Children's Hospices Across Scotland

Rewriting the future of how Scotland cares for dying children

CHAS Manifesto for the Scottish Parliament 2026 Election

Contents

Overview

Three children die in Scotland every week with a life-shortening condition. This manifesto is inspired by them and their families.

Learning a child has a life-shortening condition is devastating, but the endless fight for families to get the support they need to live well is even more so. This needs to change.

> **Children's Hospices Across Scotland (CHAS) calls on all political party candidates and the next Scottish Government to help CHAS rewrite the future of how Scotland cares for dying children.**

Families tell us there are three critical moments when support matters most:

1) When their child is diagnosed
2) While living with a life-shortening condition, and
3) When a child is dying and the years that follow.

There is only one chance to get it right for every child, and for every family.

Over 16,700 children in Scotland are seriously ill and may die young, and this number is rising rapidly, increasing by 40 per-cent over the last 15 years[1]. Thanks to medical advancements, many children now live into adulthood, but with multiple, serious health conditions which require 24/7 support. Their hold on life is fragile and uncertain.

CHAS is the single specialist provider of hospice services for babies, children and young people (aged 0-21) and their families across Scotland, giving children and families choice about the care and services they receive, wherever they are.

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[1] Children in Scotland requiring Palliative Care 3 (The ChiSP 3 Study) 2020

We know almost 50 per-cent of families caring for children living with life-shortening conditions are likely to live in the most deprived areas of Scotland[2]. This means many children are living and dying in poverty, with families unable to access all the support they need from physical and emotional care, to benefits, housing, education and recreation. This is a national injustice.

Every child with a life-shortening condition should live and die with dignity. No family should ever face the death of their child alone. Every community must be equipped to support the physical, emotional, spiritual, and financial needs of children and families with love, compassion and confidence. Service providers must think about the child within the family, and the family within their community.

The 2025 publication of Scotland's national palliative care strategy, *Palliative Care Matters for All*, is a welcome step forward to strengthen palliative care access and a and enable communities to be part of a once for Scotland approach. But without a strong statutory funding foothold, clear accountability, and coordination across public health services, vulnerable families risk losing choice over the care and support they receive.

> There are no words to explain how hard it is as a parent to plan for your child's death.
> Gillian Donald, Fin's mum

To rewrite the future of how Scotland cares for dying children, CHAS calls for action from all 2026 political party candidates in three key areas:

1) Ensure every child and their family has access to the right care from the start,

2) Help families to live well through every transition, even in the face of death, and

3) Support families to have a meaningful goodbye based on choice.

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[2] Children in Scotland requiring Palliative Care 3 (The ChiSP 3 Study) 2020

Access to the right care

Ensuring every child and their family has access to the right care from the start.

From the moment a child is diagnosed with a life-shortening condition, families begin a journey filled with uncertainty, fear and overwhelming change. To rewrite the future of how Scotland cares for dying children, support must start immediately and be delivered with compassion, skill and continuity.

Palliative care helps recognise and manage uncertainty as a shared human experience in serious illness, and responds to it with compassion, communication, and openness[3]. The goal is not to solve the unsolvable, but to help children, young people and their families to come to terms with their new circumstances and feel more supported and empowered while living with the unknown[4,5].

Many children and young people struggle to access all the palliative support they need as a result of significant gaps in end-of-life care, including 24/7 medical advice and nursing care.

> When our son Christian was born, we were met with a wave of uncertainty. He had complex medical needs, and those early days were full of hospital appointments, fear, and so many unknowns. It was overwhelming, not just for me but for our whole family.
>
> Claudia Romero, Christian's mum

Integrated model of delivery: Specialist Paediatric Palliative Care Clinical Advisory Service (CAS)

CAS is a collaboration between CHAS and NHS Health Boards for doctors, nurses, and health and social care professionals supporting children and young people with life-shortening conditions.

The service provides national, 24/7 access to specialist paediatric palliative care advice and care around dying for children and young people across Scotland who are unstable, deteriorating, or at the end of life.

CAS empowers and enables local teams to deliver high-quality care, supporting children to remain in their preferred place of care wherever possible. Long-term sustainable funding and pay parity with the NHS is needed to maintain this support for children, families and workforces.

