

# Reflections on some learning from the Covid-19 pandemic: support for parents of children facing serious parental illness and death needs to be integral to health care

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## Implications for practice

- National and regional strategy should recognise and name family-focused pre-bereavement care as a priority if the needs and rights of our children and their families facing bereavement are to be met.
- Bereavement training that covers a wider psychosocial remit than procedures following a death should be mandatory for health and social care professionals.
- All acute healthcare facilities such as hospitals need to fund a supporting specialist service to train and support their clinical teams who support families at end-of-life, and to directly support parents with the most complex needs to support their children's when faced with parental, or significant other death.

## Abstract

The Covid-19 pandemic has further highlighted the significance of pre-bereavement care for families and children facing parental death. Holistic family care, including support for the preparation of dependents, is core to specialist palliative care services in Scotland, but was hugely challenging during the height of the pandemic. It also exposed the challenges in all areas of acute healthcare for families with children, including intensive care departments. Parents need specific support appropriate to their children's needs. This includes how to share information with their children, and how to help their children to express their opinions and share their emotional responses about their experience. Parental bereavement has wide-reaching consequences for the lives of children and young people, and the ability of the surviving parent to support them is crucial. Starting to support parents before death provides the opportunity to ensure children are included in ways that are appropriate for that family. A discrete service to provide this specialised pre- and post-bereavement support to families, and training and ongoing support to practitioners across all areas of hospital and health care, is required.

Catriona Macpherson works as a children and families practitioner in specialist palliative care in NHS Fife. Fife is unusual in that all specialist palliative care in hospital, hospice and community is provided by the NHS, and families with children can be supported from our early intervention clinic while receiving oncology care through to some considerable time after bereavement. All services continued to be delivered during the pandemic by using additional resources of virtual clinics, 'garden' visits, 'drive-by' visits and outdoor groups in a local therapeutically designed space, and included support to any families with children and young people parentally bereaved by Covid-19.

'The ability to spend a short period of time with Mike for the 20 days he was a patient in ICU allowed me to process the severity of his situation, it allowed me time to tell him all I felt I needed to, I was able to see in person the highs and the lows of these final few weeks of his life and to help my children to prepare for the death of their dad. Most importantly, I was able to experience him squeezing my hand – telling me he loved me in his own way – one last time.'

**(Written communication from Rona, wife of Mike, who died in October 2021 from Covid-19)**

The question of how to take a family-centred approach which takes into account the needs of children and young people with parents facing serious illness, life-limiting disease or trauma, has never been so present in Scotland. As demonstrated in the Bereavement Charter for Scotland, bereavement support starts before death, is integral to health and social care provision, and must involve families in decision-making processes in language that they can understand (Scottish Care, 2020). Before the Covid-19 pandemic the call to 'think family' was emphasised as part of a fundamental preventive approach (Arber, 2016), and additionally set childhood bereavement within a public health perspective (Paul & Vaswani, 2020). The acute care of seriously ill patients and their families forms one key part of this approach. Holistic care, incorporating preparation of family dependents for parental death, can be inherently time-consuming, and even within specialist

palliative care, arguably more seasoned in this process, it remains a core challenge (Kissane, 2017).

During the Covid-19 pandemic, the Scottish Government provided a series of guidelines recognising the need for a balancing of risks to maintain a person-centred approach to support for families and carers. Family support was seen as essential to individual patient care<sup>1</sup>, and hospital visiting guidance provided for end-of-life care where practitioners were urged to take as broad an interpretation as possible, and not to restrict this to final hours, or to apply 'blanket' policies.

Even the most experienced practitioners can find identifying the last days of life challenging, especially with younger adults. This was heightened during the pandemic when having to make decisions about when and how to offer visiting, arguably a key time for offering family care, and was rarely a purely clinical matter. The location, travelling time and Covid-19 status of closest family members were all part of that decision-making, and under extremely challenging physical and emotional conditions. Clinicians were faced with much more complicated decisions about how to enact a flexible and compassionate approach for children visiting a seriously ill parent. The question of who has the right to make such crucial decisions and how we develop discussions collaboratively with patients and family members using sub-optimal communication tools (such as remote technology or mobile phones with unreliable signal) remain a matter for further reflection and staff education. These experiences brought into sharp focus the difficulties that practitioners faced in opening conversations with parents about the information and emotional needs of their children.

