



Time is precious,

time to act



CHAS manifesto priorities 2021-2026 (Session 6)

#IStandWithCHAS

Overview

More children in Scotland have palliative care needs than ever before. Children's Hospices Across Scotland (CHAS) is the single, national and specialist provider of hospice care to children. Help us make sure that although these children might live shorter lives, their time is filled with love, compassion and care. When time is precious, you have to act fast. Let's get it right, now.

That's why we are urgently asking candidates across all political parties to help achieve a shared vision that:

All children with life-shortening conditions and their families should have timely access to high quality care, equally across Scotland, when and where they need it. That support should be seamless, and extend from diagnosis through to either bereavement and beyond, or transition to adult services where needed. And that support needs to be sustainably resourced. When time is precious, children with life-shortening conditions have a right to live their best possible lives.



We're calling on all candidates to stand alongside the 16,700 families across Scotland facing the terrifying heartbreak their child may die young by backing:

- Continued sustainable funding for children's hospice care in Scotland over the next five years.
- A new national plan for palliative care in Scotland that addresses the needs of children.
- More specialist training for health and social care staff, to meet increasingly complex needs.
- Bespoke support for children living into adulthood.
- Better financial support for struggling families, including after a child dies.

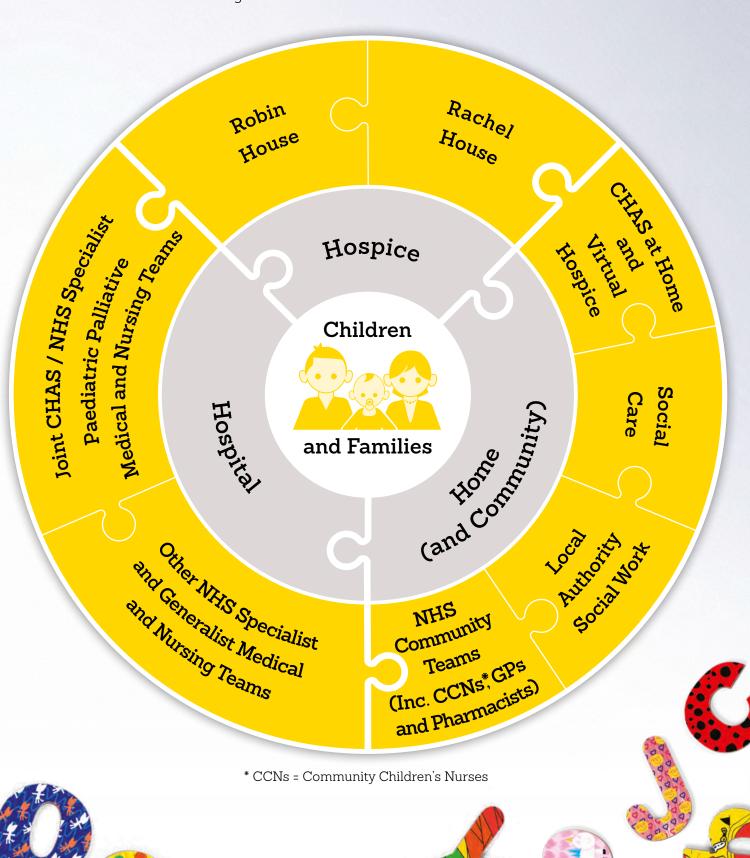






At-a-glance: children's palliative care services in Scotland

The graphic below provides a simplified snapshot of the range of services - across a number of settings - that children with a life-shortening condition and their families can access across Scotland.



Foreword

The latest research shows that there are more than 16,700 babies, children and young people¹ (aged 0-21) across Scotland who may die from a life-shortening condition – more than ever before.²

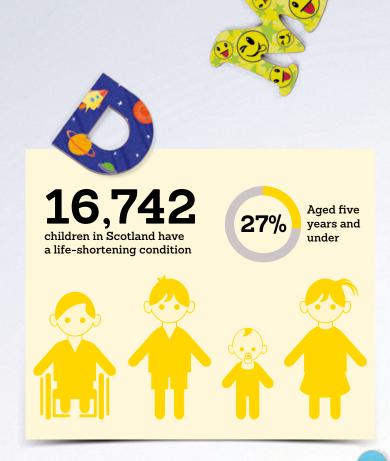
In part that's because as medicine advances, children live longer. And many are stable, for now. That's the good news.

