

COVID-19: An Added Impetus to Ascertain End of Life Wishes

D. Kelly

Department of Palliative Care, St Vincent's University Hospital, Dublin 4.

The start of 2021 was far removed from the beacon of hope we had all hoped it might be. Instead, with rising infection numbers here in Ireland over Christmas to levels much greater than ever anticipated, the 2021 death toll in turn continued to mount. Much focus was rightly cast on those many hundreds who were dying 'of Covid', and the great suffering they experienced. Alongside them however were those dying in hospital 'with Covid'. These were cancer patients, heart failure patients, dialysis patients and many others who had fought a long battle but for whom treatment options had now been exhausted – and whom in the terminal phases of their illnesses had been caught in the crossfire and infected with Covid-19 as it ravaged through our hospital systems.

In palliative care the focus is very much on a holistic model of care. An absolutely central tenet to this is being able to die with dignity, with the support of and surrounded by those we love. This is important not just for the patients approaching the end of their lives but also their family members who, having shared their lives with the patient, place so much importance on sharing their final hours with them. The fundamental human drive to 'be there' for a loved one in their final hours is often overwhelming, indeed it is a real and concrete action where one can otherwise often feel helpless. Across multiple hospitals and healthcare settings in Ireland, we have seen so many examples of this virus depriving patients and families of the possibility of performing this one great final act of love. Circumstances for example where cancer patients contract Covid-19 in hospital and partners, who had hitherto been allowed in to provide daily care and support, had to then themselves isolate at home. Circumstances where large families can spend only short intervals of time on an individual basis with parents to say their final goodbyes. Circumstances where vulnerable elderly siblings are torn between the risk of entering high risk hospital facilities and the desire to see their brother one last time. For those patients who have been battling a terminal disease or malignancy for many years with their partner or families by their side, it can feel particularly cruel to be deprived of their support in the final hours or days.

Especially in these times it is important for palliative healthcare providers, and indeed healthcare providers in general wherever the context is appropriate, to go the extra mile to present alternative care options to patients who may be in their final days, weeks or months. The majority of deaths in Ireland still occur in a hospital setting¹ - while this may be necessary for some (i.e. those with more complex care needs) and others may prefer this setting, it is vital that we do our utmost to engage with all patients with terminal illnesses and endeavour to obtain what their wishes may be. This entails having an open and sensitive conversation about places and ceilings of care and ensuring appropriate documentation of same.

The long overdue roll out of the provisions of the Assisted Decision Making Act 2015² (“the Act”) would greatly assist all healthcare providers in facilitating this – and most notably the roll out of those provisions that pertain to Advanced Healthcare Directives (“Directives”). Although the concept of these Directives is accepted in Irish courts, there is much uncertainty around their operation at present in Ireland. Such uncertainty can present tremendous difficulties to healthcare providers especially in acute or emergency settings – when such documents are often not accessible or where there may be many questions as regards their legitimacy or enforceability. So often in the face of such uncertainty, doctors will err on the side of caution and choose to admit and/or treat as applicable – the uncertainty coupled with the irreversibility often associated with choosing alternative options leaves many with little in the way of real choice.

The existing provisions of the Act do in fact provide for certain requirements around the content, witnessing and registration of directives but much of the finer details are to be set out in subsequent ministerial regulations. What we need from these regulations is a system which provides us firstly with a uniform and standardised template for such Directives, together with very clear safeguarding guidelines around how these Directives become legally enforceable. Perhaps more importantly, a centralised database where all such properly executed Directives can be accessed at any time by healthcare professionals would assist hugely in ensuring such directives are respected, most particularly in acute care settings. With the above in place, doctors would be provided with much greater certainty that the wishes which they are reading are the true and authenticated wishes of their patient. In turn, this would allow them to make decisions with confidence to respect those wishes, however irreversible those decisions may be.

Corresponding Author:

Daniel Kelly MB BCH BAO MRCP
St. Vincents University Hospital,
Dublin, D04 TC63.
E-Mail: danieldkelly@svhg.ie

References:

1. Deaths 2018 - CSO - Central Statistics Office. [online] Available at: [Link](#) [Accessed 29/08/21].
2. Assisted Decision-Making (Capacity) Act 2015. [online] Available at: [Link](#) [Accessed 29/08/21].