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[3] Dr A Dempsey; Palliating uncertainty: tools from the pragmatism of William James; University of Oxford

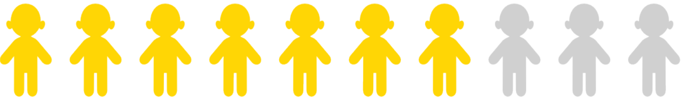
[4] Dr A Dempsey; Palliating uncertainty: tools from the pragmatism of William James; University of Oxford

[5] Etkind, S et al (2024) Uncertainty in serious illness: a national interdisciplinary consensus to identify clinical research priorities

Their families also often experience trauma and carer burnout, creating further barriers in access to and delivery of support. This is particularly acute for families living in rural and island communities, areas with high prevalence of multiple disadvantage, and minoritised ethnic communities.

Children and young people with life-shortening diagnoses are disproportionately high users of healthcare. They account for approximately 7/10 paediatric intensive care bed days, and 2/10 hospital inpatient bed days.[6]

7/10 Paediatric Intensive Care Bed Days



2/10 Hospital Inpatient Bed Days

But many children and families want to receive care close to home. Generalist health and social care professionals, including GPs and pharmacy, however, are not always resourced or empowered to deliver palliative care for children and young people with life-shortening conditions. In turn this contributes to workforce, NHS, and family overwhelm.

> Finding out what really matters to individual children and families and helps support them to make invaluable memories.
> Craig & Kimberley Turnbull,
> Layla's parents

Transforming care and support: Paediatric Care Around Dying Programme (PCAD)

PCAD is a partnership between CHAS, NHS Greater Glasgow and Clyde, and local Health and Social Care Partnerships which delivers a sustainable, child-centred model of care that provides reliable, specialist nursing support 24/7 for children who wish to die at home.

By ensuring 24/7 access to specialist paediatric palliative care nurses, the model enables more families to choose compassionate, well-supported end-of-life care in the place that feels right for them, reducing crisis admissions and easing pressure on acute services.

PCAD will support children and families to choose what matters most to them, ensuring care is delivered with dignity and comfort. To scale it across Scotland, pay parity between hospice and NHS staff will be crucial to ensure continuity of service provision.

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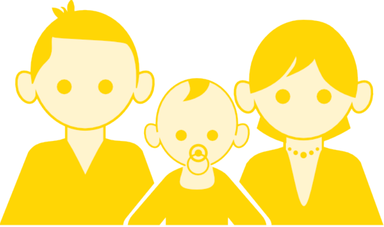
[6] Fraser, L, et all (2023). Children with a Life-limiting or Life-threatening condition in Wales: Trends in prevalence and complexity. Ty Hafen. **approximations for Scotland have been informed by Welsh data.

> We were being led by Matthew, and CHAS was being led by us about what was right for him, and what was right for us as a family, and what we could manage. They let us make the decisions when the time was right for our son.
> Mel Dyer, Matthew's mum

In 2025, CHAS...

supported 800 admissions at our two hospices

provided over 6,400 CHAS at Home hours



delivered more than 12,200 family support interventions

Scotland has a unique model of care for children who die young as CHAS works in strategic partnership with all Scottish NHS Boards, Integrated Joint Boards (IJBs) and Health and Social Care Partnerships (HSCPs).

Joint CHAS/NHS teams in every Scottish children's hospital deliver coordinated, specialist support, ensuring families have real choice at the end of life. This once-for-Scotland approach demonstrates what integrated, compassionate public services can achieve: seamless care across all settings, delivered where and when children and families need it most.

Alongside PCAD and CAS these are preventative, cost-effective services which avoid unnecessary hospital admissions, pressure on the most expensive NHS beds, and help stop families from going into crisis. For every £1 of statutory

funding CHAS receives, it generates £6.24 of public value in return[7]. This returns savings of approximately £15.6 million to the NHS every year[8].

CHAS relies on a fragile mix of public generosity and Scottish Government support to fund essential services. Longer term, if Scotland is to guarantee equitable access to world-class palliative care for everyone, the next Scottish Government must prioritise long term funding for children's palliative care.

Every £1 in statutory funds generates £6.24 of public value saving the NHS around £15.6 million every year.

