

Dear Colleagues,

RE: Draft National Framework for the Delivery of Bereavement Care in Wales

The Royal College of Paediatrics and Child Health (RCPCH) welcomes this consultation and the framework being set out to support those who are facing, or have experienced, a bereavement in Wales. We support the wider provision of home care for children with life limiting illnesses and access out of hours.

We specifically sought the view of Professor Richard Hain our Clinical Lead for the All-Wales Paediatric Palliative Care Network. We note that it is addressed primarily to commissioners of services and clinical providers and makes very little demand on government, whose role is limited in this report to ensuring that effective pathways exist.

The document highlights that bereavement causes personal suffering and demands support, both as a matter of compassion in the moment it is experienced and also because it impacts on long-term mental and physical health. The authors of the report do not cite research sources, but our understanding is that empirical evidence supports their claim.

A significant emphasis of the strategic context of the document (section 2) is on the bereavement impact of COVID-19. Although understandable, since the document was written during a time when COVID-19 was the main cause of death in Wales, the emphasis risks obscuring the fact that outside pandemics the usual causes are much more diverse. In section 9, the document again emphasises COVID-19. The title of the section is 'Learning from COVID-19', but it was not always clear what more generally applicable principles COVID-19 was being used to illustrate.

We were unclear as to what was meant by making Wales the world's first compassionate country therefore it would be good to understand this in the context of children and young people. The document also sets out the need for clear pathways. Professor Hain suggested that it would be helpful to include an illustration in relation to this such as a flow chart.

A number of references are also made in relation to the importance of the third sector providers of bereavement support. It would be useful for the document to indicate government's responsibility to develop an equitable means of including such services seamlessly in a national integrated approach.

The document references children and young people at two or three points, and signposts one publication on bereavement in children (p24). It was unclear how the distinct needs of children and young people are adequately acknowledged. The way adults die and are bereaved is different from children, and different again from young people. Furthermore, many of the factors that, among adults, make complex bereavement more likely are universally true of children and young people, such as difficulty in articulating feelings and restricted opportunity in practice to explore them.

The document could usefully emphasise more clearly that services suitable for adults are usually not equally suitable for children and /or young people, and that the lack of services to support the latter in Wales is even greater, and the need for expansion even more urgent, than for adults.

Our [State of Child Health \(SOCH\)](#) report tells us that many long term conditions develop during childhood. Our report for Wales included the following policy recommendations:

Welsh Government should implement recommendations from the Cross-Party Group on Hospices and Palliative Care 2018 Inquiry 'Inequalities in access to hospice and palliative care', which relate to paediatric palliative care services. Recommendations include access to out-of-hours services and increased resourcing of community nursing.¹

Welsh Government should undertake an impact assessment of the Cancer Delivery Plan for Wales (2016-2020), specifically looking at children and young people's cancer services, to inform planning for children's cancer services beyond 2020.²

The RCPCH engagement team have also been speaking (virtually) to children and young people across all four UK nations to understand the impact that COVID-19 has had on their lives in relation to their access to health services and support. Children and young people have highlighted bereavement services to us during the pandemic period and have said the following:

"More support for children and young people about bereavement because of COVID-19"

"Have more support for families"

"More school counsellors in and to do it in person"

"They should put good information on the school social media on where to go for support"

Should you wish to discuss these issues directly with paediatricians, please contact our Head of Devolved Nations Gethin Matthews-Jones – gethin.matthews-jones@rcpch.ac.uk

With kind regards,



Dr David Tuthill
RCPCH Officer for Wales



Professor Richard Hain
Consultant and Lead Clinician in Paediatric Palliative Medicine

¹ <http://www.rcpch.ac.uk/state-of-child-health p29>

² <http://www.rcpch.ac.uk/state-of-child-health p29>