

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

### **Action for Sick Children Scotland**

**Action for Sick Children Scotland (ASCS) works for the best quality of healthcare to be provided for ALL children and young people at times of illness. ASCS works for improved standards of healthcare and promotes their health needs and rights whatever their illness. ASCS is a member of the European Association for the Welfare of Children in Hospital (EACH) and our work is underpinned by the principles of the EACH Charter (1) - the ten rights of children and young people in health services – and their corresponding rights as set out in the UNCRC. Our work has the well-being of ALL children and young people as its central focus regardless of their condition or its duration and prognosis.**

**ASCS is a member of both the Scottish Children and Young People's Palliative care Network (SCYPPN) and Scottish Children and Young People's Palliative care Executive (SCYPPEX) as well as working in partnership with the National Managed Clinical Network for Children with Exceptional healthcare Needs (CEN) and having close links to the Children's Hospice Association Scotland.**

**We are pleased to provide a submission in response to the call for written views to inform the Scottish Parliament's Health and Sport Committee inquiry into palliative care.**

It is vitally important that MSPs and others understand the fundamental difference between adult palliative care and the term as it applies to children and young people's care. See WHO definition below:

#### **WHO Definition of Palliative Care for Children**

Palliative care for children represents a special, albeit closely related field to adult palliative care. The WHO definition of palliative care appropriate for children and their families is as follows; the principles apply to other paediatric chronic disorders (WHO; 1998a):

- 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 ; it can be successfully implemented even if resources are limited
- of available community resources
- It can be provided in tertiary care facilities , in community health centres or even in the child's home .

It is very important to note that unlike adult hospice care, hospice care for children is appropriate throughout their life journey and not just at end of life .

1. <http://www.ascscotland.org.uk/default.asp?page=36>

### **Q1 Access experience**

Care options may be restricted because of local provision and resources available closest to the child and family home.

Access also includes the need to consider financial matters and support for families who may be in need at a time of greatest stress.

### **Q2 Equitable access**

The term “ensure “is challenging and perhaps unrealistic. However, use of the principles of a Person-Centred approach should guide all decisions therefore ensuring that the child and family receive the service most appropriate to their individual needs.

### **Q3 Priority areas**

There is a need for excellent palliative care which is holistic and includes bereavement support.

A key message from practitioners and families alike is the need to talk about Palliative Care with parents as early as possible.

The likelihood is that there will be different services and agencies involved and therefore different professional leads in the different services, for example, Key Worker (Hospice), Named Person (School), Lead Professional (Paediatrician), Community Children’s Nurse Lead (Community) and GP (Community). With so many people involved, it is vital that there is a lead coordinator to ensure clear communication and a transparent overview.

A major priority area is the provision of nursing care for PEOLC children in the community. Palliative Care for children begins at diagnosis and can last for many years. The main workforce delivering this care at the moment is Community Children’s Nurses (CCN). This service allows the child to remain at home in familiar surroundings with familiar people. Currently there is no educational provision for CCNs in Scotland and therefore this workforce is reducing

### **Q4 Discussions**

As already stated, if Palliative Care means from diagnosis and encompasses the whole journey of the child’s life, then the discussion should commence from the point at which it is acknowledged that there is a life limiting/shortening element to the child’s condition.

It should be delivered by the professional who knows the family best, if possible in partnership with a colleague. There should be support for the

family immediately afterwards, follow-up and a clear way back (contact details) for when questions arise.

From a family perspective, it is very important to ensure that siblings are included as well as the wider family where appropriate. Often they are closely involved and part of the support team at home and therefore their contribution and resulting impact on their health and well-being must be taken into account.

### **Q5 Best Practice**

As above and in addition:

The dialogue should be open-ended and on-going throughout the child's life as the condition and situation changes and develops. It has to be flexible so that families can revisit the issues as many times as they need.

The 4 Cs:

- Communication
- Co-ordination
- Child-centred
- Compassion and empathetic care

Good bereavement support also includes the importance of creating memory boxes while the baby or child is still alive.

### **Q6 Planning**

The discussions and resulting care pathway and plans need clear understanding of all those involved in the care of the child - professionals, family, school, respite, hospice etc. A standardized national approach to Anticipatory Care planning may be useful.

### **Q7 Information**

Access to information also includes the need to consider financial matters and support for families who may be in need at times of great stress. Initiatives such as the financial inclusion project in NHS GGC can help to alleviate financial burdens and hardships at this time.

All information should be given face to face in the first instance but with the additional support of written documentation to summarize what has been said.

### **Q8 Training and support**

Need for Community Children's Nursing (CCN) courses and

Advanced nursing practice for PEOLC children

The impact on professionals when a child dies should never be underestimated and therefore ASCS highlights the need for support and supervision for staff working in Palliative Care as there is a lack of formal supervision for those working in the NHS.

**Q9 Ensure discussions take place**

This relates to questions 3 and 4 above and should be seen in the context of the individual child and family.

There are clear recommendations within the Children and Young People's Palliative Care Framework and the Children and Young People (Scotland) Act 2014 makes provision for ensuring the right discussions take place with the right parties through the Named Person and Lead Professional roles.

Each health board should have a named doctor and lead nurse for children and young people's Palliative Care.

**Q10 Recording and documenting**

A single person co-ordinating the recording and documenting of care planning is essential. This relates to previous responses in Qs 3 and 6

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