HOSPICE AND PALLIATIVE CARE SOCIAL WORKERS GROUP

# Guidance for Bereavement Support provided by Specialist Palliative Care Social Workers in Ireland

## Addendum – The Impact of Covid-19

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## ACKNOWLEDGEMENTS

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Palliative Care social workers in:

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| Beaumont Hospital | Milford Care Centre |
| Connolly Hospital | North East Specialist Palliative Care |
| Galway Hospice | Northern Ireland Hospice |
| Kerry Hospice and Palliative Care Service | North West Hospice and Palliative Care, Sligo |
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| Marymount Hospice | St. James's Hospital |
| Mater Hospital | St. Vincent's Private Hospital |
| Mater Private Hospital | West Cork Palliative Care |
| Mayo Palliative Care Services | |


*COVID-19 has brought new challenges to the world around us and to the issue of dying, death and bereavement. It is intended that this addendum would be read as supplementary information to compliment and expand the original Guidance for Bereavement Support provided by Specialist Palliative Care Social Workers in Ireland document to take account of the new context. None of the information in this guidance over rides or replaces the original information*

## Guidance for Bereavement Support provided by Specialist Palliative Care Social Workers in Ireland

The impact of the COVID-19 pandemic on our society has been significant across many aspects of life for everyone. It has been described as a psychological crisis in addition to an epidemiological crisis (Wellbeing Waterloo Region, 2020). The impact of the pandemic includes significant challenges in terms of dealing with the ways in which health care is delivered and in dealing with death and bereavement in this new context (Cann et al, 2020). The current situation does not allow a process of dying and death in which families and communities can be involved in a way they would normally hope or expect to be (Bear et al, 2020; IHF, 2020; NISCC, 2020). It has changed visiting policies in hospitals, hospices and community, impacting how people say goodbye to the ones they love (Sinha, 2020; Cann et al, 2020). Social Workers in specialist palliative care and in other health care settings have had to adapt the way they work with patients and families in line with national and local infection prevention and control measures. Palliative care may have to be delivered in a different way because of the physical distancing guidelines, but the philosophy behind the care remains unchanged. Therefore, we have written this addendum to our previous guidance for bereavement support for specialist palliative care social workers (Finucane et al, 2019) to take account of these factors, but the core principles and values outlined in our original document are still relevant. This document adds supplemental information and considerations to the original document to acknowledge the new context and suggest some ways of responding.

This original guidance outlined a number of fundamental principles that underpin the bereavement care provided by specialist palliative care social workers. These principles still guide our practice, but there are now additional considerations which we address below.

### 1) Access

Social workers must embrace new ways of working in order to deliver care. People are not having the same level of face to face contact with services due to public health restrictions imposed during the pandemic. Social Work is a profession based on human connection and relationships (McGarry & Jackson, 2020) and we place

significant emphasis on the importance of communication and connections to support wellbeing and development (Casey, 2020). Social Workers are used to telephone work, but now need to provide their assessments, support and follow up using technology to bridge this gap (McGarry & Casey, 2020). This can pose challenges with individual's access to and literacy in technology. Conversations about difficult topics, now must take place in ways that we would ordinarily not consider best practice. Social workers may need to increase their skills in telehealth and technology to be able to manage these conversations through various forms of technology. 'While nothing replaces human touch and connection, virtual options can create a kinder and more connected end-of-life experience' (Cann et al, 2020). Enabling patient-family communication via virtual means where there is restricted access to patients, clear communication from healthcare staff and facilitating relatives to say 'goodbye' are also associated with better outcomes in bereavement (Selman et al, 2020).

There are significant limitations on in-person visiting, both in places of care and in the community, regardless of whether or not the patient has COVID-19. This extends to both professionals and family members not living in the same household. This has shifted throughout the pandemic and generally members of a family have been facilitated to visit as someone approached the final hours or short days of life. There has been an element of fear present for some people that means they have further withdrawn from services or further restricted visiting. Some patients are not accessing care in as timely a manner as they normally would, including people presenting later with more advanced illness at point of diagnosis. Patients at home may have more limited supports than normal due to social distancing guidance and visiting restrictions and some people have refused admission to hospice or hospital because of the restriction in visiting. Social Workers need to be proactive in offering supports to patients and families.

