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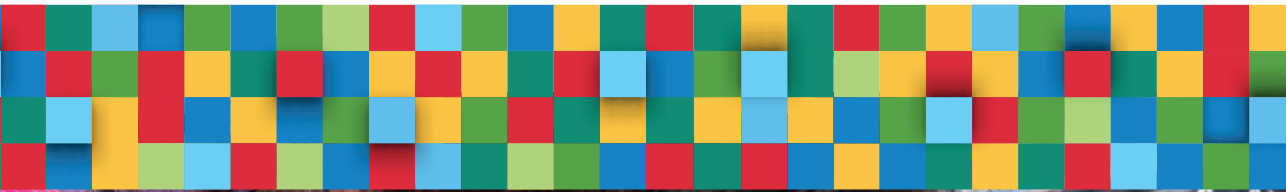


**Children's
Hospice
Association
Scotland**

Children, young
people and
their families
at the heart of
all we do.

2016 Scottish Parliament Election Manifesto

Better Care for Children with Shorter Lives



Introduction



Children's Hospice Association Scotland (CHAS) has launched a manifesto for improving holistic palliative care for babies, children and young people aged 0-25 years in Scotland.

We are asking all politicians to put hospice services for babies, children and young people with life-shortening conditions at the heart of Scotland's healthcare debate in this year's Scottish Parliament election and beyond.



Foreword



The 2012-2016 Holyrood term has delivered a range of significant milestones for children's palliative care in Scotland. From the key recommendations delivered by the Scottish Parliament's seminal inquiry, *We Need to Talk About Palliative Care*, to the pledge to support and promote the further development of holistic palliative care for 0-25 year-olds delivered in the Scottish Government's new *Strategic Framework for Action on Palliative and End of Life Care*, the services offered by CHAS have been at the forefront of policy makers' minds.



Yet there is so much more to do. The most up-to-date research tells us that there are more than 15,000 babies, children and young people with life-shortening diagnoses in this country; a far higher number than previously estimated. CHAS has a proud track record of caring for these age groups and is committed to delivering services where and when they are needed.

To do that we need to work with politicians and policy makers to ensure that CHAS has the right support from our partners across the NHS and local authorities to meet the opportunities and challenges that lie ahead. That means ensuring that every child who needs access to CHAS services has the opportunity, that families have the widest range of support that meets their individual needs, and that CHAS is sustainably funded and resourced.

Please be part of this by reading our manifesto and **helping us deliver the best possible care for children with shorter lives.**

Maria McGill
Chief Executive
CHAS

How



We're calling for politicians to ensure that Scotland offers the best possible system of holistic palliative care for the 0-25 years age group.

1. Improved access to care and support

Independent research¹ commissioned last year by the Scottish Government and CHAS established that there were 15,404 babies, children and young people aged 0-25 years with life-shortening diagnoses including congenital abnormalities, oncology and neurology; a far higher number than previously estimated.

It is clear that more children and young people of all ages in Scotland with life-shortening conditions should have input from palliative care services.

That's why we're asking politicians to ensure that:

- Children under 1 year of age are seen as a priority group for input from palliative care services
- Age-specific palliative care services for young people (16-25 years) with a life-shortening condition in Scotland are developed
- Palliative care services are able to provide culturally competent care to children and young people from all ethnic groups
- Future development of palliative care services in Scotland ensure priority access to services for children and young people from areas of high deprivation
- Specialist psychological and emotional care is available to children and young people and all their family members

¹University of York (2015), Children in Scotland requiring Palliative Care: identifying numbers and needs (The ChiSP Study) - <http://www.york.ac.uk/inst/spru/research/pdf/chisp.pdf>

2. Better services for children and families

CHAS is the only hospice service in Scotland for babies, children and young people with life-shortening conditions. Since 1992 CHAS has consistently met the needs of children and their families, but we need politicians' help to do more.

That's why we're asking politicians to ensure that:

- There is increased access to specialised palliative care and support in children's hospitals and in the community across Scotland
- Specialist residential provision is recognised as an important part of the care required by children with life-shortening conditions living in Scotland
- Tailored support is provided to young people as they plan their transition from CHAS to age appropriate care services
- Palliative care services are supported to engage more in activities which educate and challenge societal perceptions of living with life-shortening conditions and the likelihood of early death
- Palliative care services for babies, children and young people are resourced to incorporate domestic support to families within their portfolio of services
- Extensive proactive support is provided for parents that meets their personal psychosocial needs as their child approaches death and in bereavement



3. Fairer resourcing for children, young people and their families

In order to support the growing numbers of babies, children and young people and their families needing palliative care, politicians need to commit to update the way in which services are funded.

More reliable funding from public sector partners will allow CHAS to reach and support more of the two thirds of babies, children and young people who die each year in Scotland without access to specialist palliative support.

The most recent statutory guidance requires the NHS to fund 50% of agreed service costs for adult hospices and 25% of agreed service costs for childrens hospices in Scotland. However, CHAS is yet to receive the full 25% statutory funding to deliver and improve services for children and young people (aged 0-25 years) with palliative care needs.

This is a matter for the Scottish Government, MSPs, NHS boards and local authorities to address together and that's why we're calling on all politicians to support the principle that statutory funding for CHAS must be brought in line with the 50% of costs rightly provided to adult hospice services.



About CHAS



Children's Hospice Association Scotland (CHAS) is the only hospice service in Scotland for babies, children and young people with life-shortening conditions. CHAS was set up in 1992 by a group of parents who wanted to provide a free, dedicated hospice service in Scotland that met the needs of children and their families.

We provide Scotland's only specialist palliative care service responding to the needs of children and their families, offering care and support wherever the family chooses. This support can either be at our two hospices, Rachel House in Kinross and Robin House in Balloch, and / or in a family's home through CHAS at Home or in a children's hospital setting.

For further information on the [CHAS manifesto for improving holistic palliative care for children and young people aged 0-25 years in Scotland](#), please contact **0131 444 1900**.