But that also means these children and their families are often living with increasing medical and social complexity. They need the integrated care and support of CHAS, the NHS, Local Authorities and others more intensively, and over a longer period of time. Instability and deterioration, leading to end of life care, may occur at any time. Sadly, three children a week die from a life-shortening condition in Scotland.

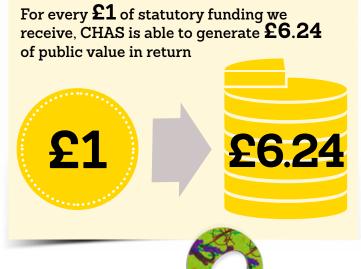
Scotland has a unique model of children's palliative care, with CHAS at the heart of it as the single, national and specialist provider of hospice care to children. Working in partnership with NHS and Local Authority colleagues, we aim to deliver integrated care across a variety of settings: in our two hospices, in hospital, at home and – since the pandemic started – virtually.

Much has been achieved over the course of the last Parliament, and everyone involved with children's palliative care in Scotland should rightly be proud of the progress made. We've seen a recognition of children within the Scottish Government's Strategic Framework for Palliative and End of Life Care (2016); the commissioning of the national Paediatric End of Life Care Network (PELiCaN), which aims to improve access to high quality end of life care for children; and the creation of the first paediatric palliative medicine consultant posts in Glasgow and Edinburgh.

And importantly, the number of children CHAS has been able to support has increased by more than 25% over the past five years. We have been able to reach more children and families thanks to the sustained investment from the Scottish Government of £30m over five years and three-year funding agreements with COSLA, mirrored by the humbling generosity of the Scottish public. We use this funding wisely. For every £1 of statutory funding we receive, CHAS is able to generate £6.24 of public value in return.







¹ Further references to 'children' should be taken as shorthand for babies, children and young people.

Children in Scotland requiring Palliative Care (ChiSP) 3, Public Health Scotland. Sept 2020.



Our ambition is to continue to work in partnership with others to ensure Scotland is the best place to live if you or your child has a life-shortening condition. The current Scottish Government is incorporating the United Nations Convention on the Rights of the Child (UNCRC) into Scots law, and aims for 'Scotland to be the best place in the world to grow up'. CHAS is proud to play our part in ensuring that this is true even for children who may not 'grow up' into adulthood. The UNCRC principles are threaded throughout our work.

We have the ambitious goal to reach every family in Scotland that needs our help, concentrating our efforts where we can make the most impact – among the children who are least stable. And while 2020 has been an extremely difficult year for the families we support – many of whom have been shielding throughout the COVID-19 pandemic – we're determined to learn from this experience.

Our model of care has had to adapt to accommodate the changing circumstances, and support families whose resilience has been challenged, yet some of those innovations brought with them unexpected benefits.

Our 'virtual hospice' brought our services into the homes of families right across Scotland, and we expanded our outreach work to provide more at-home care while our hospices operated under reduced capacity. These changes helped us to widen access to CHAS's services at the most difficult of times, and we are committed to

remaining flexible with our service model as we strive to reach every family who needs us.

We can't do it alone however, and we can't do it without sustainable resourcing. Only together can Scotland deliver world-class care to every child and family, when and where it's needed most – in really tough days, at end of life, and after a child dies.

Working together, we can ensure that all children with life-shortening conditions live their best possible lives; and that when the time comes, no family has to face the death of their child alone.



Rami Okasha CHAS Chief Executive

Rami Charles

In our own voices

All our work is directly informed by the views of the children and families we support. For example, the CHAS Alphabet letters that form the heart of our brand are created by the very best designers – the children we care for.

Over 80 children and families have participated directly in producing this manifesto, and many more have fed into the insights we've drawn on.

We are calling on all candidates, and the next Scottish Government, to listen to their views and hear about their lives.

