

*Please include these seven pledges in your party's manifesto. They will transform the short lives of children and young people with life-limiting and life-threatening conditions and their families:*

**1. Parity and sustainable funding: *funding not failing children's palliative care services***

"We value the life of a child as much as the life of an adult. We will therefore make sure that children's hospice and palliative care charities in England receive the same share of state funding that adult hospices do (33% of charitable costs). We will increase the Children's Hospice Grant to £25million per year for the lifespan of the next Parliament. We will also review the amount of statutory funding being allocated to NHS-provided palliative care services in England. We will do this with a view to making sure that these services are also put on an equitable and sustainable financial footing."

**2. DLA: *lifting the unfair 'baby benefit bar'***

"We will lift the baby benefit bar by giving financial support to seriously ill children under the age of three which is equal in value to the higher rate mobility component of the disability living allowance (DLA). This will support over 2,700 seriously ill children and their families in the UK to access the vital transport they need to have the best quality of life possible."

**3. Social care: *ensuring a further crisis is averted by recognising the needs of children now***

"Thousands of children need social care too and some rely on services throughout their childhood and beyond, including short breaks for respite. We will therefore include children's services in new proposals for ensuring long-term, sustainable funding for social care in England."

**4. Workforce: *investing in a children's palliative care nursing workforce to avoid a crisis in support***

"We will convene a UK-wide summit to develop an approach to boosting the number of nurses available to provide palliative care to children and young people with life-limiting and life-threatening conditions."

**5. Transition: *building a bridge over the cliff edge of care between children's and adult services***

"We will invest in seed-funding for voluntary sector organisations to set up age-appropriate services for young people in England transitioning from children's to adult palliative care services."

**6. Funerals & bereavement: *supporting families when they are most in need***

"Losing a child is a parent's worst nightmare. Sadly, for thousands of parents every year, this nightmare becomes a reality. So that bereaved parents across the UK to have some time to

grieve, we will give them two weeks' statutory leave following the death of their child. We will also make child deaths exempt from the new death certification fees structure."

## **7. A holistic approach to children's palliative care: *joining up services through a people centred approach***

"Families of children or young people with life-limiting or life-threatening conditions should not have to fight to get the care and support they need. We will make sure that every child and young person in England with a life-limiting or life-threatening condition has access to a single assessment and plan which integrates their health and social care, whether they have a special educational need (SEN) or not. We will also produce a cross-departmental strategy for children's palliative care with a clear ministerial lead."

### **Background to the manifesto asks**

- There are more than 49,000 children and young people in the UK with life-limiting and life-threatening conditions, a number which is growing as a result of advances in medical technology and better care. However, this has not been matched by an increase in financial support for these children and their families.
- The current policy and funding environment has failed to adequately acknowledge these children, the needs of their families, nor those that work tirelessly to support them. The quality of support received is largely [determined by where they live](#), not what they need. They are just about managing, but families are reaching breaking point.
- The 2017 General Election provides an opportunity for all political parties to respond to this crisis by making seven simple manifesto commitments to improve the quality of life and the quality of end of life care for children with life-limiting conditions.
- Together for Short Lives is the UK wide charity which, together with our members, speaks out for children and young people who are expected to have short lives. We are here to help these children and their families have as fulfilling lives as possible and the very best care at the end of life. with our members, gives voice, help and guidance for these children, young people, their families and those that support them.

### **The economic case for investing in children's palliative care**

- In December 2016, the National Institute for Health and Care Excellence (NICE) published the clinical guideline on '[End of Life Care For Infants, Children and Young People with Life-Limiting Conditions: Planning and Management](#)'.
- NICE calculate that by investing £12.7million in implementing the guidance, non-cash savings worth £34.7million would be released back into the NHS in England.
- Voluntary sector children's palliative care providers offer further savings: a [report](#) published by the Rainbow Trust Children's Charity calculates that the family support it offers saves the health and social care system at least £2 million each year.
- We are asking all political parties to show leadership, commitment and political will to realise the potential of this investment, the benefits to children and families, those that support them and to the NHS.

