

T J Fleming
An tArd-Chláraitheoir
Consultation
General Register Office
Government Offices
Convent Road
Roscommon
F42 VX53

Wednesday, 14 April 2021

Dear Mr Fleming,

Re: Consultation on changes to improve Efficiency of the Death Registration Process

Irish Hospice Foundation (IHF) welcomes an opportunity to express an opinion and make a submission to developing the policy initiative on changes to improve Efficiency of the Death Registration Process and the resultant operational and legislative changes outlined.

Irish Hospice Foundation is a leading voice in Ireland on matters relating to dying, death and bereavement. With over 30 years' experience, we believe everyone facing end of life or bereavement, and those who care for them, should be provided with the care and support that they need, wherever the place.

We agree, with the consultation document, that mortality data is very important in helping shape the future direction of health and social services. **IHF welcomes the proposed process to shorten the length of time from the notification of a death to the registration of the death and reporting of same.** Such process will ensure more timely analysis of cause of death and place of death in Ireland. This information was sadly missing during COVID-19.

Irish Hospice Foundation, alongside our partners in HSE and all care settings, has had considerable success with the use of the **end-of life symbol** in care settings. This symbol used in signs, drapes and bags flags that a death is imminent or has occurred in the care setting. It alerts staff and others of the need for sensitive communication. We are particularly proud of the success of the 'handover bag'. This bag has replaced previous non-descript bags (including black refuse bags), which were used in a hospital environment to hand over the precious belongings of a loved one to relatives. We feel a similar concept could be developed for death certificates. We therefore add in an additional recommendation into the process of death registration. **We recommend that death certificates are placed in a custom envelope – with the End-of-Life care symbol on the outside.** This means that if they are



left for collection at a reception desk there is immediate and outward recognition of the sensitivity of such communication.

We note in the consultation document that no changes are recommended to the **Medical Certification of cause of Death (MCCD) stage**. However, we would recommend the Department of Social Protection to look to other jurisdictions as to how they notify cause of death (e.g. in UK several primary, secondary and tertiary causes are noted). We would also recommend that the Department consult with medical public health colleagues on this issue. As our population ages, more people are dying with a range of conditions (multimorbidity). It is becoming more important to know both the primary cause of death and contributing causes of death. For example, dementia interacts with other conditions to predispose to early death. However, rates of death due to dementia are much lower than rates of deaths with dementia. Such knowledge can be gained by small changes in the death certification form to facilitate recording all chronic conditions and mental illnesses, but which would yield great information for service planning. Given the Department is proposing move to an electronic process this could be achieved relatively simply. In the UK, it has been demonstrated that the standard of death certification may be improved with changes in practices, but doctors completing death certification forms need to be encouraged to change practice.

In these exceptional times, people need support in grief more than ever. Whether someone is grieving a COVID-19-related death, a death from other causes or maybe a previous loss is feeling more difficult due to the ongoing restrictions, the bereaved need to be supported by all – including through our state services.

In 2017, the Government produced a seminal report on the response of state services to Dying , Death and Bereavement, called Finite Lives (available on <http://marielouiseodonnell.ie/wp-content/uploads/2017/05/Marie-Louise-ODonnell-Finite-Lives.pdf>). Compiled by Senator Marie Louise O'Donnell, this report contains many recommendations relating to State departments, including the Department of Social Protection, many of which remain relevant today and are of relevance to the efficiency of the death registration process. As noted in the report

“The State counts us at key times in our lives – our births, our marriages and our deaths. In turn, the public should be able to rely on the State at the times that count for them such as the death of a loved one. It can do this by being mindful to citizen’s needs and putting in place protocols and systems to meet those needs.”

Much of our comments relate back to recommendations from this report. We draw your attention to and reiterate the recommendations made in the report in relation to registrars of Births, Marriages and Deaths around the country. These are offices where people register a birth, collect a marriage certificate, buy a birth certificate and ultimately get a certificate to mark the death of a loved one.

1. **Review of forms and processes for death registration:** In addition to the physical space of our public offices, the State should look at easing the administrative burden it places on the seriously ill and the bereaved. The State should regularly review all of its forms to see if they are necessary and concise. Every effort should be made to eliminate multiple form filling which are confusing for people in the full of their health not to mind people whose health is compromised or who are enduring a stressful period in their life such as a bereavement. If and where possible (perhaps as a next step), we recommend that the Death Notification Form process should be enabled to link with already existing Electronic Patient Record Systems, therefore enabling the notification to be made as part of the in-hospital care after death documentation process.

2. **Minimisation of bureaucracy and initiation of a ‘Tell Us Once’ approach to registration of details of a person’s death.** It is essential that every effort is made to ensure that information such as bills are not sent to the deceased. This can be distressing for the bereaved. While efforts are made between different arms of the state to ensure that databases were updated, vigilance is required in this area and new approaches should be investigated. The use of a system similar to the **UK’s Tell Us Once** service should be considered in Ireland. With the Tell Us Once service, a death can be reported by telephone or on-line and this information is communicated to most government organisations. (see page 60 Finite Lives)

3. **Consideration of physical space as an element of a compassionate approach towards registration of death.** The report notes that an appropriate space should be allocated for people who are registering deaths and specific times for registering deaths could be scheduled in an effort to spare the bereaved any upset. In time, any allocated space for the bereaved should be specifically designed to secure dignity and comfort. In this, the Health Service Executive, which is ultimately responsible for the registration function, could look to its **Design and Dignity Programme** in acute hospitals which it has developed with the Irish Hospice Foundation (see <https://hospicefoundation.ie/our-supports-services/healthcare-hub/design-dignity/>). The report contains examples of where physical space impacts heavily on those bereaved – one example is where death registrations take place in the same setting as birth registration and this becomes very traumatic for parents registering the death of a child (see page 164 Finite Lives). **We also recommend that staff and officials providing services to those bereaved, should receive regular training in communications and specific information on the needs of the bereaved as well as supports if needed regarding their role interacting with those bereaved.** Irish Hospice Foundation is happy to assist in this regard.

We look forward to further consultation and discussion on any matters listed above and welcome the opportunity to consult to this process contribute to this process.

I remain yours sincerely



Sharon Foley
CEO