

Influencing National Policy and Practice Frameworks: A Hospice Perspective



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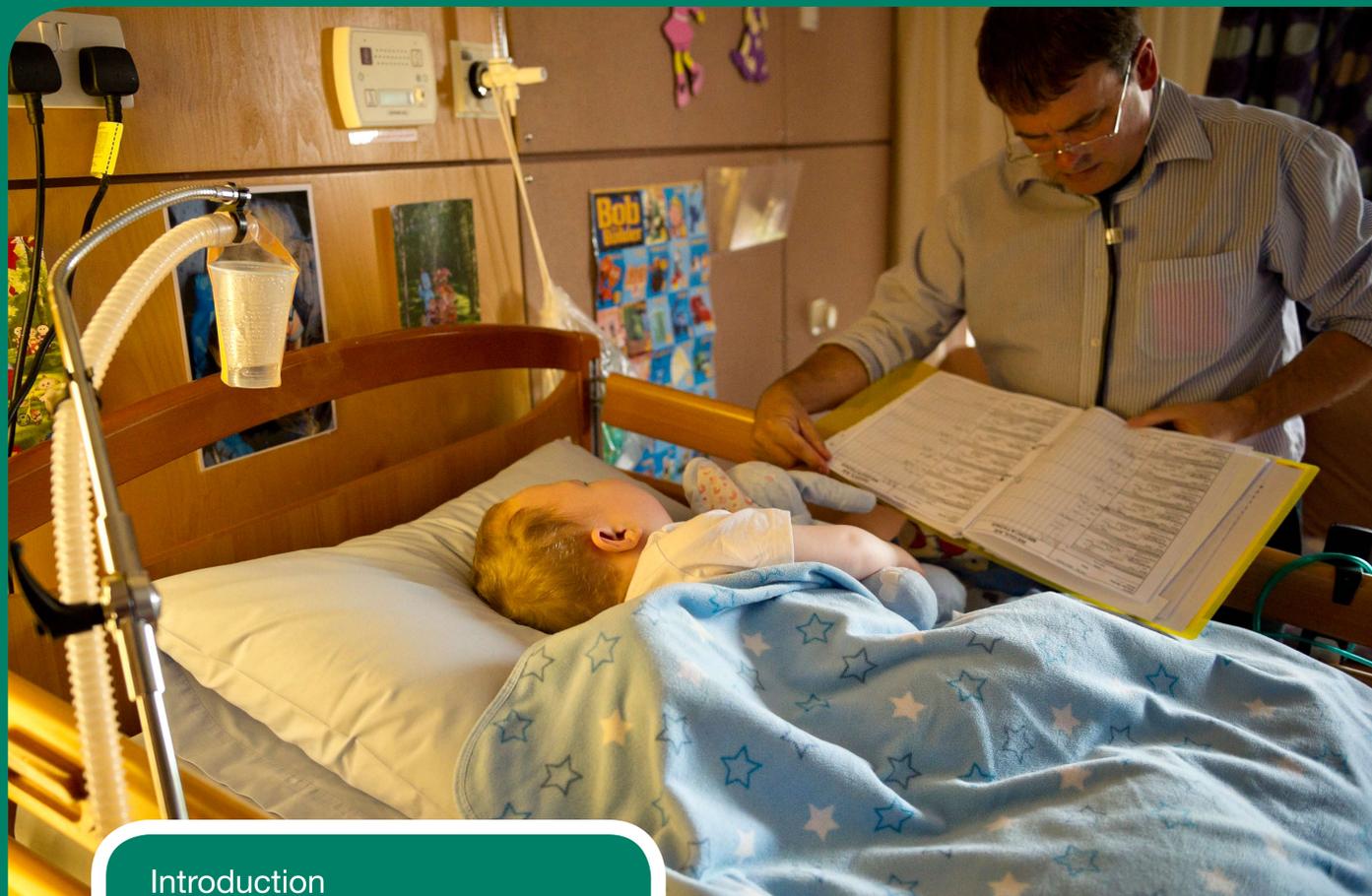


Photo: Paul Hampton

Introduction

Children's Hospice Association Scotland (CHAS) provides the only hospice services in Scotland for children and young people with life-shortening conditions. CHAS offers care in two children's hospices, Rachel House in Kinross and Robin House in Balloch. CHAS also provides a home care service, called CHAS at Home, staffed from both hospices and with dedicated teams based in Aberdeen and Inverness.

