

Rt Hon Matt Hancock
Secretary of State for Health and Social Care
Department of Health and Social Care
39 Victoria Street
London
SW1H 0EU

cc. Simon Stevens, Chief Executive, NHS England

Dear Secretary of State

My daughter Thea died in February this year aged two years and nine months as a result of Niemann-Pick disease type A, a very rare, life-limiting condition. Thea received incredible palliative care from our local children's hospice, Forget Me Not in Huddersfield. I am writing to ask you to make sure that NHS England re-commits to protecting the Children's Hospice Grant for the long-term and increasing it to £25million per year.

When Thea was diagnosed just before her first birthday in April 2017, we were floored. Her condition was degenerative and progressive; she would be fed through a tube for her whole life and lose the few physical abilities she had. She could die before she ever started school. There was absolutely nothing anyone could do about it. I did not want to go anywhere near a hospice. I thought they were for people who were dying – and there was no evidence of my daughter being anywhere near that point.

But as time passed, it became clear that we needed support to make our new normal and to live now. Forget Me Not gave us that support. They gave us our lives back when we had thought that would not be possible; we received play therapy using their music and sensory rooms, hydrotherapy and even overnight stays. They came to our house to support us in day to day life. They were always at the end of the phone, and of course they cared for us all at the end of Thea's life and have continued to support me, my husband and son as we try to come to terms with her death. Our lives were not easy, but without Forget Me Not we would not have been able to give Thea the quality of life that she deserved.

I was shocked to learn that children's hospices are struggling to find the money they need to provide this care and support to families like ours. A recent Together for Short Lives study has shown that the average funding each children's hospice charity receive from NHS clinical commissioning groups (CCGs) has fallen by 2% in the past two years. The state provides just one pound in every five spent by children's hospices. I just can't believe that 15% of children's hospices receive nothing at all from CCGs.

Like other parents of seriously ill children, I was delighted that NHS England chief executive Simon Stevens announced in December that, over the next five years, funding in addition to the £11million grant could be available to children's hospices each year, if CCGs also match it. I am, however, dismayed by subsequent announcements that have suggested that children's hospices are not actually guaranteed to continue to receive the grant, or even get more NHS money.

Thea has sadly passed away. But I will make it my life's mission to ensure that every child like her has a hospice to support them. That every family who has a child who will likely die before they reach adulthood has the support to ensure that the years that they have with that child are the best years of their lives. Please help me achieve this by guaranteeing the Children's Hospice Grant for the future – and increasing it to £25million.

Yours sincerely

Gabriella Walker