

The response of Aberlour - Scotland's children's charity to the Scottish Parliament's inquiry – "We need to talk about palliative care" August 2015

About Aberlour

Aberlour is Scotland's largest solely Scottish children's charity. Working in over 40 locations across Scotland in fields such as disabilities; residential and foster care for looked after children and parental substance use. We have been helping to improve the lives of Scotland's most vulnerable children, young people and their families for 140 years.

Introduction

We currently provide long and short stay respite care for children with disabilities in ten locations across Scotland. Through our work in such services, we have amassed experience and understanding of the end of life and palliative care needs of children with profound life limiting conditions. Although we do not directly deal with palliative care, issues surrounding the subject are relevant to many of the children and families who have used our services for many years. By communicating with these families we have been able to understand the areas of palliative care which work well and those areas which are less successful. Therefore, as this response will go on to discuss, we feel that a more holistic, multi-agency approach to palliative care, with a role for respite services such as ourselves, could give children and their families a greater number of options and additional support.

Our experience and understanding of children's palliative care is encapsulated in this definition provided by the Children's Trust:

"Palliative care for children and young people with life-limiting or life-threatening conditions is defined as an active and total approach to care, from the point of diagnosis or recognition throughout the child's life, death and beyond. It embraces physical, emotional, social and spiritual elements and focuses on enhancement of quality of life for the child/young person and support for the family. It includes the good management of symptoms, provision of short breaks and care through death and bereavement."

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

n/a

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?

In order to improve equal access to palliative and end of life care in all areas, more children's hospices; such as the Kinross based Rachel House operated by the Children's Hospice Association of Scotland, should be established. Currently, many families have to travel a great distance to reach a children's hospice which can cause practical difficulties and additional stress. In terms of access to information, there lacks a specialist palliative care contact who can discuss the subject and meaning of palliative care with families who use respite services and the many options which may be available to them.

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

As previously mentioned, creating more places such as Rachel House should be a priority. There are not enough places for terminally ill children to go where families are able to spend quality time with them without having to act as carers. The creation of more hospices would ease this burden and also enable more children to be able to receive both the health and social care they require in one place.

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?

There is a general consensus across Aberlour services that the right time to begin discussions surrounding Palliative Care tends to be the 'sooner the better'. The discussion should involve medical experts; including both the lead doctor and paediatrician, and of course the family. The hospital should ideally initiate the conversation and the family should have a choice as to where it takes place.

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

Open, honest discussions which provide families the chance to be listened to and supported are vital to ensure good practice is communicated. A key challenge which remains is the uncertainty over at which point end of life plans should be discussed. End of life plans are a key way of enabling families to feel as though they have an element of control back. The plan also ensures that health and care staff are informed of family wishes and agreed procedures well in advance.

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

Generally, there seems to be some dissatisfaction towards the failing of anticipatory care plans to explicitly tie in to the broader notion of palliative care. The anticipatory care plans tend to focus on the practical elements of caring for the individual's complex medical needs

without addressing the wider issues surrounding the individual's social care needs. Although there are some mentions of outcomes in the plans, more could be done to support more honest and open discussions about palliative care and its meaning. There have been suggestions that if hospitals were perhaps more fully committed to administering anticipatory care plans for patients, uptake would improve.

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?

It is our duty to ensure that children who have the capacity to make decisions are provided with a full explanation of the choices they may have to make and the potential consequences that may follow. Article 12 of the UN Convention on the Rights of the Child declares that the voice of the child should be heard and acted upon in all decisions that affect them. Therefore, it is of vital importance that information about palliative care is as accessible and straightforward as possible. Choices over issues such as symptom management will be person specific; those involved in the initial discussions should aim to neutrally portray the advantages and disadvantages of the possible options available to the child so that they can make a fully informed decision. The child must be given the right support and resources to be able to choose how their care is delivered as well as their preferred place of death.

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

Currently there is a notable lack of training and support for staff with regard to discussing Palliative Care. Families should be able to decide who they wish to discuss Palliative Care issues with. Therefore, staff such as those in our Aberlour respite care services, should be supported and efficiently trained so that families are able to have conversations about Palliative Care if they so wish. Staff should be fully trained in order to adequately meet the emotional support needs of families and the children. Training geared around awareness and understanding of Palliative Care is still essential for those members of staff who are not involved in the initial Palliative Care discussions. Such support would enable staff to have a deeper understanding of the emotional and psychological needs of families who are dealing with different aspects of Palliative Care and how to sensitively but openly discuss issues of concern.

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

Ultimately, the responsibility to ensure palliative and end of life care discussions are taking place at the right time lies with the lead professional. A multi-agency approach should enable health and care organisations to communicate with each other to ensure that such conversations are indeed 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?

Experiences of communication between different health and care providers have varied. However, there have been some incidences where communications have been poor which has prompted calls for the need of further emphasis on the importance of the multi-agency approach. All sides should be kept informed of priorities from the point of first discussing Palliative Care.