

## **We need to talk about Palliative Care**

### **Children's Hospice Association Scotland**

#### **About us**

Children's Hospice Association Scotland (CHAS) is the only provider of children's hospice services in Scotland, caring for babies, children and young people with a wide range of life-shortening conditions, many of which are rare. We offer care through our two children's hospices, Rachel House and Robin House, and the CHAS at Home service, which aims to augment care at home and in hospitals for babies, children and young people with palliative care needs.

To date, CHAS have only ever been able to estimate the numbers of babies, children and young people with palliative care needs in Scotland. For many years we have worked on estimates of between 800 and 1,200 babies, children and young people at any one time and CHAS currently cares for approximately 370 of these families. We provide holistic care and support to the whole family regardless of care setting or geographical location through a comprehensive range of services for children and young people aged up to 18. The CHAS Model of Care is available [here](#).

Statutory funding of children's hospice services in Scotland is currently guided by the Scottish Government CEL 12 (2012) which states that NHS Boards and local authorities will jointly meet 25% of the mutually agreed running costs'. Within the same CEL, funding for independent adult hospices is at 50% of mutually agreed costs. Current statutory funding levels for CHAS are around 13.5% of total costs. Our services are funded predominantly through the generosity of supporters across Scotland and beyond.

#### **How many children need palliative care in Scotland?**

Every year approximately 450 babies and children under the age of 18 die in Scotland. This includes all causes of death but of those, we believe around half could have met the criteria and could benefit from palliative care.

We believe that there are many children and young people who would benefit from ongoing palliative care, but are not currently receiving it.

A study<sup>1</sup> in 2011 concluded that there could be as many as 4,000 children and young people in Scotland who could benefit from palliative care.

To gain a better understanding of the paediatric palliative care needs in Scotland, we commissioned a research project, in partnership with the Scottish Government, led by Dr Lorna Fraser and Professor Bryony Beresford from University of York, which will determine the number of babies and children in Scotland with life-shortening conditions and assess the needs of

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<sup>1</sup> Fraser et al, (2011) "Life-limiting and life-threatening conditions in children and young people in the United Kingdom; national and regional prevalence in relation to socioeconomic status and ethnicity" University of Leeds <http://bit.ly/1z24ZQw>

children and young people and their families and their location by NHS Board in Scotland. This study will report in November 2015 and a dissemination plan is being developed. We are in discussion with colleagues in the Child and Maternal Health Department and Healthcare Quality and Strategy Directorate of Scottish Government about the implications of the research results.

### **Definitions and categories**

Children's palliative care is different to adult palliative care as children and young people may require palliative care over a longer period rather than just towards the end of their lives. There is also a significant range of conditions in babies, children and young people who have palliative care needs.

### **Definitions**

Palliative care for children represents a special, albeit closely related field, to adult palliative care. The World Health Organisation's <sup>2</sup> definition of palliative care appropriate for children and their families is as follows:

- Palliative care for children is the active total care of the child's body, mind and spirit, and also involves giving support to the family
- It begins when illness is diagnosed, and continues regardless of whether or not a child receives treatment directed at the disease
- Health providers must evaluate and alleviate a child's physical, psychological and social distress
- Effective palliative care requires a broad multidisciplinary approach that includes the family and makes use of available community resources; it can be successfully implemented even if resources are limited
- It can be provided in hospitals, in community health settings and even in a child's home.

Together for Short Lives, the UK charity representing children's palliative care, provides the following definition and categories:

Palliative care for children is an active and total approach to care, from the point of diagnosis or recognition, throughout the child's life and bereavement. It should meet their physical, emotional, social and spiritual needs. It should focus on enhancing their quality of life and providing support for their family. It should include managing distressing symptoms, providing short breaks and care through death and bereavement. Palliative care for children and young people should be provided in age and developmentally appropriate settings by professionals who are skilled in working with their age-group.

### **Categories**

Life-shortening conditions and life threatening conditions affecting babies, children and young people can be defined broadly into four groups. There is a wide range of diagnoses associated with babies, children and young people

<sup>2</sup> <http://www.who.int/cancer/palliative/definition/en/>

who have palliative care needs, with the number in excess of 400. Over 30% of those who die in the age range 0-18 years, are within the first year of their life, and there is a growing awareness for the development of standards to ensure that palliative care is optimal for those babies in this age group.