## Seven manifesto pledges which will transform the short lives of children and their families

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We are asking all political parties to make seven simple manifesto pledges which would transform the short lives of children with life-limiting and life-threatening conditions - and their families. We can't change the diagnosis, but we can help children and families make the most of their time together.

### 1. Parity and sustainable funding – *ensuring the life of a child is as valued as the life of an adult*

We value the life of a child as much as the life of an adult. We will therefore make sure that children's hospice and palliative care charities in England receive the same share of state funding that adult hospices do (33% of charitable costs). We will increase the Children's Hospice Grant to £25million per year for the lifespan of the next Parliament. We will also review the amount of statutory funding being allocated to NHS-provided palliative care services in England. We will do this with a view to making sure that these services are also put on an equitable and sustainable financial footing.

*"Those commissioners who constructively engage continue to do so; those who don't, don't! Without any levers for commissioners to engage with us - or a change of ethos - it is hard to make in-roads. Despite our own efforts and encouragements from both the strategic clinical network and a local MP, engagement in meaningful dialogue with our most local commissioner remains a challenge.*

*"Relationships are improving but it is hard work mostly due to NHS systems and processes that do not make it easy for voluntary sector involvement... [W]e have to fight hard to stay at the table whereas previously we were recognised in our own right as experts in our field regarding the management of palliative patients."*

A children's hospice in England

- Children's palliative care is [woefully underfunded and resourced](#). For example, on average, adult hospices in England receive 33% of their funding from statutory sources and children's hospices receive an average of 22%. Unless this funding gap is addressed, then we, as a country, are making a judgement that we place greater value on the life of an adult than that of a child. This is neither moral nor fair.
- In England, local authorities' contribution to the cost of providing children's palliative care in the voluntary sector fell significantly by 61% between 2014/15 and 2015/16 when the cost of providing complex care increased (up 10% this year). It is simply unsustainable for [local authorities to contribute just 1% to the costs](#) incurred by children's palliative care charities.
- We are asking all parties to follow the example of the Scottish Government, who have allocated £30million over 5 years for children's hospices so there is parity with funding for adult hospices. Children and young people with life-limiting and life-threatening conditions in England, Northern Ireland and Wales deserve the same recognition, opportunity and support as those in Scotland.

## **2. DLA – lifting the unfair ‘baby benefit bar’**

We will lift the baby benefit bar by giving financial support to seriously ill children under the age of three which is equal in value to the higher rate mobility component of the disability living allowance (DLA). This will support over 2,700 seriously ill children and their families in the UK to access the vital transport they need to have the best quality of life possible.

*“My daughter has had a tracheotomy with a ventilator attached 24/7 since the age of eight months. She needs these for an undiagnosed neuromuscular condition. She cannot support herself at all. Carrying her, her vent, her suction machine, her oxygen, her emergency equipment to our car and back for two years was extremely difficult. We ended up selling our family car and purchasing a wheelchair accessible vehicle (WAV) privately as it just became too hard to carry her as she grew.”*

A parent of a child who needed palliative care

- We are calling on all parties to commit to righting a wrong by lifting the baby benefit bar which currently means that families with children under three are unable to access the mobility component of the Disability Living Allowance (DLA) available to those with children over three.
- This benefit would allow families to buy or have access to a specially adapted vehicle which would allow families to travel safely with their children and the bulky life support equipment they need.
- The change required to support these families would amount to just over £8m a year. It would transform the lives of over 2,700 children and their families across the UK.

## **3. Social Care – ensuring a further crisis is averted by recognising the needs of children now**

Thousands of children need social care too and some rely on services throughout their childhood and beyond, including short breaks for respite. We will therefore include children’s services in new proposals for ensuring long-term, sustainable funding for social care in England.