The Scottish Government has approved The United Nations Charter for the Rights of the Child (UNCRC) toward the process of incorporation into Scottish law. This includes Article 12 (respect for the views of the child) which states that 'Every child has the right to express their views, feelings and wishes in all matters affecting them, and to have their views considered and taken seriously'. To ensure children's rights are met when a parent has a serious illness, Sweden has incorporated healthcare regulations that require professionals to consider the needs of children (Karidar *et al*, 2016). This has long-term implications because open and

<sup>1</sup> [www.rcpe.ac.uk/sites/default/files/sa\\_statement\\_-\\_patients\\_and\\_family\\_at\\_end\\_of\\_life\\_care\\_final\\_-\\_updated\\_september\\_2020.pdf](http://www.rcpe.ac.uk/sites/default/files/sa_statement_-_patients_and_family_at_end_of_life_care_final_-_updated_september_2020.pdf)

honest communication with children is key to improving family adaptation to parental death (Wray *et al*, 2022).

Parental bereavement has wide-reaching consequences for children's lives and the ability of the surviving parent to support them is crucial (Worden, 1996). Not every parent wishes to include their child in the end-of-life process, but many seek specific support from the health professionals around them (Fearnley & Bolund, 2017). However, both in Sweden and the UK, lack of confidence is one of several barriers experienced by professionals when considering facilitating parents to share age-appropriate information with their children and often results in patients remaining the primary focus (Franklin *et al*, 2019; Karidar *et al*, 2016). Despite the aspiration to provide family-focused care, and the knowledge that early intervention is preferable, developing the skills to work collaboratively with parents and support them in their preparation of their children, for their stage of development, and within the very particular circumstances and experiences they face, is challenging. This is a big ask for practitioners in acute hospital settings already regularly dealing with critical staffing shortages and difficulties releasing key members for training.

Practitioners working and researching in this field have developed guidelines for healthcare professionals to help parents consider their children's agency and address their emotional needs. These stress early intervention where possible, and for every patient with dependents to be offered support, and not exclusively those that receive specialist palliative care (Marshall, 2022; Marie Curie, 2021). Intervention programmes designed to support families with parental cancer rely on clinicians to offer information routinely (Inhestern *et al*, 2016). Such programmes are not available UK-wide, and the difficulties of reaching isolated, or more vulnerable families with complex needs have been clearly identified (Hanna *et al*, 2019).

In Scotland, we know that childhood bereavement is associated with disadvantage (Paul & Vaswani, 2020). We risk worsening health inequalities further if we don't proactively think through for every family the offer of parental support to ensure their children receive the information they need to understand the dying and bereavement process. If focused family-centred care is needed for all children who face the loss of a parent or carer,

even more intensive care and support is required for those families already living with additional vulnerabilities and where communication is inherently challenging, or conflictual (Kissane, 2017).

All parents may waver in their ability to address their child's need for information, even when certain they want to do it, and the process is often complicated by their own co-parenting relationship and their personal history which may include multiple forms of trauma (Macpherson, 2009). The tension between the needs of children and parents can create a complex dynamic, and manuals and guidance need to be treated with caution (Dencker *et al*, 2019). Thus, we need to tailor the right approach for each family situation (Kopchak Sheehan *et al*, 2014), and this often requires the ability to support individuals to manage nuanced, complex or conflicting needs. Thus a range of support from short, focused discussions to highly skilled early intervention is required within service provision.

Currently, bereavement training for health and social care practitioners is not mandatory. Training specifically based around care for the family unit, especially where children face parental or carer loss, is undeniably scarce in mainstream healthcare. Arguably, all health and social care practitioners have such training needs, not least because we can be highly influential in modelling communication and behaviours around serious illness and dying to parents, young people and children who have not experienced the dying process.

A health board-funded service to facilitate parents to talk to their children about potential parental serious illness and death and to co-ordinate training for practitioners potentially able to facilitate patients who are parents, can increase practitioner confidence. Such a service also needs to be able to directly support vulnerable families with more complex needs and ensure referral to relevant agencies. This could also go some way to ensuring that services begin to consider their accountability for the rights of children at a systemic and organisational level.

As shown by the words of Rona, this need for family members to be alongside, collaborating with the clinical team cannot be understated. Through the Covid-19 pandemic we have seen how health professionals understand, and can take on, the feelings of helplessness that families experience

when they have to depend on us for their loved ones' care. Clinicians who care for dying people and their families also need support and this should be part of any specialist service working in this area. Parents have described feelings of 'worthlessness' when not able to visit, or fully contribute, as if somehow they had lost their value to the person we call the patient. We have a responsibility as a community to ensure that close family feel valued and included when facing parental death.

## Conclusion

The Covid-19 pandemic has further highlighted the need to ensure person-centred and family-focused pre-bereavement support. The onus is on us to debate how we ensure that the needs and rights of children facing parental death are met and that they are considered as fundamental to healthcare for our whole community in Scotland, including those families who do not have the confidence to ask. Family-focused bereavement care must make it into national and regional strategy, and it is then for health boards and health and social care partnerships to ensure that this vital support, delivered by an appropriately trained and skilled workforce, is accessible to all who need it.

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