Categorising the variety of children's conditions is not easy and the following examples used are not exclusive. Diagnosis is only part of the process; the spectrum and severity of the disease; subsequent complications, the needs of the child and their family; and the impact on the child and the family also need to be taken into account. The four categories<sup>3</sup> are:

**Category 1: Life threatening conditions for which curative treatment may be feasible but can fail.**

Access to palliative care services may be necessary when treatment fails or during an acute crisis, irrespective of the duration of threat to life. On reaching long-term remission or following successful curative treatment there is no longer a need for palliative care services. Examples: cancer, irreversible organ failures of heart, liver, kidney.

**Category 2: Conditions where premature death is inevitable.**

There may be long periods of intensive treatment aimed at prolonging life and allowing participation in normal activities. Examples: cystic fibrosis, Duchenne muscular dystrophy.

**Category 3: Progressive conditions without curative treatment options.**

Treatment is exclusively palliative and may commonly extend over many years. Examples: batten disease, mucopolysaccharidoses.

**Category 4: Irreversible but non-progressive conditions causing severe disability, leading to susceptibility to health complications and likelihood of premature death.**

Examples: severe cerebral palsy, multiple disabilities, such as following brain or spinal cord injury, complex health care needs, high risk of an unpredictable life-threatening event or episode.

These categories were developed by Together for Short Lives (formerly ACT) and Royal College of Paediatrics and Child Health in 1997 and updated in 2009. In our experience, they remain relevant and useful but the understanding and awareness of many groups previously not considered to have palliative care needs has increased enormously and may not be fully reflected in these categories. These groups should include neonates, intensive care patients, certain disease specific groups, those with a shorter period of palliative trajectory and those in transition between children and adult services.

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<sup>3</sup> Together for Short Lives/Royal College of Paediatrics and Child Health (RCPCH) (2009)

**What has been your experience in terms of access to palliative and end of life care?**

We currently support between 350 and 400 families every year. Of those, approximately 60 children die each year. The research study being conducted by York University, which reports in November 2015, will provide a more accurate assessment of the numbers but we currently believe that many children do not receive the full benefit of palliative care when and where they need it.

In our experience, home is increasingly stated by families as where they would like their children be cared for at the end of life. Whether this is achievable is dependent on whether they can access a sustainable local children's community nursing service. A shortfall in these nurses is affecting the choice families have. Additionally, children's community nursing teams, where they exist, often do not provide a service out of hours.

The Electronic Key Information System (EKIS) has improved support but the temporary suspension of Children and Young People's Acute Deterioration Management Plan (CYPADM) from the system is making effective out of hours support more challenging.

Families face physical, emotional and financial pressures in caring for a seriously ill child. Our experience is that not all have access to an equitable level of support.

It is common for children and young people's conditions to fluctuate and, as such, it is often much more difficult to identify when they are moving into their end of life phase. Due to the variety and complexity of conditions, each child's prognosis, treatment and support needs will be unique.

We also provide support to over 250 bereavement.

**How could it be ensured that access to palliative and end of life care is equitable and available in all areas and for all types of terminal illnesses?**

A comprehensive coordinated local children's palliative care service that spans health, social care and education. It is a whole-family approach and:

- is flexible and focussed on children, their parents and their siblings
- is accessible 24 hours a day, seven days a week, 365 days a year - from diagnosis or recognition to bereavement
- supports and enables children and families to choose the type, location and the provider of the care they receive and allows them to change their mind
- supports and enables children to exercise their right to education
- supports children to achieve the outcomes they want from their lives

- is not age, time or diagnosis specific - 15% of children who need children's palliative care have no definitive underlying diagnosis
- is multi-disciplinary and multi-agency
- advocates an approach which recognises the diversity of life circumstances of people who will need palliative and end of life care
- is responsive to these circumstances, whether they relate to age, disability, gender, race, religion/belief or sexual orientation
- includes pre and post-bereavement support for families
- is able to manage pain and other symptoms
- supports parents in caring for their children according to their needs and wishes
- supports and enables smooth transitions for young people with life-shortening conditions - who move from children's to adult's services.
- supports children, young people and their families at the end of their lives, helping them to plan and receive care which is consistent with their needs and wishes.