"Any minute she could die, I'm so nervous it could happen, I live in fear all the time." (Sibling)

Over 90% of the children and families we spoke to said Scotland is a good place to live if you or your child has a life-shortening condition.³ But what is day-to-day life like for these families?

In their own words, here's what children, parents, carers and siblings told us about their lives.

"It's hard knowing you're going to die young. It's difficult to live like that, you want to fit it all in, everything, and you want to do everything before it's too late. Can you image how difficult that is to deal with every day – knowing what's going to happen? It's devastating." (Young person)

"My brother is inspirational, he goes through so much but always smiles." (Sibling)

"My daughter inspires me every day. Give our children a chance. Look past their condition, understand them, and include them properly. What you see isn't who they are." (Parent)

"There is no break, no lie-ins, no lunch, can't stop for a cup of tea, most days I just fight to get up, to have the will to carry on through another day." (Parent)



³ Survey conducted by CHAS September 2020. The survey received 67 responses.

1 Timely access to care and support, when and where needed

66 Having a child with a life-shortening condition means that circumstances can change very quickly. It's difficult to plan when health changes day to day. Being able to access support quickly when things are tough would help so many families. (Parent)

Scotland's Health and Social Care Standards are clear that people should expect 'care and support [that] meets my needs and is right for me'.4

But not every child in Scotland with palliative care needs receives the care and support they need, when and where they need it.



Only a third of families say they have been able to access all the care and support they need.⁵

A new national plan for palliative care

Children's palliative care is different to adult palliative care. Rather than focussing only on the very end of life, it should focus on ensuring quality of life for both the child and the family beginning at the point the condition is diagnosed or recognised onwards. This is especially important as children's conditions can change rapidly and unpredictably.

The next Scottish Government should commit to a new national plan for palliative and end of life care in Scotland. This plan should build on the previous framework and specifically reflect and address the needs of babies, children and young people.



Sustainable resourcing for children's hospice care

The death of a child is indescribably devastating and we will always be grateful to the entire CHAS team. I cannot imagine getting through those days, weeks and months without their support and it's heartbreaking that these services are not an option for all that need it within Scotland – yet. (Parent)

Uniquely in the UK, Scotland has a national model with CHAS as the single specialist provider of hospice care to children. CHAS is here to support children and their families with medical, nursing, social work, emotional and family support, and aims to do so equitably and accessibly in every part of Scotland. Thanks to support from the Scottish Government and COSLA, and the generosity of our donors, we provide all care without charge. For every £1 of statutory funding we receive, CHAS is able to generate £6.24 of public value in return.

We have done this for almost 30 years, but demand for our expertise is rising.

⁴ Health and Social Care Standards: my support, my life, Scottish Government, June 2017.

Survey conducted by CHAS September 2020. The survey received 67 responses.

In the five years since 2014/15, the number of children CHAS has supported has increased by more than 25%, and bed nights for children have seen a 20% increase.

But the stark reality is that we're not currently able to support every child who needs us.

At a time when the number of children in Scotland requiring palliative care is going up, the next Scottish Government should maintain its support for the unique Scottish model of children's hospice care, by continuing its national funding agreement with CHAS at 50% of agreed service costs over five years.

This will allow CHAS to plan and grow our services to meet future demand in the community and in hospitals, working alongside the NHS and Local Authorities to support more children and families who need us.

Number of children supported by CHAS Over 25% increase since 2014/15 +25% Now

For us [CHAS] was an invaluable, and life changing service... giving us some peace in our hearts at least that everything that could have been done for [our son] was done with such love, and such care. (Parent)

Equitable access to 24/7 support at home, at end of life

Provision of palliative and end of life (EOL) care in the preferred setting of children, young people and their families is a priority within palliative care policy and practice. CHAS already works closely with NHS colleagues to support children and families with step-down care from hospital should they want it – either to their home, or to one of our hospices. This enables care in a setting of the family's choice – with associated savings to the health service.

Yet in Scotland, not all families are equally able to access consistent 24/7 support for end of life care at home, if they choose it. And indeed, they may be deterred from choosing this option due to lack of dedicated services.

