



To die and grieve well wherever the place

## Irish Hospice Foundation Submission

### Department of Social Protection Statement of Strategy 2023 – 2026

#### Overview of Irish Hospice Foundation

Irish Hospice Foundation is a national charity that addresses dying, death and bereavement in Ireland. Our vision is an Ireland where people facing end of life or bereavement, and those who care for them, are provided with the care and support that they need. From advocacy and education, to services such as Nurses for Night Care and our Bereavement Support Line, Irish Hospice Foundation believes in the importance of dying well and grieving well wherever the place.

#### Strategy Statement Considerations

We welcome the opportunity to submit our views on a number of strategic and cross-departmental issues that we consider should be included in the Department of Social Protection's new Strategy Statement 2023 - 2026.

Our focus will be on areas related to dying, death and bereavement and we wish to highlight five themes that should be considered in the context of the development of the Strategy Statement.

- Integration and cross departmental collaboration between health and social services.
- Continuity and ease of access to payments and supports during dying, death and bereavement.
- Improved public awareness, knowledge and equity of access to payments and supports.
- Responsive & compassionate staff.
- Appropriate systems and environments for registering a death.

#### Integration and cross departmental collaboration between health and social services

We note that a key objective in the previous Strategy was to *“Put the Client at the Centre of Policy and Service Delivery”*. We welcome this objective and see high level integration and cross department collaboration as key to this. The collaboration is particularly important in terms of working with key departments such as Health, Education, Children, Equality, Disability, Integration and Youth and Enterprise, Trade and Employment.

It is a source of real frustration when services and supports designed to enable people to live well do not communicate or interact effectively with one another to deliver this shared goal. There needs to be more recognition and collaboration at key points where your clients'

journeys intersect with other Departments such as entry to the health system via a Medical Card or exit from the health system following the death of a loved one and the ceasing of payments to a person in that respect.

We recognise and welcome the ongoing work undertaken by the Department of Social Protection to promote integration and cross departmental collaboration. In particular the cross departmental annual Family Carers forum and the annual Pre-Budget forum organised by this Department. These opportunities should be continued, and every support given to expanding the range of issues discussed at these cross departmental forums.

We would advocate that bereavement is one such issue that has a cross departmental impacts on the lives of people. There is a lack of any sort of coherent national policy on bereavement in Ireland. In late 2022 we launched a report [“The Real Financial Impact of Bereavement”](#) detailing the impact of bereavement on home life in Ireland, including the impact on employment, health and the overall financial burden. The study was supported by a grant from the Department of Social Protection.

This report (see attached with submission) highlights real needs across Irish society in relation to grief, funeral costs and the impact of bereavement on employment and wellbeing. The report also highlights the cross-cutting nature of the impact of bereavement. The adverse economic impacts of bereavement are intertwined with the sometimes very intense adverse emotional impacts of bereavement.

The report is evidence that the impact of bereavement does not belong to any one Department. Irish Hospice Foundation has long advocated for a strategic and coordinated approach to bereavement care. We would urge the Department of Social Protection to use the opportunity of developing this new Strategy statement to seek support to host a cross departmental forum examining the impact of bereavement.

Another key area where cross departmental collaboration and support will be critical is the operationalising of the new legislation the Assisted Decision Making (Capacity) Act 2015. We would urge your Department to take key steps to ensure your staff are trained and informed about the wide ranging implications of the Act on their work and how they undertake it. The Assisted Decision-Making (Capacity) Act 2015 provides for a range of decision supporters, who can be appointed to support a person whose capacity is in question to make their own decisions regarding their personal welfare, property or affairs.

A key implication of this Act will be the Department’s staff interactions with the different levels of decision supporters who will have increasing levels of function and responsibility for another person’s affairs, depending on that person’s capacity at that time.

## Continuity and ease of access to payments and supports during dying, death and bereavement

The Strategy Statement should take the opportunity to explore the difficulties people experience in terms of continuity of their payments and supports. This is particularly evident at key junctures of people’s lives. For example, when they move from disability allowance to the state pension at age 66 or when a family is supporting a child to transition to the disability allowance at age 16. Another key point of concern is when a family carer loses their payments when the person they cared for has died.

The period of a loved one’s end of life and death can be traumatic and disruptive. We recommend further attention to the timeliness of support payments to carers, and continuity of social support for individuals who might transition between eligibility for different social support schemes. We would like to see steps taken where extra support and time is spent with people whose circumstances do not fit with the typical course of applicants. By way of

example, a family carer, caring for both parents and receiving the relevant benefits, when both parents die in quick succession (within three weeks).

We would urge the Department to facilitate staff to explore if there is a compassionate clause that can be taken for the person and their circumstances. In this example, the former family carer would receive 12 consecutive weeks of Carer's Benefit payment so that the second six weeks starts after the first six have expired. There would be many examples like this where more time is allowed to explore the person's case and to incorporate a compassionate clause into them.