**Can you identify any areas in terms of access to palliative and end of life care that should be focused on as priorities?**

There is a shortage of skilled professionals in Scotland able to support these families, particularly outside core hours. This can be addressed by:

- Equipping staff with the skills to have difficult conversations and then share that information appropriately.
- Having a national shared understanding of Anticipatory Care Planning and a workforce skilled in helping families to develop theirs.
- Ensuring that staff members have the relevant skills to complete and deliver the care in the plan.
- Embedding of CYPADM forms (Children and Young People's Acute Deterioration form) into practice – this is the form similar to (adult) Do Not Attempt Cardio-pulmonary resuscitation (DNACPR).
- Electronic access to all relevant health and social care clinical information by all services.

The lack of community children's nurses (CCNs) is also restricting the access which children and young people should have about where they would like to be cared for and die.

Parents of children with palliative care needs struggle to access psychological services to address their own mental health and wellbeing - and help them become more resilient.

We have worked with a number of young people well over the age of eighteen who remain under the care of a paediatrician.

Bereavement support – the death of a child has enormous and distressing impact on the whole family and there is a need to support parents, siblings and extended family in bereavement.

There are many examples of good practice in the voluntary sector such as the Butterfly Project which is a five year Big Lottery funded partnership with an aim to deliver child bereavement care to children and young people who are facing challenging times due to loss and bereavement of the significant person.

An excellent resource<sup>4</sup> pack for teachers working with children and young people affected by loss and bereavement has been produced by a group of organisations.

However, instead of services to bereaved parents extending, services appear to be contracting as evidenced by the suspension of any service from The Royal Hospital for Children in Glasgow.

**When is the right time to begin discussing options for Palliative Care, who should be party to that discussion, who should initiate it and where should it take place?**

Children’s palliative care begins at the point the condition is diagnosed or recognised. This makes it different from adult palliative care, which is largely focused on the last year of life. We encourage the Committee to ensure this distinction is made during its considerations.

There is sometimes reluctance on the part of professionals to talk to parents at an early/earliest stage about the possibility their child may die and to introduce the concept and need for palliative care. This is particularly the case in life threatening illnesses where cure is a potential outcome, however unlikely that is.

In our experience, anticipatory care plans (ACP) are an important method of ensuring parents’ and professionals’ views are understood, and then recorded. We have been working closely with NHS Lothian to develop ACPs for use in the Lothian and other Health Board areas. We believe this has the potential to be a shared national document.

**What works well in discussing palliative and end of life care and how is good practice communicated? Where do the challenges remain?**

It is often challenging to introduce the concept of palliative care in paediatrics. This relies on clinicians having high levels of communication skills, but also a knowledge of the need for and benefits of palliative care. The use of CYPADM and a paediatric ACP provides the option of having such discussions and an effective way of recording this conversation.

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<sup>4</sup> Glasgow Council (2013) “A whole school approach to Supporting Loss and Bereavement” [http://www.goodlifedeathgrief.org.uk/content/resources/Whole\\_School\\_Approach\\_to\\_LossAndBereavement\).pdf](http://www.goodlifedeathgrief.org.uk/content/resources/Whole_School_Approach_to_LossAndBereavement).pdf)

The challenges include:

- ensuring the family has a professional they know and trust and who is skilled at such conversations, and who has a knowledge of how to offer optimal palliative care.
- ensuring it is captured in a universally recognised format
- enabling it to be shared by all services caring for the family
- ensuring professionals caring for children at end of life have a comprehensive knowledge of all support available to families

### **What is the role of anticipatory care plans in supporting Palliative Care discussions and how can their uptake be improved?**

Anticipatory Care Plans (ACP) underpin effective children's and young people's palliative care as they allow the recording of discussions between parents and health care professionals. They record the options at different phases of a child's or young person's condition, and there is increasing evidence<sup>5</sup> that when they are completed, it is more likely that a parent's/child's choice in terms of end of life care will be met.

