



Children's Hospices Across Scotland

Reaching every family in Scotland  
2017 - 2020



## Foreword

With the help of the Scottish Government, we commissioned a ground-breaking piece of research that established, for the first time, the full scale of the number of children in Scotland with life-shortening conditions. It is from this work that we know three children die each week but the more compelling statistic for us was that we are reaching only one of these families. We need to do much more to reach out to every family that needs our help and this theme of reaching every family is at the very core of our new three year strategic plan.

We hope that you will be both inspired and excited by what you read. We have a chance, with your support, to make life that little bit better for many more families. As you read on please keep in mind the children and their families who receive that most devastating of news. They are the focus of our planning and our aim is to reach them all and offer the support, care and love that has characterised the work of CHAS for so many years.

This plan is the result of many months of planning and consultation. We reached out to many individuals, organisations and most importantly the families we support. Our sincere thanks go out to everyone who participated and contributed.

We will not stop until we have reached every family in Scotland that needs us. Please help us make this happen.

Professor Gordon Dickson, Chairperson  
Maria McGill, Chief Executive



# Statement of ambition

**Knowing that your child may die before you do, is the unthinkable reality that thousands of families across Scotland have to cope with every day. Each week, three children die in Scotland from an incurable condition.**

Children's Hospices Across Scotland – better known as CHAS – is dedicated to supporting every single member of these families as they face the toughest challenge of their lives.

We are committed to making sure that no matter how short their time together may be, it is a time filled with happiness and fun.

We make sure children have the opportunity for experiences they cannot have elsewhere, to feel the wind and sunshine on their faces, to sparkle, to laugh, to smile and to have those memorable moments of joy – moments that will be treasured forever.

The doctors thought Abbie would never live to see her fifth birthday. Today she is 11, and still a fighter. We will not let Abbie and her family struggle alone.



## Introduction

**We are Children's Hospices Across Scotland, and we like to be known as CHAS. For over twenty years we have been caring for families and their babies, children and young people by offering palliative care, family respite and support.**

During this time we have built two hospices, developed our outreach service, CHAS at Home and established a presence in hospitals. We have initiated research, represented families at the highest levels and campaigned for improvements to palliative care in Scotland. However, at the heart of all this is our absolute commitment to supporting children and families when they need it most. Reaching every one of those children is what this plan prioritises – please join with us and ensure we are there for every one of them.

This is a really challenging journey. It relies on the trust, courage and love of the families with whom we work, the dedication, compassion and expertise of our team, and the professionalism of our partners from across health and care services. Along the way something truly amazing happens, because in the pain of terrible grief, joy lives on.

We are dedicated to helping families celebrate the lives of their children whilst they are together – and to honour their memory after they are dead.

Today, CHAS can reach only one in three of the families across Scotland who need our support. We are determined to reach them all. And that means, quite simply, that we need to raise more money. Only then can we keep the joy alive for every family as they face the hardest challenge of all.



**Emmy's mum recently told us, 'CHAS has helped us do things as a family that we never thought possible.' We're going to make sure Emmy's family continue to share precious time together.**



## Children in Scotland requiring palliative care

**To be told that your child has only a few days, weeks or years to live is an inconceivable shock. It is news no parent wants to hear, yet this is happening in Scotland on an almost daily basis.**

The Strategic Framework for Action (2015) sets out the Scottish Government vision that by 2021 everyone who needs palliative care will have access to it. Within the framework there is a clear commitment to promote the development of palliative care for babies, children and young people aged 0-25 years.

In 2014, we commissioned The ChiSP Study (Children in Scotland requiring Palliative Care: identifying numbers and needs). The results were startling - there are 15,404 babies, children and young people aged 0-25 years in Scotland living with life-shortening diagnoses. Of this number, two thirds of the babies, children and young people who die from a life-shortening condition each year in Scotland are not known to CHAS and do not get the benefit of our specialist support. We believe this must change.

The children and families we must reach in Scotland by 2020

ABELLE



15,404 with life-shortening conditions

6,600 hospital contacts

2,200 classified as unstable or deteriorating

195 children and young people die each year

4,783 children under five



EMMY



CHRISTIAN

ZOEE

The ChiSP Study is an internationally recognised and ground-breaking piece of research. Combined with a comprehensive consultation with families who use our service, it has been vital in expanding our knowledge of the needs of families in Scotland. Therefore, we will not only continue to develop our specialist care but also reach out to the significant number of families who do not currently receive our support.