This is the only way to future-proof the support people rely on. Without this commitment CHAS will be unable to meet growing demand and complexity of palliative care needs.

To bring certainty to how Scotland cares for dying children and support public service reform, the next Scottish Government must:

1) **Fund CHAS sustainably to future-proof the unique and holistic support it provides. This should include inflationary uplifts year on year and pay parity for hospice staff aligned with NHS Agenda for Change.**

2) **Strengthen seamless, community-enabled palliative care across home, hospice and acute hospital settings through coordinated CHAS/NHS action, ensuring children and families have meaningful choice over where they receive care and support.**

3) **Work collaboratively with IJBs to ring fence funding for all health and social care professionals caring for children and young people with life-shortening conditions to be specially trained in supporting their needs in every care setting.**

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[7] York Health Economics Consortium: CHAS - Economic Evaluation of Hospice Services 2021
[8] York Health Economics Consortium: CHAS - Economic Evaluation of Hospice Services 2021

Helping families to live well

Helping families to live well through every transition, even in the face of death.

Rewriting the future of how Scotland cares for dying children means ensuring families can live well today, while preparing for the hardest moments ahead making the choices that are right for them.

Between the ages of 14 and 21, young people with life-shortening conditions will typically navigate a range of transitions across healthcare, social work and education. This process is a struggle, and a source of enormous stress for all involved.

Currently, many young people face limited access to tailored, age-appropriate services that meet their care needs.

Service development is not keeping pace with the increasing numbers of young people with life-shortening conditions transitioning to adult services, resulting in inconsistent support across Scotland.

Families currently experience significant gaps in their care which deteriorate over time. Parents report difficulty in accessing the right social care packages due to staff shortages, a lack of staff with the right skills, unattractive pay and conditions, and location of the family home. This becomes more challenging for families living in rural and island communities.

> “There is limited respite in the Highlands and employing carers is extremely difficult due to our location. Grace Dennison White, Evelyn’s mum”

Parents and carers of children with life-shortening conditions often provide round-the-clock care. This is socially isolating, stressful, and exhausting. The accessibility and quality of support young people receive is critical to the wellbeing of parents and carers and their children, as well as being a cost-effective measure to reduce wider system pressures.

Serious illness, disability and medical complexity all lead to increased costs, such as regular hospital appointments and stays, having to drive bigger vehicles to fit a child's equipment, and housing adjustments to ensure a child can be cared for safely at home.

For families with complex conditions, including children, systemic failures have led to delayed moves out of unsuitable homes. Families are often living in severe hardship while waiting for social housing which meets their needs, impeding their human rights[9,10].

Energy bills are one of the biggest outgoings for families with a child who has a life-shortening condition, averaging over £500 per month. In some cases, this is higher depending on equipment needs, age and efficiency of medical devices, and fuel types which are more variable and expensive in rural and island communities. When combined with income loss from parents having to give up work, many families are living below the poverty line.

The financial, physical and emotional cost of caring for a child or young person can also be a limiting factor in whether parents, guardians or carers are able to get the right support for their own health needs. This contributes to 'missingness' from community health and social care services as a result of not being able to take up or attend appointments which increases reliance on NHS and hospital services and leads to poorer health outcomes and social disadvantage[11].

Parents should be able to be parents, not just carers. Children and siblings should be able to be children, fulfilling their human rights to play, live and have fun[12].

> **Because I look after Kayden full time only my husband can work and, when you have a child with complex needs who relies on a lot of electrical equipment such as a feeding pump, electric bed and overhead hoist, costs add up. I don't know what we would do other than just suffer in silence.** Valerie Trayner, Kayden's mum

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[9] Hasan, S, Menezes, D; Housing for Complex Needs; Heriot-Watt University 2025

[10] Scottish Federation of Housing Associations: Still Waiting 2025

[11] Williamson, A et al 'Missingness' in health care: Associations between hospital utilization and missed appointments in general practice. A retrospective cohort study

[12] United Nations Convention on the Rights of the Child (Incorporation) (Scotland) Act 2024

To rewrite the future and address child poverty once and for all, the next Scottish Government must take preventative measures which support the whole family looking after a child or young person with a life-shortening condition:

1) **Work with IJBs and HSCPs to scope and fund access to age-appropriate services across health and social care for children and young people transitioning into adult services, recognising this may require additional support to recruit and retain highly skilled care assistants.**
2) **Work with IJBs and HSCPs to embed annual health checks, flexible GP and hospital appointments, and improved access to regular screening for families[13,14] of children with life-shortening conditions.**
3) **Implement a Minimum Income Guarantee to ensure an acceptable standard of living that promotes dignity and a decent quality of life.[15]**
4) **Work with UK Government to commit to and implement a social tariff which would reduce energy bills for families by at least 50 per-cent.[16]**
5) **Build more safe, secure, and affordable social homes which meet children and families' needs.**

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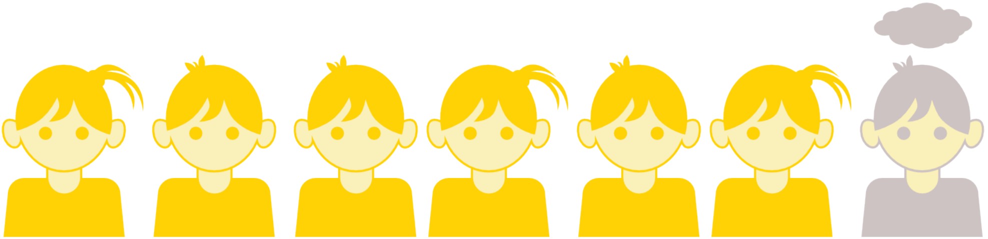
[13] National Carers Organisations Manifesto 2026: Supporting unpaid carers in 2026 and beyond
[14] Williamson, A: Applying a missingness lens to healthcare: missed appointments letters
[15] The Poverty Alliance: Minimum Income Guarantee
[16] Marie Curie Scotland: Dying in Poverty 2025

Supporting families

Supporting families to have a meaningful goodbye based on choice.

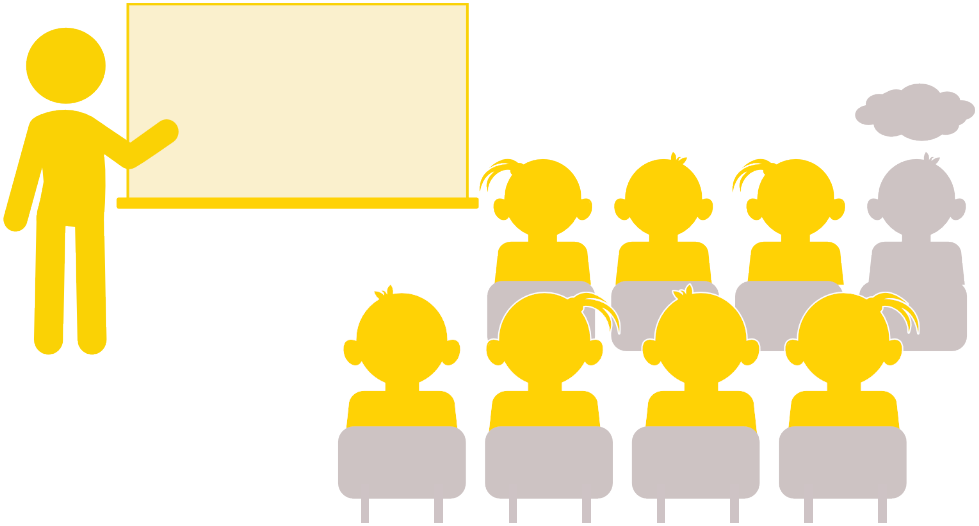
Rewriting the future of how Scotland cares for dying children means ensuring that every family can say goodbye in the way that feels right for them, with dignity, compassion and choice, and continue to be supported for as long as they need.



Approximately 3.5% of children aged 5-16 in the UK (1 in 29) have experienced the death of a sibling or parent

The death of a child is profoundly life changing for every family, often leading to a sense of brokenness, as well as a sudden end to support and benefits, all while families are grieving.

Approximately 3.5 per-cent of children aged 5-16 in the UK (1 in 29) have experienced the death of a sibling or parent[17]. This means a bereaved child is likely to be present in every school class in Scotland.



