

Irish Hospice Foundation Submission on the Civil Registration (Electronic registration of births, marriages and deaths) Bill – June 2023

Introduction

Irish Hospice Foundation (IHF) is a national charity that addresses dying, death and bereavement. Every death matters – and we only have one chance to get it right. Our vision is an Ireland where people experiencing dying, death and bereavement are provided with the care and support they need. This support is needed both during and after death.

We advocate for excellent palliative, end-of-life and bereavement care so as to ensure that every person's physical, psychological, practical, and spiritual needs are comprehensively and compassionately met.

Since 1986 we have worked to promote understanding, awareness, and access to services, to enable people and their families to receive good care at the end-of-life, and to ensure appropriate bereavement support and interventions for those who experience a loss.

Through this submission we welcome the opportunity to contribute our expert views and experiences to inform the Civil Registration (Electronic Registration) Bill 2023 which will enable families to register births and deaths online for the first time, revise the criteria for the registration of stillbirths, improve access to the stillbirth register and to register a death where a coroner's inquest has not been concluded.

Background

Our proposals continue to be informed by our submission to the General Register Office in 2021 on the revision of the method by which deaths are notified and registered in Ireland. With Minister Humphreys securing Cabinet approval for the Civil Registration (Electronic Registration) Bill, we welcome and seek further opportunities to engage with this process of change.

In 2017, the Government produced a seminal report on the response of state services to dying, death and bereavement, called [Finite Lives \(available here\)](#). 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. Many of our proposals relate back to the recommendations from this report.

Registering a death

a.) Review of forms and processes for death registration

The Civil Registration (Electronic Registration) Bill is a key opportunity to ease the administrative burden it places on the seriously ill and the bereaved. The new process being legislated for should ensure that every effort is made to eliminate multiple form filling which may be confusing or distressing. We would particularly emphasise the importance of ensuring that the revisions of registering a death being introduced by this Bill are grief literate. Grief literacy is about recognising that everyone who is grieving can benefit from community-based acknowledgment and validation of their grief. The physical process of registering a death is a key opportunity to acknowledge the significance of a person's grief. The registration staff are in the position to offer condolence and human compassion to bereaved people and this should be encouraged and supported. While the ability to avail of

online registration of a death may be of benefit to a cohort of people, the opportunity to register a death in-person must remain.

Online registration processes, as well as fulfilling the core function of registration, should also provide information on bereavement support and signpost to services – for example the IHF/HSE [Bereavement Support Line](#) and for stillbirths to the [Irish Pregnancy and Infant Loss website](#) which IHF funded and continues to support. IHF would be happy to explore with the Committee similar signposting pathways for the death registration process.

Online registration must have easy access to the technical support available to the user. Ideally a helpdesk which can bring a person through the process should they encounter difficulty. It is imperative that the registration process is seamless and smooth and in no way adds to a person's distress or to the burden of administration required after a death.

b.) Investment in 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 a deceased person as this can be understandably distressing for the bereaved. While efforts are being made between different arms of the state to ensure that databases are updated, vigilance and sensitivity 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.

The introduction of online registration represents an opportunity to provide for a joined-up online system.

c.) Investment in physical space, staff and documentation to ensure a more compassionate approach to the registration of a death

As mentioned above online registration will be a choice for some people and will be engaged in by a specific cohort. However, the Civil Registration (Electronic Registration) Bill is an opportune time to highlight the need for investment in appropriate spaces for people who are registering deaths to ensure the environment is as sensitive as possible. In time, any allocated space for the bereaved should be specifically designed to ensure dignity and comfort.

The HSE ultimately has responsibility for the registration function and could look to their [Design and Dignity Programme](#), which it has developed with IHF, in acute hospitals for further guidance.

Face-to-face registration offers the opportunity for information on bereavement support to be provided verbally by registration staff, or for hard copies of bereavement information resources to be made available to people. For example information on our [Bereavement Support Line](#), which we deliver in partnership with the HSE, could be provided for people who are registering a death. As noted above, equally we would welcome and encourage consideration being given to including information about the Bereavement Support Line on the website or portal which people will use to register the death of a loved one.

d.) Education and training

Staff and officials providing registration services in physical spaces, through online chats and over the telephone should be supported with training for interacting with people who are grieving. Staff should receive regular training in communication and specific information on the needs of the bereaved. Staff may also require their own supports to enable them to continue ongoing interactions with people who have been bereaved.

A recent study by IHF – [The Real Financial Impact of Bereavement](#) – highlighted the importance of bereaved people having access to supportive staff, cognisant of their needs. Participants in the qualitative part of the study explained that one “nice” person who had an insight into their situation could completely change their experience of navigating the system and support them in addressing their needs.

IHF would be happy to explore how we could support this work –with our knowledge and expertise in this area.

Stillbirths

e.) HSE National Standards for Bereavement Care following Pregnancy Loss and Perinatal Death

We welcome that the Bill seeks to revise the criteria for registering stillbirths and improve access for families to the stillbirth register. These are important steps in acknowledging a families loss following a stillbirth. We would recommend that the Committee familiarise themselves with the [HSE National Standards for Bereavement Care following Pregnancy Loss and Perinatal Death](#) and the implications these changes will have in terms of improving the standards. The standards clearly define the care parents and families can expect to receive following a pregnancy loss or perinatal death.

Registering a death where a Coroner’s Inquest has not concluded

The plight of bereaved families who have endured significant delays in receiving a coroner’s inquest date, cause of death and therefore a death certificate demands resolution. We consider the proposed change allowing registration prior to the conclusion of the inquest to be an important contribution to the bereavement care of these families. We would draw the Committee’s attention to the difficulties that individual families face through engagement with the coroner’s system - [ICCL-Death-Investigations-Coroners-Inquests-the-Rights-of-the-Bereaved.pdf](#).

IHF are pleased to be working with the National Office for Suicide Prevention and the HSE on a project to improve bereavement care in this area. We would be delighted to have an opportunity to inform the Committee about this work.

It is vital that the online system for registering these often traumatic and sudden deaths is technologically easy to use, sensitive to language used and that it is supplemented with signposting to appropriate bereavement care supports. In this regard, we would once again draw attention to the IHF/HSE Bereavement Support Line and to our website www.bereaved.ie.

Recommendations

1. Ensure that the review processes required for death registration are grief literate and appropriately acknowledge the bereaved person’s loss and incorporate an opportunity to signpost people to bereavement supports.
2. Invest in a ‘Tell Us Once’ approach to the registration of details of a person’s death.
3. Invest in physical spaces, staff and documentation to ensure a compassionate approach to the registration of a death (in person but also online).
4. Support staff and officials providing registration services with training for interacting with people who are grieving.

5. Ensure that the Committee familiarises themselves with the HSE National Standards for Bereavement Care following Pregnancy Loss and Perinatal Death and the implications the Bill will have in terms of improving the standards.
6. Progress the registration of deaths where a Coroner's Inquest has not been concluded and ensure that bereavement supports are incorporated into the registration system.