sign Gabriella’s letter. This, alongside the full report of Together for Short Lives’ survey findings, will be available on Thursday 20 June from

<https://www.togetherforshortlives.org.uk/statutoryfunding>

ENDS

Notes to editors

[1] NHS England. 2018. NHS England announces £25million boost for children's hospices: <https://www.england.nhs.uk/2018/12/nhs-england-announces-25-million-boost-for-childrens-hospices/>

[2] UK Parliament. 2019. Hospices: Children: Written question – 235379. <https://www.parliament.uk/business/publications/written-questions-answers-statements/written-question/Commons/2019-03-21/235379/>

[3] UK Parliament. 2019. Hospices: Children: Written question – 238420. <https://www.parliament.uk/business/publications/written-questions-answers-statements/written-question/Commons/2019-03-28/238420>

- Families of seriously ill children rely on palliative care provided by children's hospice and palliative care charities. They provide services including vital short breaks (respite) for exhausted families, end of life care and bereavement support, in children's hospices and in family homes. They give choice and control to families facing their worst nightmare. They help ease pressure on our overstretched NHS. It is right that they receive money from the NHS and local councils.
- There are 34 children's hospice charities in England.
- 27 children's hospice charities (79%) responded to Together for Short Lives' survey of the way in which they are funded and commissioned by the NHS and local councils.
- In total, children's hospice charities in England had an estimated 10,060 babies, children and young people on their caseload during 2018/19. This is based on an average of 309 children per children's hospice charity.
- In total, children's hospice charities in England provided active clinical support to an estimated 8,160 babies, children and young people in 2018/19. This is based on a mean of 240 children per children's hospice charity.
- The total number of children receiving active clinical support includes an estimated:
 - 5,643 who received respite or short breaks (based on an average of 166 children per children's hospice charity)
 - 518 who received end of life care (based on an average of 15 per children's hospice charity)
 - 2,949 who received bereavement care (emotional and/or psychological support, based on an average of 87 per children's hospice charity)
 - 2,775 who received support to manage their symptoms (based on an average of 82 per children's hospice charity)
 - 3,944 who received children's hospice care at home (based on an average of 116 per children's hospice charity)
 - 326 who received step-down care (based on an average of 10 per children's hospice charity).
- In 2018/19, the state's contribution overall (including the NHS England Children's Hospice Grant and funding from CCGs and local councils) to the average charitable costs incurred by children's hospices stayed relatively static compared to 2016/17.
- However, because of the increase in charitable costs incurred by children's hospice charities, the contribution to these made by state funding fell from 22% in 2016/17 to 21% in 2018/19. This is a significant fall compared to the 27% contribution that the state made in 2013/14.
- During 2018/19, the state's 21% contribution to the charitable costs incurred by children's hospice charities comprised 10% from CCGs (down from 11% in 2016/17), 9% from the

Children's Hospice Grant (unchanged from 2016/17) and 2% from local authorities (also unchanged from 2016/17).

- This means that CCGs contributed an estimated total £12.4million to children's hospice charities across England in 2018/19.
- The Children' Hospice Grant, which is allocated to all children's hospices by NHS England, is worth a total of £12million per year in 2019/20. This has grown incrementally from £8.8million in 2006/07, when the grant was introduced as a £27million award over three years. In 2006/07, the grant contributed an average of 14% towards the cost of providing clinical care in children's hospices.

About Forget Me Not Children's Hospice

- More information about Forget Me Not is available at <https://www.forgetmenotchild.co.uk>
- Forget Me Not Children's Hospice is a charity founded over 14 years ago when a local mum became concerned about the lack of support available for her son. Her fundraising made a 'hospice at home' service possible in 2010, and Russell House in Huddersfield was opened two years later.
- Forget Me Not offers a wide range of services right from pregnancy, including practical family support, counselling and bereavement support, sibling support and much more, all available to the whole family.
- Forget Me Not has two hospices: Russell House in Huddersfield supporting families across West Yorkshire and Grace's Place in Bury, for families in Bury, Oldham and Rochdale.
- Forget Me Not was the first children's hospice in Europe to employ a midwife.
- With just 3% of funding coming from the government the charity must raise over £4.5m each year to ensure it is able to give the children and families the support they need.

About Children's Hospice Week 2019 (17-23 June)

- Children's Hospice Week is the only week in the year dedicated to raising awareness and funds for children's hospice services across the UK, and the thousands of seriously ill children and young people that they support. [Find out more](#)