As the sole provider of children's hospice services in Scotland, CHAS has a responsibility to share skills and experience with colleagues in other sectors, and to develop strong partnerships to shape the development of palliative care for this group across all settings.

These are objectives in CHAS's strategic plan and one way CHAS has met these objectives is through the development of a national palliative care framework for children and young people.

Background to the Framework

Although health services provide diagnosis and ongoing management of healthcare needs for children and young people, symptom management and other palliative care needs frequently become fragmented in all stages.

It was apparent that guidance was required to help health services create a coordinated and structured approach to delivery of care. This would allow families to experience a more integrated and consistent level of service. The way to achieve this was through a framework document describing how care pathways for paediatric palliative care could be established.

Aims

The Framework (2012) was developed through the Scottish Children and Young People's Palliative Care Executive (SCYPPEX) in consultation with paediatricians and lead children's nurses throughout Scotland.

The aim of the Framework is to:

- Make sure there are recognised pathways for palliative care within and between health and care providers for every child and young person with a diagnosis of a life-shortening condition.
- Outline the available support to children and young people at all stages through to the end of their lives.
- Assist the development of equitable, sustainable, age appropriate support, independent of the geographical area in which the child or young person lives.
- Set out a safe, effective and person centred approach to palliative care for children and young people.
- Provide guidance for health and care services, and a self-assessment tool.

Dissemination

The Framework was introduced at a National Square Table event in Scotland hosted by CHAS in November 2012. This event was attended by families, representatives from all the key public and voluntary organisations supporting the delivery of palliative care for children and young people, and by the Scottish Government's Cabinet Secretary for Health and Wellbeing.

The Framework was formally launched at an event supported by an NHS Chief Executive's Letter to all NHS boards in Scotland. SCYPPEX were sponsored by the Scottish Government to provide three follow up roadshow workshops on consecutive days in various parts of Scotland. These events attracted strong interest with representatives from the NHS, hospices, social services, education and voluntary sector, who attended all three. The workshops were hosted by the local NHS boards in those areas, and facilitated by CHAS.

Workshops were intended to raise awareness and understanding of the expected outcomes and key objectives in the Framework. They were also an opportunity to highlight the role of CHAS and the NHS in providing effective palliative care services for children and young people, and some of the challenges. Finally, participants were invited to identify how the Framework could be applied in their own services through breakout workshops that explored a typical case study. The situation pre and post introduction of the Framework was explored to emphasise why it was needed.

Outcomes

The Framework is an important development in children's palliative care in Scotland and has positioned children's hospice care as having a central role. It will contribute to improving care for children and young people with life-shortening conditions.

Feedback from the roadshow events highlighted that participants valued the opportunity to explore children's palliative care issues collaboratively, and to discuss the implications arising from the Framework. The inter-agency, multi-disciplinary and interactive nature of these workshops generated a lot of positive discussion and reflection. The feedback also illustrated that there are many different types of services contributing to palliative care support for children and young people, and that currently there are not enough opportunities to network, learn and share best practice.

For CHAS, this was also a valuable opportunity to promote a greater understanding of our role in supporting the Framework, and more widely in providing palliative care support for children, young people and their families.

A selection of the feedback comments to the sessions are given below:

"Very informative and relevant to my practice."

"Very useful opportunity to hear perspectives from wide variety of professionals. We need to work across boundaries."

"Brought framework to life and perspective."

References:

A Framework for the Delivery of Palliative Care for Children and Young People in Scotland. Scottish Children and Young People's Palliative Care Executive Group (SCYPPEX). Edinburgh. Scottish Government. (2012)

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