

Unwavering Care: A Manifesto for Children Who Die Young General Election 2024

“Children with short lives can't wait... They need to be making memories, experiencing what they can, being happy”
(Parent of a child supported by CHAS)

Three children die each week in Scotland from an incurable condition - and the number of children in Scotland with palliative care needs is going up.

Their time is precious, and so ahead of the General Election, we are urgently calling on all political parties and candidates to back a number of key priorities.

Together, we can ensure that seriously ill children and their families receive unwavering care, at every step on this hardest of journeys.

Increased access to services

Although health and social care is devolved to the Scottish Parliament, funding for services in England has significant implications for the funding and provision of services in Scotland and the other devolved nations through Barnett Consequentials. In Scotland, children's hospices are still not funded sustainably on a long-term basis.

We are calling on all parties and candidates to support children who may die young and their families by:

- Ensuring that there is sufficient and sustainable funding for health and social care, including a new funding solution for hospices and palliative and end of life care – to end the postcode lottery in access, strike a fair balance between state funding and charitable donations, and ensure services are fit for the future.
- Increasing funding for palliative and end of life care research from 0.2% of health-related research spending to 0.5%.

Improved support for families

“Having a disabled child costs so much more than having an able-bodied child, just to do simple things... as well as life being so much more difficult in general. Having financial stress on top of that is an added burden we don't need”

(Parent of a child supported by CHAS)

We know there is a strong link between deprivation and having a seriously ill child – the families who need our services are 50% more likely to be living in the most deprived parts of Scotland compared with the least deprived.

Life with a child with complex medical needs can result in additional expenses – such as specialist equipment, adaptations, and higher energy bills – at a time when family members are often less able to work due to their caring responsibilities. We are calling on all parties and candidates to support children who may die young and their families by:

- Protecting everyone with a terminal illness from high energy costs through targeted support, a social tariff on energy prices, and a commitment to cover the cost of running essential medical devices at home.
- Improving support for families and carers of people living with a terminal illness – including by better identification, needs assessments, financial and bereavement support for carers and extending statutory bereavement leave and pay to more bereaved people.

About CHAS

Children's Hospices Across Scotland (CHAS) is the single specialist provider of hospice services for babies, children and young people (0-21) and their families across Scotland. We provide unwavering care for children who may die young and their families, at every step on this hardest of journeys – focussing on the three critical stages where families tell us they need help most.

These are: learning your child is seriously ill and may die young; living well; dying well and bereavement. CHAS' services include:

- **Two hospices:** Rachel House (Kinross) and Robin House (Balloch) that provide respite, palliative and end of life care from CHAS doctors, nurses, pharmacists, physiotherapists and other professionals.
- **Outreach:** Our outreach team operates in every local authority area - providing highly-skilled nursing care for children in their own homes, as well as a full family support service. This includes social work, income maximisation, bereavement support, transition to adult services for 16 – 21s, and a dedicated activities team.
- **Hospital Teams:** CHAS funds a specialist team in every children's hospital in Scotland, including funding the only specialist medical posts in paediatric palliative care in Scotland. Our nurses provide specialist support alongside the NHS in Glasgow, Edinburgh and Aberdeen.

For further information, please contact:

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