National End of Life Survey finds majority of people feel their loved ones receive very good end-of-life care in Ireland, but areas for improvement remain

11 April 2024: The results of the first National End of Life Survey have been published today.

The survey asked bereaved people about the care provided to a family member or friend in the last months and days of their life in order to improve care.

In total, 4,570 bereaved family members and friends participated in the survey. The findings showed that almost 74% of participants rated the care that their relative or friend received at the end of their life as 'very good', 15% rated it as 'good', while 11% said that their relative received 'fair' to 'poor' care.

The survey included the experiences of people who received care or died in various settings. The most common place of death was a hospital (39.4%), followed by a nursing home, home and hospice. The people who died experienced a variety of pathways of care, involving multiple care settings and services in the last months and days of their lives. Differences were seen in the types of deaths that took place across settings. For example, those who died in hospitals typically had shorter illnesses than those in other settings.

Participants highlighted positive experiences across several areas of care, including the respect and dignity with which their relative or friend was treated and the standard of care provided by staff. The survey found that most participants had confidence and trust in the healthcare staff who were caring for their relative or friend, and felt that they explained their relative or friend's condition and care in a way that they themselves could understand.

The survey also identified several areas where care could be improved. Issues that were highlighted included the continuity, availability and responsiveness of care, timeliness of care and support for emotional needs. For example, 23.9% of participants answered 'no' when asked if there was good coordination between the different services and staff that cared for their relative or friend in the last three months of their life. Some participants also felt that their relative or friend did not get help from healthcare staff as soon as they needed it.

The most positive ratings of overall care at the end of life were from bereaved relatives of people who died in a hospice, with almost 94% of people rating the overall care that their relative or friend received in a hospice at the end of their life as 'very good'.

Responding to the survey findings, Minister for Health Stephen Donnelly said: "I wish to thank all the participants for taking the time to complete the survey. I acknowledge this was a particularly difficult task for people, following the death of their loved one.

"The results of the survey overall, provide a positive view of care near end of life. There are high levels of satisfaction with the level of care received. However, I recognise there are still areas for improvement, particularly in the areas of integration and coordination of services. The findings of the survey will be used to inform Department policy in improving end-of-life care for everyone. It will also make sure that the goal of providing the right care, at the right time, in the right place and by the right people is achieved."

Minister of State for Mental Health and Older People Mary Butler said: "I welcome the findings of this survey which was a key recommendation of the COVID-19 Nursing Homes Expert Panel. The significant level of satisfaction reflected in the survey findings in relation to nursing home care is heartening and reinforces our commitment to provide compassionate end-of-life care. As well as the positive views expressed, I also acknowledge the areas identified which can be improved to better ensure people receive the dignity and support they deserve nearing end of life. Strong communication between care providers, residents and their families is paramount. The insights gained will help inform the further rollout of the CARU end-of-life programme for the nursing home sector which is being delivered by the Irish Hospice Foundation and the All Ireland Institute of Hospice and Palliative Care, in collaboration with the HSE."

HSE CEO Bernard Gloster said: "The death of a loved one is a very difficult time for families and friends. I'd like to thank every person who gave their time to participate in the first National End of Life Survey and shared their experiences of the care their loved one received in those last precious months and days of their life.

"Improving the experience of end-of-life healthcare services is a key priority for us. This survey provides valuable information and important insights across our services in hospitals, hospices, nursing homes and the community. It lets us know what is working well, such as hospice care which is rated highly, and also, perhaps more importantly, the areas where we can and must improve. Our HSE detailed response report, 'Listening, Responding and Improving', which is also being published today, outlines the work underway to address the issues highlighted by participants in the survey findings."

Speaking on the release of the survey results, HIQA CEO Angela Fitzgerald said: "Experiencing the loss of a loved one or a dear friend is a particularly sad and difficult time in a person's life so we really appreciate that so many people took the time to tell us about their experience. This survey has provided us with valuable insights into the final days and months of those who are in end-of-life care, as well as the experiences of their relatives and loved ones during this time.

"It is encouraging to see that a significant majority of participants were happy with the overall care that was received. We must also be ready to act in those areas of care that can be improved. The survey findings also demonstrate the importance of close integration and coordination between the care settings and the services that are provided in terms of overall care experience for patients and their families."

Responding to the survey findings, CEO of the Irish Hospice Foundation Paula O'Reilly said: "Firstly, we would like to thank all those who shared their experiences of the end-of-life care of their loved one. Dying, death and bereavement will affect us all at some point in our lives and as such the findings in this report inform so many facets of healthcare provision in Ireland. This survey provides us with information that we can use to monitor and improve the delivery of end-of-life care informed by real life experiences.

"Any focus on end-of-life care must also examine the impact on those who are left to grieve the death of their loved one. This survey will provide valuable information on the emotional impact of end of life on family and friends. Irish Hospice Foundation will continue to advocate to ensure people have access to appropriate bereavement care and supports."

To find out more about the National End of Life Survey, read the full report on www.yourexperience.ie, watch the animation or visit Instagram, X (Twitter) and Facebook.

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Notes to the editor:

- The National End of Life Survey is part of the National Care Experience Programme — a partnership between the Heath Information and Quality Authority (HIQA), the Health Service Executive (HSE) and the Department of Health.
- The development and implementation of the National End of Life Survey was a recommendation of the COVID-19 Nursing Homes Expert Panel.
- People who registered the death of a family member or friend that occurred between 1 September and 31 December 2022, were invited to participate in the survey between March and May 2023. The survey closed in July 2023.
- 77% of participants said that their relative or friend received 'very good' care at the end of their life in a nursing home or residential care facility, while 76% and almost 65% of participants rated the care received at home and in a hospital respectively as 'very good'.
- It was evident that participants' relatives and friends typically received care in more than one setting in their last months and days. Those who died received care in approximately 1.6 settings on average.
- Almost 18% of participants said their relative or friend did not get help from healthcare staff as soon as they needed it while being cared for at home. In acute hospital care settings that figure was 16.8%. Just over 7% reported similar experiences in a nursing home or residential care facility.
- The Bereavement Support Line is a national Freephone service on 1800 80 70 77 which was set up and managed by Irish Hospice Foundation, in partnership with the HSE. It provides a safe space for those who have lost a loved one, friend or colleague to talk about loss and grief. This service is available Monday to Friday from 10am to 1pm. Irish Hospice Foundation resources are available at www.bereaved.ie
- Samaritans provide emotional support for anyone who is struggling to cope or needs someone to listen to them without judgement or pressure. You can contact Samaritans 24 hours-a-day, 7 days-a-week on Freephone 116 123 or by emailing jo@samaritans.ie. For more information, please visit www.samaritans.ie