*“Without Naomi House, you just wouldn’t be able to take a break. There isn’t anywhere else that offers the care and support we get there.*

*“Naomi House has had a major impact on our family. Lloyd is a growing boy and Naomi House gives him the independence that boys at his age need. The fact that there are male carers and nurses around is really important and the hospice is so flexible; it is great that they are able to take in and care for so many different children with diverse conditions and needs.*

*“Naomi House allows us to have a more normal life and the same is true for Lloyd. He met his best friends at the hospice. He loves catching up with them and they have such a great time together. They couldn’t do that without Naomi House. He can’t have his friends stay over like normal children do; there simply isn’t space for all of the wheelchairs.*

Neil, father of Lloyd, a young man with Duchenne muscular dystrophy. From Together for Short Lives guide to jointly commissioning children's palliative care, available at [www.togetherforshortlives.org.uk/jointcommissioning](http://www.togetherforshortlives.org.uk/jointcommissioning)

- The recent focus on social care across all parties is welcomed. However, [children and their families are excluded from this debate](#).
- Children and young people with life-limiting and life-threatening conditions and their families rely on lifeline social care services like short breaks (respite care), transport, counselling, equipment and home adaptations. Despite this, [evidence uncovered by Together for Short Lives](#) has found that 4 out of 5 (81%) local authorities are failing to plan and fund care for children and young people who need palliative care. 1 in 7 (14%) councils are failing to commission short breaks for children with life-limiting and life-threatening conditions.
- [Local authority funding for children's palliative care charities has fallen dramatically](#), down by 61% over the last year - only contributing 1% of the costs incurred by these organisations.

We are asking all parties to hold local authorities to account to increase funding for short breaks for disabled children, provided at home, in the community and in children's hospices.

#### **4. Workforce – investing in a children's palliative care workforce to avoid a crisis in support**

We will convene an UK-wide summit to develop an approach to boosting the number of nurses available to provide palliative care to children and young people with life-limiting and life-threatening conditions.

*"We have recently stopped providing 24/7 care, even for those at end of life, which is very difficult for staff and families as this should be our 'core business'. Previously we have offered 24/7 advice for all, however this is no longer sustainable. We hope that, if we can recruit to vacant posts, we will resume 24/7 end of life care as soon as we can."*

A UK children's hospice

- There is currently a [shortage of children's palliative care nurses](#) and this limiting the care provided to children and families.
- The number of children with life-limiting and life-threatening conditions who rely on children's hospice services is increasing. Yet the nursing shortfall means that children's hospices are increasingly being forced to cut back the vital palliative care they can offer to families.
- The majority of services (58%) say that vacancies are having an impact on care - including a reduced offer to families or reduced short breaks. Nearly one fifth (17%) state that they are being forced to close beds. 13% of services report that vacancies affect their ability to provide 24/7 care. Short breaks are a lifeline to families and can reduce parental stress and the risk of family breakdown.

- The average nurse vacancy rate in UK children’s hospice organisations was 11% in December 2016 (an increase of 1% on the rate in 2015) and higher than the overall NHS nurse vacancy rate of 9% in England, Northern Ireland and Wales. This represents over 130 full time posts unfilled.
- [Evidence published](#) by the Royal College of Paediatric and Child Health (RCPCH) shows that in the year to September 2015, shortages of nurses and/or doctors led to periods of closure to new admissions by 31% of paediatric inpatient units and 41% of neonatal units across the UK. The evidence also highlights substantial vacancies at both consultant and trainee levels, the low number of academic consultants and the fact that General Practitioners and Practice Nurses have limited training in child health.
- We are asking all parties to take action to address this gap across the voluntary and statutory sectors. We would like the next government to convene an UK-wide summit to develop an approach to boosting the number of nurses available to provide palliative care to children and young people with life-limiting and life-threatening conditions.

**5. Transition – building a bridge over the cliff edge of care between children’s and adult services**

We will invest in seed-funding for voluntary sector organisations to set up age-appropriate services for young people transitioning from children’s to adult services in England.