The choice of care at home may be particularly important for families who, for various reasons, cannot travel from home to hospice or hospital for end of life care, or indeed for families with babies in neonatal units who would otherwise never have the opportunity to take their baby home.

Some Health Boards in Scotland are able to consistently offer this service. In NHS Ayrshire and Arran, the Paediatric Supportive Care Team was put in place specifically to address this issue. The team provides round the clock out of hours medical and nursing support to families in their chosen place of care and CHAS part-funds the doctor leading this team. In NHS Lothian, CHAS has partnered with the Health Board to provide the Care 24 Lothian service, allowing children and their families access to specialist end of life care in their own home. In time, we hope to provide even more out of hours care across Scotland.



⁶ A realist evaluation of the Care 24 Lothian service: summary report, Edinburgh Napier University and Edge Hill University, 2020.



The whole support at home was really amazing. I think it would have been so much more different for me and my grief if [child] died in hospital and we hadn't been given that choice, or in the hospice. (Family who used the Care 24 Lothian service)

CHAS is committed to continuing to work in partnership with NHS community and acute teams across Scotland to support the delivery of this type of care. However, more planning is needed to ensure a consistent and sustainable workforce solution. CHAS would be delighted to support this work, and lend expertise from the Care 24 service.

The next Scottish Government should establish a multi-disciplinary palliative and end of life care workforce plan, covering the next 20 years. This should specifically consider how a specialist 24/7 at-home service at the end of a child's life could be sustainably resourced and delivered - supported by the Paediatric End of Life Care Network (PELiCaN), CHAS, and other partners.







Swift access to critical clinical information

As the clinical complexity of the children we support increases, we are seeing more children transferring between acute (hospital), primary care, community and hospice settings.

Being able to access the most up-to-date clinical information quickly is therefore hugely important to providing swift yet safe care, including in emergencies and at end of life.

CHAS currently does not have access to Health Board clinical portals, which means we do not have direct access to critical information such as test results, current medication and blood work. This can have an impact on how quickly we can deliver care.

In order to receive timely clinical information and deliver better care, CHAS would like to work with NHS Scotland and all Health Boards, to secure a single national data sharing agreement to facilitate CHAS's access to Health Board clinical portals.

And once the new National Digital Platform is developed, the next Scottish Government should ensure that all health and social care professionals involved in the care of the child are able to access, enter and update information on it.

Case Study: CHAS works hand in hand with rural Health Board to deliver EOL care at home

In 2020, CHAS worked closely with a local Health Board to deliver EOL care at home for a child who was not stable enough to transfer to the hospice from her home in a remote, rural location. Her parents and care team felt that end of life care at home was in the best interests of the child and her siblings.

A CHAS Advanced Nurse Practitioner and a CHAS doctor worked closely with the child's NHS team – including the Community Children's Nurse (CCN) and consultant paediatrician – to offer specialist advice on symptom management. A rota was developed with CHAS and the NHS team to cover overnight and daytime support at home. This ensured that the child had prompt symptom relief, allowing her to remain comfortable with her family around her.

On the night she died, the CHAS nurse was present. The child's symptoms worsened and the nurse was able to contact the on-call CHAS doctor to review and prescribe further medication. The child died peacefully with her mum by her side. The NHS team visited the next morning and provided ongoing support to the family.

High quality care and support

66 [Palliative care] is not about giving up but about improving quality of life. (Parent)

Whether it extends only a few days, in the case of a baby born with a severe perinatal condition, or over many years for a child with a long-term respiratory illness, we believe the care and support that children with life-shortening conditions receive should be of the highest possible standard.

Training the next generation in Scotland, for Scotland

Quality of care is directly connected to the quality of a workforce, and in Scotland we have the benefit of a world-class health and social care workforce. But in order to provide children with life-shortening conditions with the highly specialised care they need sustainably into the future, Scotland not only needs a clear workforce plan, as outlined above. It also needs its own training infrastructure.

Paediatric palliative medicine is a medical sub-specialty, however, it is not currently possible to train in Scotland. Those wanting to do so currently have to apply to training programmes in England or Wales.

