

# **Child Rights and Wellbeing Impact Assessment of the Strategic Framework for Action on Palliative and End of Life Care**

**August 2016**



**Scottish Government**  
Riaghaltas na h-Alba  
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**July 2016**

**Policy/measure** Strategic Framework for Action on Palliative and End of Life Care

**Summary of policy aims and desired outcomes**

**Palliative and End of Life Care Aims**

- Access to palliative and end of life care is available to all who can benefit from it, regardless of age, gender, diagnosis, social group or location.
- People, their families and carers have timely and focussed conversations with appropriately skilled professionals to plan their care and support towards the end of life, and to ensure this accords with their needs and preferences.
- Communities, groups and organisations of many kinds understand the importance of good palliative and end of life care to the well-being of society.

**Palliative and End of Life Care Outcomes**

- People receive health and social care that supports their wellbeing, irrespective of their diagnosis, age, socio-economic background, care setting or proximity to death.
- People have opportunities to discuss and plan for future possible decline in health, preferably before a crisis occurs, and are supported to retain independence for as long as possible.
- People know how to help and support each other at times of increased health need and in bereavement, recognising the importance of families and communities working alongside formal services.
- People access cultures, resources, systems and processes within health and social care services that empower staff to exercise their skills and provide high quality person-centred care.

**Directorate; Division; Team** Healthcare Quality and Strategy Directorate  
 Planning and Quality Division  
 Palliative and End of Life Care Policy Team

**Executive Summary**

On 18 December 2015 the Scottish Government published the Strategic Framework for Action on Palliative and End of Life Care (SFA).  
<http://www.gov.scot/Publications/2015/12/4053>

The SFA sets out the approach and shared vision for people in Scotland where by 2021 everyone who needs palliative care will have access to it, including children and young adults.

The SFA recognises that children and young people in Scotland have different needs to the adult population when it comes to

	<p>living with life limiting illness and for palliative and end of life care. The SFA sets out 10 commitments including a specific commitment to support and promote the provision of palliative care in the 0-25 years age group.</p>
<p><b>Background</b></p>	<p>The SFA sets out the Scottish Government’s commitments in support of the continuous improvement in the quality of palliative and end of life care, reflecting the commitment to the quality ambitions outlined in the Healthcare Quality Strategy (2010), the National Performance Framework Outcomes and also the National Health and Wellbeing Outcomes. It is part of the Scottish Government’s transformational change programme and is consistent with the recently published National Clinical Strategy.</p> <p>In 2012, the Scottish Children and Young People’s Palliative Care Executive (SCYPPEX) published a framework for the delivery of palliative care for children and young people in Scotland. This document aimed to ensure that recognised pathways for palliative care exist for every child and young person from the point of diagnosis of a life-limiting condition.</p> <p>The SFA aims to build on this and other evidence to enhance palliative and end of life care for children and young people.</p>
<p><b>Scope of the CRWIA</b></p>	<p>A CRWIA is required so that the impact of the SFA can be assessed over time.</p>
<p><b>Children and young people’s views and experiences</b></p>	<p>The Scottish Government held three engagement events in Aberdeen, Glasgow and Edinburgh to discuss the development of the SFA. An engagement paper was also written to support the development of the SFA.</p> <p>The Palliative and End of Life Stakeholder Group included input from a Children’s Hospice Association Scotland (CHAS) young adult and a parent. Both have been involved in meetings where this policy has been discussed at length.</p> <p>Commitment 9 of the SFA includes that a measurement infrastructure will be developed to ensure real-time data is available. This will include that the experiences of the child and family is appropriately captured to inform further and future policy developments.</p>
<p><b>Key Findings</b></p> <p>To include impact on UNCRC rights and contribution to wellbeing indicators</p>	<p>The SFA sits alongside the Scottish Government’s commitment to person centred care. In line with the principles of the United Nations Convention on the Rights of the Child (UNCRC) and Getting It Right For Every Child (GIRFEC) the Scottish Government affirms that children must be included in making decisions about their care and treatment where they have the capacity to do so.</p>

As a result of conducting the CRWIA there were several aspects of children and young people's palliative and end of life care identified for improvement and further research as the SFA is implemented.

**(i) Need for more parental support**

- Parents want more support in the provision of a break from caring. Parents value a model of care that provides holistic, family-focused support that is responsive to individual needs and which promotes control and active involvement in decision making.

- Most parents prefer to share in decisions to forgo life-sustaining treatment from their children. Parents are able to handle a more active role than they are currently being given.

- Written resources impact positively on the understanding of medical facts, including diagnoses and prognoses, communication between families and healthcare professionals, and the emotional wellbeing of families after their child's death.

- Parents need to be better informed of the doctors role in end-of-life decisions in order to better inform clinical practice.

- CYPADM and ancillary care plans provide a structure for these important conversations. These conversations also take place with children.

**(ii) Need for more education and training**

- Joint learning educational initiatives can assist to better understand children's palliative care needs.

- Nurses caring for dying children need to be experienced and have advanced communication skills to understand the ethical and legal knowledge relating to end-of-life care and to be comfortable talking to parents about death and dying and treatment choices. Children should also be included in these conversations.

- Palliative care staff especially need training concerning spiritual issues, and further studies need to be performed.