*“The jump into adult services - and it is a big jump - was hard for me. There is very little support specifically for young adults. We are no longer children in the medical and social definition, we are young adults, but adult services aren’t equipped to deal with the wants and needs of young adults.*

*“What do I want to see changed? I want the NHS to recognise that young adults are distinct from both paediatrics and adults, we are a subgroup of adults who are no longer children but are not mature adults yet either. We want to be helped to live our lives, to gain some independence and to allow us to do things other people our age do. I want to see more individualised care, we aren’t a one-size-fits-all group. We’re unique individuals, with different wants, needs, hopes and dreams.*

Lucy Watts MBE, a young woman living with a life-limiting condition

- Advances in medical technology mean that the number of young people with life-limiting and life-threatening conditions is increasing, but a shocking number of young people are not getting the support and care they need. There is an urgent need for new initiatives to transform the experience of young people with life-limiting conditions as they move from children to adult services.
- Together for Short Lives has launched a grant programme to help support innovative approaches and partnerships to address this gap and generate learning to build an evidence base of good practice.
- We are asking all parties to invest in seed-funding for voluntary sector organisations to set up age-appropriate services for young people transitioning from children’s to adult services.

## 6. Funerals & bereavement – *supporting families when they are most in need.*

Losing a child is a parent's worst nightmare. Sadly, for thousands of parents every year, this nightmare becomes a reality. So that bereaved parents across the UK have some time to grieve, we will give them two weeks' statutory leave following the death of their child. We will also make child deaths exempt from the new death certification fees structure.

- Every bereaved parent should be able to bury their child without having to worry about the bill.
- As part of the [Fair Funerals Campaign](#) we are calling on all parties to [follow the lead in Wales](#) to scrap burial charges for children.
- Support for families following the death of their baby is a crucial part of the children's palliative care pathway. Yet support for bereavement is woefully inconsistent across Clinical Commissioning Groups and Local Authorities, leaving many families isolated and alone: Nearly a fifth (17%) of CCGs do not commission bereavement support; More than two-thirds (68%) of local authorities do not commission bereavement support.
- The new children's palliative care funding model produced by NHS England does not include bereavement care for parents after a baby or child dies.
- We call all parties to commit to ensuring that bereavement support is offered and engaged at the time of diagnosis and not just at the time of death and to support the introduction of two weeks' statutory bereavement leave, as detailed in the [Parental Bereavement Leave \(Statutory Entitlement\) Bill](#).

## 7. A holistic approach to children's palliative care – *joining up services through a people centred approach*

Families of children or young people with life-limiting or life-threatening conditions should not have to fight to get the care and support they need. We will make sure that every child and young person in England with a life-limiting or life-threatening condition has access to a single assessment and plan which integrates their health and social care, whether they have a special educational need (SEN) or not. We will also produce a cross-departmental strategy for children's palliative care with a clear ministerial lead.

*"It's a minefield and you get frightened going through it. Services don't join up and people don't explain things to you. By the time I had made it all fit together, my child had passed away.*

*"That makes me sad that he could have had so much more out of life.*

A parent of a child who needed palliative care

- Palliative care is a holistic approach which includes health, education, social, community engagement and spiritual intervention and support. Many children and young people with life-limiting and life-threatening conditions would benefit from an integrated single assessment and plan. Children who need palliative care who have complex special educational needs (SEN) can access an education, health and (EHC) plan. However,

children and young people with life-limiting conditions who do not have SEN are not able to do so.

- A focus on government departmental budgets mean that the possible benefit of a holistic approach to care around the person is fragmented and siloed.
- We are calling for all parties to commitment to developing a cross-departmental strategy for children's palliative care with the appointment of a minister with clear leadership and focus for this work.
- A strategy and ministerial post which focusses on implementing the policy framework we recommend in this document would enable the next government to realise the [2016 end of life choice commitment for children and young people in England](#). It would also help to implement the NICE clinical guideline on '[End of Life Care For Infants, Children and Young People with Life-Limiting Conditions: Planning and Management](#)'.