The two consultant posts in paediatric palliative medicine in Glasgow and Edinburgh, funded by CHAS, will now enable NHS Scotland to apply for recognition to deliver a national training programme in the sub-specialty, delivered jointly by the NHS and CHAS working in partnership.

The next Scottish Government should support the development of a dedicated training programme for paediatric palliative medicine in Scotland as a collaboration between NHS Education Scotland, the General Medical Council, the Royal College of Paediatrics and Child Health, NHS Boards, PELiCaN, and CHAS, to ensure that the consultants in paediatric palliative medicine of the future can train and remain in Scotland.



66 There is a critical need to invest in sub-speciality paediatric palliative medicine training in Scotland, to enhance our ability to deliver high-quality care to children and their families. (Dr Jonathan Downie, Consultant in Paediatric Palliative Medicine - part of the Paediatric Supportive and Palliative Care Team at Royal Hospital for Children, Glasgow, funded by CHAS)

Similarly, it is no longer possible to study for a Community Children's Nursing (CCN) qualification in Scotland.

CCNs are a core part of children's palliative care services and are often described as the bedrock for good palliative care.7 Yet some nurses are having to piece together modules from other courses, or are receiving local training which does not carry a qualification.

With many of Scotland's experienced CCNs coming up to retirement in the coming years, succession planning is urgently needed.

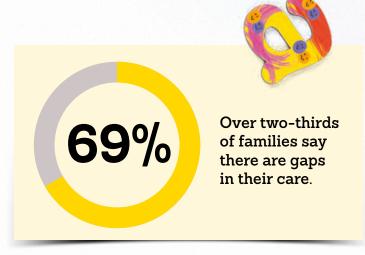
The next Scottish Government should support the development of a Specialist Practitioner Qualification, at Masters level, for Community Children's Nursing.

Futureproofing Community Children's Nursing - RCN Guidance, Royal College of Nursing, 2019.

Dedicated, specialised and streamlined social care support

Parents and carers of children with life-shortening conditions often have to learn complex new skills and procedures in order to care for their child – frequently providing round the clock care. This can be socially isolating, stressful, and exhausting. The quality of the social care support they receive is therefore critically important to the wellbeing of parents and carers, as well as children.

Over two-thirds of families told us there are gaps in their care. There are many contributing factors and differing experiences, however, many families reported that assessments take too long to happen, and that once in place, their care packages do not provide them with the right level of skilled support - such as carers capable of assisting with equipment or checking medications. A key contributing factor that families identified is the level of pay rate they are entitled to under Self-Directed Support - which in turn limits the skillset of the care support they can access.



Some families also reported a lack of allocated social work support for significant stretches. This gap in support can leave parents feeling deprioritised, and having to 'retell their story' to multiple professionals.

Families with children who have a palliative care need often find that they are the liaison point between multiple authorities and professionals involved in their child's life. As professionals who may not be specialists in this area work out the best way to provide support, families describe a lack of joined up working between health, social care, social work and education.

If I have an emergency there's no one to administer controlled drugs. I need to be at home at 8am and 8pm relentlessly because no one can do this. (Parent)

Families need a multi-agency team around a child communicating and sharing information effectively. Without this, it is harder for their needs to be met. CHAS's engagement with families has suggested that professionals would benefit from additional expertise to ensure that there is a confident and supported 'lead professional' assigned within each Child's Plan as part of the GIRFEC approach. Families need this to avoid being left to join the dots themselves.

The next Scottish Government, Local Authorities and Integration Authorities should support families to access more dedicated, specialised and streamlined support, including ensuring that:

- Children with complex needs are assessed quickly for Self-Directed Support.
- Decisions about social care entitlements are focussed primarily on quality and outcomes for the child and family, recognising this may require additional support to recruit and retain highly skilled care assistants.
- Families are supported in line with guidance and standards to work out what they need to improve their lives, and what options are available to them, so that they can have the skilled care they need in place quickly when they need it.
- Each child with a life-shortening condition is allocated a dedicated, named social worker at a Local Authority level. CHAS has committed to linking a specified CHAS social worker with each Local Authority social work team, to provide specialist input to statutory services.
- Health Boards, Local Authorities and Integration Authorities all reinforce the critical role of the lead professional, and the team around the child.