## Improved public awareness, knowledge and equity of access to payments and supports

The new Strategy Statement is also an opportunity to review the knowledge and communication about various payments and supports provided by the Department. We would call for a review of the awareness, knowledge and access to the Exceptional Needs Payment (ENP).

Bereavement is an experience that will affect most people in their lifetime – over 30,000 people die in Ireland each year. For some the impacts of bereavement are temporary, while for others they can be significant and impact on their ability and capacity to continue with daily life. The ENP (or Additional Needs Payment) has the potential to alleviate some of the significant costs that people may incur following a bereavement. However, [The Real Financial Impact of Bereavement study](#) found that awareness and understanding of the ENP among the public is low and in its current form would warrant further review.

Another concern highlighted in the report was the need for clearer qualifying criteria, better explanation of the discretionary nature of means testing and simpler and more standardised information requirements that would make the ENP easier to access, as would more and better signposting. The recommendations in the report provide an outline of the proposed reviews that could be undertaken in this regard.

Overall, the respondents highlighted that the ENP process is difficult to navigate for those unfamiliar with accessing welfare supports. Although study participants in the study did not call for the return of a non-means tested payment, it was felt a payment that clearly highlighted the word bereavement and the costs it covered would be more likely to reach those most in need.

In this Strategy Statement we would also like to see measures where there is a more proactive approach taken to ensuring that vulnerable groups such as older people, family carers, people with disabilities, migrants and asylum seekers are accessing the relevant supports and payments which their circumstances may qualify them for.

This Department and your staff will have a deep understanding of the distress and upset that differing circumstances can cause for people. In this Strategy Statement we would welcome and encourage further promotion of clear, easy to read information including obvious naming and language translation being made available for people. Additional emphasis should be given in the Strategy to supporting local Citizen Information Centres and MABS offices that can provide people with information specific to their circumstances and support with completing detailed forms. We would also like to see further initiatives that promote outreach to people that may be particularly isolated or vulnerable that may qualify for supports they may be unaware of.

We note that your Department recognise the importance of timely applications, particularly when people find themselves in difficult circumstances, often suddenly and unexpectedly. We also note that, in particular, family carers are very complimentary of the empathic and understanding approach they have received from staff based in the carers office in Longford.

## Responsive & compassionate staff

We welcome and support the emphasis given in the previous Strategy to providing “*high-quality, tailored training, accredited learning and education opportunities for staff.*” This is an objective that should be maintained and developed in the forthcoming Strategy Statement.

In this regard, we would like to emphasise the importance of the Department ensuring that their staff are cognisant of the needs of bereaved people. This would be with regards to the tone that is used and the questions that are raised when a payment is being ceased following the death of a recipient. Equally this applies when a bereaved person may seek financial support to cover some of the costs associated with the death of a loved one.

In the report “[The Real Financial Impact of Bereavement](#)” those interviewed as part of focus groups and individual interviews were either bereaved themselves or worked closely with bereaved people. Participants explained that one “nice” person who appeared to have an insight into their situation could completely change their experience of navigating the system and support them in addressing their needs. The respondents noted some very positive statements about good practice among Department of Social Protection staff.

Staff should receive regular training in communication and specific information about their role when interacting with those who have been bereaved and supporting them to identify their needs. Irish Hospice Foundation offer a [Bereavement Support Line](#) which is a resource that staff can signpost people to, if they are need of more time to talk about their grief. The Bereavement Support Line is there to provide connection, comfort and support to people who have been bereaved. We would be happy to engage with the Department to highlight and promote this service with your staff.

## Appropriate systems and environments for registering a death

These proposals are based on a submission to the General Register Office in 2021 for their consultation on the revision of the method by which deaths are notified and registered in Ireland.

### **Review of forms and processes for death registration**

The Department should use the new Strategy Statement as an opportunity to ease the administrative burden it places on the seriously ill and the bereaved. There should be a systematic review of all forms to see if they are necessary, clear and concise. Every effort should be made to eliminate multiple form filling which is 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, we propose that investment should be sought to link the Death Notification Form process with existing Electronic Patient Record Systems, therefore enabling the notification to be made as part of the in-hospital care after death documentation process.

### **‘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 or notices are not sent to a deceased person as this can be understandably distressing for their families.

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.

### **Commitment to investing in the physical space, staff and documentation to ensure a more compassionate approach to the registration of a death**

The new Strategy Statement is an opportunity to recognise and invest in the necessity to provide appropriate and comforting spaces for people who are registering deaths. We would strongly advocate that any allocated space for the bereaved should be specifically designed to secure dignity and comfort.

While we recognise the HSE ultimately has responsibility for the registration function, the Department's role in this cannot be overlooked. This once again highlights the necessity for cross collaboration with other departments on key issues such as this that require compassion, understanding and discretion at all times.

We would be happy to explore how we could support this work based on our knowledge and expertise in this area.