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[17] Childhood Bereavement Network: Key Statistics

Unsupported childhood bereavement can lead to a significant and often traumatic adverse childhood experience (ACE). An ACE can have a profound, long-lasting public health impact on a child's mental, physical, and emotional health, including increased risk of low school attainment, depression, anxiety, suicide attempts, and substance misuse in adulthood[18].

It is vital siblings and families can access the support they need to help them grieve.

For parents, this could mean help with re-entering the labour market which may require support, counselling and retraining. The more that can be done to help people back into work, the better it is for them, for our communities and wider society[19].

Bereavement support for all health and social care staff involved in supporting children and families is also equally as important, to help them process the impact of caring for dying children often over long periods of time. This is crucial for protecting staff wellbeing and enabling system resilience.

> Grief doesn't have a timeline. And neither does love. CHAS continues to support families, long after the last goodbye.
> Claudia Romero, Christian's mum

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[18] Bereavement in childhood: What we know in 2015; Childhood Bereavement Network accessed via Child Bereavement UK: For adults bereaved as children

[19] Life after death: supporting carers after bereavement: (2020) Marie Curie, Sue Ryder, Enlighten

To truly rewrite the future of how Scotland cares for dying children, the next Scottish Government must ensure families and workforce are supported, not left behind. This means:

1) **Extend Carers Support Payment from 12 weeks to six months after a person's caring role comes to an end to enable parents to grieve, and access support they may need to re-enter the labour market[20].**
2) **Require every school in Scotland to have a bereavement policy as part of ongoing support to children who have experienced a bereavement[21].**
3) **Embed bereavement support in paediatric palliative care training for generalist health and social care staff.**

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[20] Life after death: supporting carers after bereavement: (2020) Marie Curie, Sue Ryder, Enlighten

[21] UK Commission on Bereavement: Bereavement is Everyone's Business: Children & Young People

Making it happen

CHAS knows time is precious for children, young people and families and we have a clear message for the next Scottish Government and all political party candidates in the 2026 Scottish Parliament Election:

> **We need to be courageous, and we need to play as one team, with children, families, Governments, Scottish Parliament, communities, the NHS, hospices and care providers working together.**

We want every candidate to help CHAS rewrite the future of how Scotland cares for dying children, to walk with them and their families with love and compassion during the hardest of times.

Let's get to work.

Ensure every child and their family has access to the care from the start

1) **Fund CHAS sustainably to future-proof the unique and holistic support it provides. This should include inflationary uplifts year on year and pay parity for hospice staff aligned with NHS Agenda for Change.**

2) **Strengthen seamless, community-enabled palliative care across home, hospice and acute hospital settings through coordinated CHAS - NHS action, ensuring children and families have meaningful choice over where they receive care and support.**

3) **Work collaboratively with IJBs to ring fence funding for all health and social care professionals caring for children and young people with life-shortening conditions to be specially trained in supporting their needs in every care setting.**

Help families to live well through every transition, even in the face of death

1) **Work with IJBs and HSCPs to scope and fund access to age-appropriate services across health and social care for children and young people transitioning into adult services, recognising this may require additional support to recruit and retain highly skilled care assistants.**
2) **Work with IJBs and HSCPs to embed annual health checks, flexible GP and hospital appointments, and improved access to regular screening for families[22,23] of children with life-shortening conditions.**
3) **Implement a Minimum Income Guarantee to ensure an acceptable standard of living that promotes dignity and a decent quality of life.[24]**
4) **Work with UK Government to commit to and implement a social tariff which would reduce energy bills for families by at least 50 per-cent.[25]**
5) **Build more safe, secure, and affordable social homes which meet children and families' needs.**

Support families to have a meaningful goodbye based on choice

1) **Extend Carers Support Payment from 12 weeks to six months after a person's caring role comes to an end to enable parents to grieve, and access support they may need to re-enter the labour market[26].**
2) **Require every school in Scotland to have a bereavement policy as part of ongoing support to children who have experienced a bereavement[27].**
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[22] National Carers Organisations Manifesto 2026: Supporting unpaid carers in 2026 and beyond
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[25] Marie Curie Scotland: Dying in Poverty 2025
[26] Life after death: supporting carers after bereavement: (2020) Marie Curie, Sue Ryder, Enlighten
[27] UK Commission on Bereavement: Bereavement is Everyone's Business: Children & Young People

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