It is now vital to spread the use of the ACP within paediatrics, as this allows parents and professionals to record the mutually agreed plans of what to do in different clinical circumstances, including end of life and into bereavement.

In our experience, there are a number of templates in use throughout Scotland, there is a lack of clarity about who can do them with families and they are not consistently available on EKIS.

The key benefits of an ACP being part of care planning from the earliest stage are:

- They are completed at a pace comfortable to the family
- They capture what matters to each family
- They prevent the need for families repeatedly having to have difficult conversations
- They allow families and those caring for them are able to have a shared understanding about care options

### **How should information about Palliative Care be made available to patients and their family during any initial discussions and how easily available is this information?**

CHAS is already raising awareness for the need for improved palliative care in children's units across Scotland, and this includes in paediatric intensive care

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<sup>5</sup> Jones, Y (2013) "Anticipatory Care Plans and preferred place of end of life care/death" Edinburgh <http://www.palliativecarescotland.org.uk/content/publications/01.-Anticipatory-Care-Plans-and-preferred-place-of-end-of-life-care-death.pdf>

and neonatal intensive care units, which is particularly important as this is where the largest number of babies, children and young people die.

A number of new positions in CHAS over the past few years have supported this. CHAS appointed a team of three Diana Children's Nurses, based in Glasgow, Edinburgh and Inverness along with a consultant paediatrician with a special interest in paediatric palliative medicine, as a joint appointment between NHS Lothian and CHAS, commenced in July 2015. It is likely that a further joint appointment consultant paediatrician will be appointed later in 2015 between CHAS and NHS Greater Glasgow and Clyde. These posts contribute to working towards more parents "finding out" about the possibility of high quality palliative care for their child, should their child's condition begin or to continue to deteriorate.

However, more generalist and condition specific teams need to have a greater understanding of or the need for referral for palliative care.

A further train the trainers set of events, in conjunction with NHS Education Scotland (NES), to highlight good practice after the issue of the "light touch review" of CYPADM and DNACPR is completed in late 2015, would allow a further dissemination of this knowledge to care professionals, and then on to parents and families of babies, children and young people with palliative care needs.

NHS Inform website has a specific section for palliative care and there is a specific area on babies, children and young people. This helpfully signposts both CHAS and Together for Short Lives websites as areas of vital information.

**What training and support is provided Health and Care staff on discussing Palliative Care with patients and families and are there any areas for improvement?**

In paediatrics this has been limited, and until June 2015 the only doctors and nurses working with babies, children and young people with palliative care who had any recognised and specific post graduate training in children's palliative medicine had worked with CHAS.

Currently in Scotland, there is one NHS doctor, three CHAS doctors and one CHAS nurse with a post graduate diploma in children's palliative care.

The only Paediatric Palliative Care education is run in Cardiff University which is internationally recognised.

CHAS was asked by the East of Scotland Deanery to run a series of palliative care events for trainee paediatricians. Our own evaluation feedback of the pilot event in July 2015 demonstrates this was well received and indicates a great enthusiasm for this subject.

We know that there is interest in learning opportunities in paediatric palliative care. In 2013 Yorkhill Foundation funded a one day conference in Glasgow



attended by 180 delegates. CHAS hosted an event in Aberdeen in June 2015 attended by 130 delegates.

Three NHS Doctors are considering a Special Interest in palliative medicine as recognised by the RCPCH and will be supervised by CHAS.

**How do Health and Care organisations ensure that the discussions about palliative and end of life care are taking place at the right time?**

**What are the challenges in recording and documenting Palliative Care priorities and how well are those priorities communicated between different health and care providers?**

In paediatrics, where such discussions can be quite infrequent, it is challenging to ensure that this is happening. One way to do this is to reinstall a monthly request to all paediatrics working at consultant level to complete an electronic form which surveys whether they had had any such discussions, and to list the outcomes of these forms. Nurses working within this field in such health board areas as Lothian, and Arran and Ayrshire are also developing methodologies which record and also encourage such discussions.

The Child Death Review steering group is due to report its recommendations on how every baby, child and young person who died in Scotland will have their death and the events leading to it reviewed by an expert panel. CHAS believes there is potential to include consideration of whether palliative care was, or could have been included in the care provided.

**Children's Hospice Association Scotland**