The study highlighted that the greatest number of deaths occurred in children under one year of age. For so many families, they have such little time together; it can be as little as days or weeks to create family memories and to cherish their child. This is a heartbreaking time and we want to make these families a priority. When time is short, we want to make it fulfilling.

Families can be overwhelmed by the responsibilities of 24/7 care, experience financial hardship, lose touch with friends and become incredibly isolated. For many, the immense strain on families, can lead to relationship breakdowns, separation and divorce. We will increase the psychological and practical support for the families, and we will help them enjoy special family moments, to help them relax, smile and connect. We will strengthen the bonds that tie a family together and that can be so easily broken.

For a growing number of children, medical advances mean they can now hope to live longer than was expected when they were first diagnosed with their life-shortening condition. For these young people, moving from children's to adult's services is an important and sometimes difficult period. Our Transition Team offers specific services to young people and their families facing this previously unexpected development. We help them focus on their aspirations and ideas for future adult life and work with them to reach these goals. However, although we

focus on living well, we don't shy away from talking about their fears of dying and when young people are ready, we help them decide how they would like things to be for them at this time.

Complex diagnoses and medical terms can be bewildering. Travel to and from hospital can be expensive, lengthy and affect the financial security of families leaving them unable to continue to work. We help families understand a complex diagnosis, unfamiliar medical terms and the care needs of their child. CHAS at Home brings our services to families' homes throughout the whole of Scotland. We want to work in communities and hospitals across Scotland with all families who have a child with a potentially life-shortening condition, and especially those who currently receive little to no support from CHAS.

**Christian's parents have to live every day with the knowledge that he could die at any time. We are there for them now. And we'll continue to be there for as long as they need us.**



**CHRISTIAN**

## What drives us

What drives us at CHAS? Making a difference to the children and families we support. Throughout our organisation, determined and passionate leaders work collaboratively and inclusively with their teams, all of whom are constantly seeking to improve quality and performance. This determination allows us to offer the highest levels of care and support.



When Zoë was born the doctors told Heather and her husband, Gerry, to enjoy every day they had with her. We're helping them all to make sure that's exactly what they do.

ZOË

## Our strategic themes

We now have enough detailed knowledge and data to understand where need is greatest and have created a three year plan with four key strategic themes:

### Reach

By transforming the way we deliver care, we will reach more babies, children and young people with palliative care needs across Scotland.

### People

By attracting, developing, supporting and retaining staff and volunteers of the highest quality, we will be able to offer the highest standards of care throughout Scotland.

### Growth

Our fundraising activity will generate the increased income required to realise our ambition and our improved support infrastructure will ensure we make the best use of our resources.

### Influence

Our work in research, advocacy and education will inform improvements in paediatric palliative care. This, in turn, will benefit children with life-shortening conditions and their families across the whole of Scotland.

We recognise that the scale of need for our services across Scotland is immense. Our ambition is that every family in Scotland who is living with the heartbreaking knowledge that their child is dying, will be supported, cared for and helped to make the most of that precious time.

Being a service at the heart of children's palliative care, we want to contribute to the successful implementation of a wide range of health and social care policies in Scotland. We will ensure the services we offer are person-centred and promote wellbeing, in line with Getting It Right for Every Child (GIRFEC), the articles contained within the United Nations Convention on the Rights of the Child (UNCRC) and National Health and Wellbeing Outcomes.

### **Will you help us?**

**If you want to talk about The ChiSP Study and our ambitions for 2020, please do get in touch.**

**We'd love to talk to you.**

**[support@chas.org.uk](mailto:support@chas.org.uk)**



**Reference List** Fraser, L. R., Jarvis, S. W., Moran, N. E., Aldridge, J., Parslow, R. C., & Beresford, B. A. (2015). Children in Scotland requiring Palliative Care: identifying numbers and needs (The ChiSP Study). University of York.

**Key Policies** • Scottish Government (2015) Strategic Framework for Action on Palliative and End of Life Care • Scottish Government (2014) Public Bodies • (Joint Working) (Scotland) Act 2014 • Scottish Government (2017) The Best Start: A Five-Year Forward Plan for Maternity and Neonatal Care in Scotland • Scottish Government, Getting it Right for Every Child (GIRFEC) • <http://www.scotland.gov.uk/Topics/People/Young-People/gettingitright>, (2006) • UN General Assembly, United Nations Conventions on the Rights of the Child (UNCRC), (1989)



**Keep the joy alive**

**[www.chas.org.uk](http://www.chas.org.uk)**

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