- Health professionals providing paediatric palliative care should be appropriately trained in this specialist field and the best interests of the child should always be at the forefront of care.

**(iii) The need for strategic allocation of resources**

- Resources may need to be redistributed and prioritised to ensure that children and young people and their families receive the care and services they need.

- It has been recognised that families of children with life-limiting health conditions struggle with significant financial demands, yet may not have awareness of resources available to them.

- The prevalence of children and young people (aged 0 – 25 years) with life-shortening conditions in Scotland has risen

between 2003-04 and 2013-14 and this change needs to be effectively resourced. The CHiSP<sup>1</sup> study states that the absolute number of children and young people with a life-limiting condition in the complete estimates is 15,404.

**(iv) Need for a more joined up approach to children's end-of-life care**

- Further research needed to be conducted to look at the possibility of developing a multi-agency workforce strategy, and to increase capacity in the children's sector to undertake academic research measuring the impacts of interventions.
- There is a need for "joined up" palliative care services, particularly concerning timely referral to the range of support services.
- Within an ethos of family centred care, the needs of siblings should be addressed as well.
- Health and social care services need to support families to provide care that is in the child's best interests. This will include working through the cultural backgrounds and preferences to ensure the child's needs are met.
- Children have the right to know what is happening to them and be involved in decision making about their care.

**(v) More of a needs-based / person-centred approach to children's end-of-life care**

- There needs to be a situational perspective of children's participation to act in the child's best interest and to balance protection with shared decision-making, according to children's rights and desires.
- Children's voice.
- An increasing number of children require care at home owing to life-limiting illness.

**(vi) Increase research to support children's needs in Scotland**

- The evidence base for current policies that stress the need to increase home death rates for children and young people with life-limiting and life-threatening conditions is inadequate but could be real. More research needed and an issue to consider.
- respite (in an inpatient unit) for children stops at 18. From then on it is available in care homes or adult respite facilities where they exist. Also there is a recognition that respite can take many forms and it is intended that SDS provides an way of increasing choice and independence. In recognition of some of the difficulties experienced by children transitioning to adult services, Children's Hospice Association Scotland (CHAS) made the decision to continue to support young people up the

<sup>1</sup> Fraser, L., Jarvis, S., Moran, N., Aldridge, J., Parslow, R., and Beresford, B., 2015, 'Children in Scotland Requiring Palliative Care: identifying numbers and needs (The ChiSP Study)', University of York, York

	<p>age of 21. It should be noted that this is only available for children already being supported by CHAS and is a very small number of those who may need respite.</p> <p><b>(vii) More support needed for child to adult transition</b></p> <ul style="list-style-type: none"> <li>- Primary care practitioners needs to be more actively anticipated and negotiated at the transition to palliation.</li> <li>- The lack of respite support that exists once such young people reach age 21 has an adverse effect on the families of young people</li> </ul> <p>The SFA is and will be implemented in a way which complements children’s rights under the UNCRC, specifically the following articles:</p> <ul style="list-style-type: none"> <li>• Article 2: Non-discrimination</li> <li>• Article 3: Best interests of the child</li> <li>• Article 4: Protection of rights</li> <li>• Article 6: Life, survival and development</li> <li>• Article 12: Respect for the views of the child</li> <li>• Article 13: Freedom of expression</li> <li>• Article 24: Health and health services</li> <li>• Article 25: Review of treatment in care</li> </ul> <p>The following children’s wellbeing indicators will be enhanced as a result of the SFA: Safe, healthy, achieving, nurtured, respected, included and responsible.</p>
<p><b>Conclusions and Recommendations</b></p>	<p>The SFA will have a positive impact on children and young people in Scotland including those living with life limiting illnesses and those with family members with palliative and end of life care needs.</p> <p>The SFA includes a commitment to support and promote the further development of holistic palliative care for the 0-25 years age group.</p> <p>As a result of the CRWIA it is concluded that the Scottish Government should proceed with the SFA because it will build on and improve the palliative and end of life care available to children and young people who are living with life limiting diseases as well as children who are bereaved or have a family member with palliative care needs.</p> <p>The SFA is compatible with, and complementary to the intentions of the UNCRC.</p>
<p><b>Monitoring and review</b></p>	<p>The SFA will be monitored by the Palliative and End of Life Care policy lead in the Scottish Government. SFA implementation will also be formally overseen by a National Implementation Advisory Group (NIAG).</p>

	<p>The development of the SFA was assisted by the membership of the Palliative and End of Life Care National Advisory Group and Stakeholder Group. The Scottish Government is committed to ensuring that the membership of these groups, as well as the public at large including children and organisations that represent children, will be able to contribute to future implementation actions.</p>
<b>CRWIA Declaration</b>	
<b>CRWIA required</b>	
<b>CRWIA not required</b>	
<input checked="" type="checkbox"/>	
<b>Authorisation</b>	
<p><b>Policy lead</b>  Tim Warren  Palliative and End of Life Care Policy</p>	<p><b>26 July 2016</b></p>
<p><b>Deputy Director or equivalent</b>  Elizabeth Sadler  Deputy Director  Planning and Quality Division</p>	<p><b>26 July 2016</b></p>



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