⁸ Survey conducted by CHAS September 2020. The survey received 67 responses.

3 Time is precious

Looking after a sick child is stressful enough without worrying about money. (Parent)

Social security

Children with a life-shortening condition 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 and adaptations – yet family members are often less able to work due to their caring responsibilities.

Research carried out into the experiences of fathers of children with life-shortening conditions reinforces this point. Many fathers who took part in this study revealed how they had to reduce their hours, and in some cases completely stop working to support their wife or partner in providing care to their child, resulting in a reduction or loss of income.

There is always something she needs, specific to her medical issues, and I often find out too late that there was some grant which could have helped with funding some of it. (Parent)

All Local Authorities should work with CHAS and other third sector partners to compile comprehensive advice and guidance for families of children who have life-shortening conditions and may be entitled to financial support. This should pull together into one place all the support and resources that families in their Local Authority area may be entitled to, across public and third sectors.



25%

Children with a life-shortening condition living in the most deprived areas.

17%

Children with a life-shortening condition living in the least deprived areas.

Children with a life-shortening condition are 50% more likely to be living in the most deprived parts of Scotland compared with the least deprived.

Following the death of their child, better support is needed for the parent who has been the child's carer. CHAS supports recent calls by Reform Scotland, Sue Ryder and Marie Curie, to increase the support for bereaved carers in Scotland.¹⁰

Carer's Allowance payment continues for eight weeks after a bereavement, and while the UK Government which will not impose a 'work search requirement' on someone whose spouse or child has died for six months after such a bereavement, recent research shows this is not always matched with additional financial support. 11

The next Scottish Government should extend eligibility for the Carer's Allowance and Carer's Allowance Supplement for up to six months after the person's caring role comes to an end (extending from the current eight weeks), and carers should be supported to re-enter the workforce.

⁹ Exploring Fathers' experiences of living with a child who has a life shortening condition: A Phenomenological approach, Nicky Bridges, CHAS, 2019

Life After Death: supporting carers after bereavement, Sue Ryder, Marie Curie and Reform Scotland, July 2020

Life After Death: supporting carers after bereavement, Sue Ryder, Marie Curie and Reform Scotland, July 2020

Meeting basic needs

It sometimes feels like as a mum all I do is fight for things for my daughter, right down to basic things such as nappies. (Parent)

While caring for children with life-shortening conditions can involve complex medical procedures and specialist equipment, equally important is meeting a child's every day needs.

Some families have reported struggling to get adequate supplies of basics necessities such as the right sized nappies and continence pads. These supplies are typically obtained through a specialist continence service, funded by Health Boards. But in some cases the numbers of items are restricted, and the quotas often do not account for the specific needs of a child who may, for example, be on medication that causes chronic diarrhoea.

The next Scottish Government should work with all Health Boards to support a needs-based approach to accessing to basic supplies for children with life-shortening conditions.

You shouldn't have to compromise. We're told we can't change [our child] before they go out as the pad isn't full. We're told it's OK they're wet, to sit that way. (Parent)





Accessibility and inclusion

Going anywhere for a day out – shopping centres, concert venues, etc – means that if [my daughter] goes to the toilet, I have to either leave her unchanged or we have to leave and go home. Even if it's an hour after we've arrived. (Parent)

The absence of fully accessible toilets means that many children with complex disabilities who need assistance cannot take part in activities such as shopping, going out for a meal or attending a sporting event.

Changing Places toilets are in addition to standard accessible toilets, and are designed to meet the needs of people with complex care needs. ¹² CHAS welcomes the recent Scottish Government requirement that planning applications for new large, public buildings in Scotland must include a Changing Places toilet. ¹³ However, more can and should be done to ensure a greater number of existing venues offer these vital facilities.

The next Scottish Government should continue to promote more accessible and inclusive environments for people with complex care needs, including supporting the adaptation of more existing venues to accommodate Changing Places toilets.

¹² http://pamis.org.uk/campaigns/changing-places-toilets/

Guidance on the requirements for Changing Places Toilets introduced by the Planning (Scotland) Act 2019, Scottish Government, March 2020.

