Influencing National Policy and Practice Frameworks: A Hospice Perspective

Dr Pat Carragher, CHAS Medical Director
Colin Boscott, CHAS Learning and Development Manager

Introduction

Children's Hospice Association Scotland (CHAS) provides the only hospice services in Scotland for children and young people with life-limiting 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 other stakeholders to ensure the development of a national palliative care framework. CHAS is also committed to ensuring that any national framework results in a more consistent approach to the delivery of care for children and young people with life-limiting conditions. CHAS is a member of the Scottish Children and Young People's Palliative Care Executive (SCYPPCEx) in consultation with Scottish Children and Young People’s Palliative Care Executive Group (SCYPPCEG). The Framework (2012) was developed through the collaborative work of SCYPPCEx in consultation with Scottish Children and Young People’s Palliative Care Executive Group (SCYPPCEG). The Framework was launched at an event supported by an NHS Clinical Executive’s Letter to all NHS boards in Scotland. SCYPPCEG were supported by the Scottish Government to provide these follow-up roadshows workshops on consecutive days in various parts of Scotland. These events attracted strong interest with representatives from the NHS, hospice, social services, education and voluntary sector, and attended all three. The workshops were hosted by the local NHS boards at these areas, and facilitated by CHAS.

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 at all stages.

At an apparent that guidance was required to help health services create a co-ordinated 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 development of a national palliative care framework. CHAS has met these objectives is through the development of a national palliative care framework for children and young people.

Aims

The Framework (2012) was developed through the Scottish Children and Young People's Palliative Care Executive (SCYPPCEG) in consultation with professionals and key children’s services in Scotland. The aims of the Framework are 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-limiting 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 patient-centred approach to palliative care for children and young people.
- Provide guidance for health and care services, and self-assessment tool.

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-limiting conditions.

Feedback from the roadshow events highlighted that participants were enthusiastic 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 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 to Children and Young People in Scotland (Scottish Children and Young People’s Palliative Care Executive Group (SCYPPCEG), Edinburgh, Scottish Government, 2012)

www.chas.org.uk