From diagnosis to transition, bereavement and beyond

At CHAS, we are committed to supporting families throughout their journey, however, we know that transition points can often be extremely difficult, and that additional support may be needed.

Transitioning between child and adult services

There should be a better system in place for the children's to adult services transition...
I co-ordinated all of my care and without this I am scared to think of where this would have ended. I was the first complex needs case my social worker has worked with.

(Young adult)

As medicine advances, more of the young people we support survive into adulthood. Over recent years, the CHAS transitions team has supported 287 young people and bridged the gap between child and adult services in Scotland for 99 young people aged 18-21.

Transition is often a stressful time for young people with life-shortening conditions and their families, as they navigate a range of transitions across healthcare, education, and social work. They will move from being supported by a specialist paediatric palliative care team to a wider range of adult services, and may face changes to the social care support they receive, because the availability or criteria for adult services are different to children's services. The uncertainty transitions can bring can impact on a young person's emotional and mental wellbeing.

In 2017, CHAS worked with the Scottish Transitions Forum to develop a supplement to *Principles of Good Transitions 3*, focussed particularly on life-shortening conditions. Yet more work needs to be done to embed best practice and put suitable services in place for young people to transition into.



CHAS would like to work with the Scottish
Government, Local Authorities, Integration
Authorities and Health Boards to develop a national,
standard pathway for children with complex medical
needs transitioning between child and adult services.
This should be multi-disciplinary, needs-led, adhere
to the *Principles of Good Transition*, and include
scoping of and access to age-appropriate services.

Better bereavement

I want people to know that death is the norm for my family. That talking about it, planning for it, helps. This is a journey and planning makes the journey easier. (Parent)

Nearly three-quarters of families told us they do not think Scottish society is open enough when it comes to death and dying. ¹⁴ Yet grief and bereavement are natural parts of life. More can and should be done to help ease the pain of those who experience this. CHAS offers a wide range of bereavement support to the whole family, and we are a supporter of the Bereavement Charter for Children and Adults in Scotland. ¹⁵

In particular, the psychological impact of bereavement on siblings should be a priority. While CHAS supports siblings throughout a family's journey, feedback from bereaved siblings – and in particular some older siblings as they move into adulthood – is that age-appropriate support from other sources can be lacking.

¹⁴ Survey conducted by CHAS September 2020. The survey received 67 responses.

¹⁵ A Bereavement Charter for Children and Adults in Scotland, Scottish Care, April 2020

In its 2016/17 manifesto, the Scottish Government committed to reviewing childhood bereavement support. We welcome the recent appointment of a National Childhood Bereavement Coordinator.

There's nothing out there for siblings when their brother or sister dies... There are for parents, even for grandparents, but there's nothing for us, the 'forgotten grievers'...
Who can we reach out to? (Sibling)

The next Scottish Government should implement the National Childhood Bereavement Coordinator's findings to address gaps in current provision. We would like to see a particular focus on ensuring adequate support for bereaved siblings, and more support for specialist resources and materials on bereavement within schools.

The next Scottish Government should promote the embedding of the Bereavement Charter for Children and Adults in Scotland across all settings in Scotland.

73%

Nearly three-quarters of families say Scotland is not open enough about death and dying.

15

CHAS reaches families all across Scotland in hospice, home and hospital



Hospice



CHAS at Home base



Hospital

All over Scotland

CHAS at Home Family support services Virtual children's hospice

Aberdeen

CHAS at Home base Royal Aberdeen Children's Hospital

Balloch

CHAS at Home base Robin House Children's Hospice

Edinburgh

Care 24

Simpson Centre for Reproductive Health Royal Hospital for Children and Young People

Glasgow

Royal Hospital for Children

Inverness

CHAS at Home base

Kilmarnock

University Hospital Crosshouse

Kinross

CHAS at Home base Rachel House Children's Hospice

Contact details:

For more information, or to set up a meeting, please contact: Mona Vaghefian, Policy & Public Affairs Manager (MonaVaghefian@chas.org.uk) Susanne Cameron-Nielsen, Associate Director of External Affairs (scn@chas.org.uk)

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