Vulnerable groups often have more challenged in access to health and social care. This can be heightened in the current context. Social workers, like many other professionals are creatively restructuring, reorganising and finding new and creative ways to proactively respond to patient's needs (McGarry & Casey, 2020).

Vulnerable populations warrant particular attention and may require more proactive offer of and deliver of support.

**2) Values and diversity**

COVID-19 has impacted many aspects of people's day to day life experience, for example through unemployment, financial distress, loss of structure and routine, loss of supports, unexpected burdens including childcare, additional family members within the house, supporting those with vulnerabilities. There may be additional stresses and vulnerability within the family context that may not have existed or been so prevalent before the pandemic. Social workers are well place to complete detailed psychosocial assessments of people's situations and develop appropriate care plans for both patients and family members tailored to their unique situation and need.

**3) Partnership**

Social workers approach their role from a perspective of collaboration with both the patient and family and with the multi-disciplinary team. Social workers continue to be embedded in the multi-disciplinary team. They also have key skills in liaising with other agencies and making appropriate links and referrals. This may need extra attention in the current context as most services are operating differently due to the pandemic restrictions. People may require extra assistance to access community supports, other agencies or services. Or the social worker may need to remain involved for a longer period of time with the person due to the current gap in other support services.

**4) Quality Assurance**

It can be a challenge to ensure quality when services need to adapt rapidly. However, social workers can still provide patient and family centred care according to social work norms and values, even when the situation is bounded by serious infection control procedures and protocols. Ethical frameworks continue to provide guidance, as well as using the overarching values and principles of current service provision to ensure quality is maintained (IASW, 2007; IASW, 2009; CORU, 2019).

**5) Governance**

New guidelines and protocols will need to be developed to ensure that any new practices introduced maintain the highest standards of governance. Current guidelines and protocols may need to be reviewed and adapted to ensure that any new practices introduced continue to meet the highest standards of governance. New guidelines, if needed, must meet the requirements of CORU code of ethics (CORU, 2019).

**Guidance for bereavement care**

Bereavement care continues along a continuum from the time of diagnosis, throughout the illness, to death and afterwards into bereavement. Given the current restrictions on visiting, families are more reliant on the social worker and other members of the multi-disciplinary team to provide support along this continuum. Below are some supplementary considerations to those outlined in the original document.

## I. Pre-death: assessing risk and resilience during Covid-19

Anticipatory grief for families is happening virtually and in isolation (Sinha, 2020). It is important that social workers offer a safe space for individuals and their families to have a conversation about what matters to them to help reduce the feelings of isolation, loneliness and distress. Social workers need to listen to both the content and the feeling of what people are sharing and need to make sure they have the time and the space to ask the questions that are important to them (SSSC, 2020). Due to the use of personal protective equipment and the new challenges of care, doctors and nurses do not always have the same amount of time they had previously to communicate with families. Families may have less opportunities to ask questions or see changes due to restricted visiting. Social workers have a particular skill set and competencies in communication, family systems, grief and loss, psychosocial aspects of people's lives (McGarry & Casey, 2020). "Failure to treat a communication emergency could result in years of avoidable guilt, regret, and sadness" (Pickering & George, 2007:1274). Social Workers are well placed to support and facilitate patients and families in communicating both with each other and with the wider multi-disciplinary team and to explore the emotional impact of this communication (McGarry & Casey, 2020). This begins with an assessment of

communication needs and information gaps. Follow up intervention may involve engaging with families to understanding and appreciate the changes in the patients' stage of illness, in collaboration with other members of the multi-disciplinary team.

**New Ways of Communicating**

As part of psychosocial assessment, extra emphasis must now be placed on assessing communication needs, preferences and abilities of patients and families and the extent to which these can be facilitated and supported by members of the multi-disciplinary team, including social work.

Some things to consider -

- use of visual technology may be impacted by concerns, on the part of patient or relative about body image and change in physical appearance. We cannot assume that visual communication has the same meaning or benefit for everyone. To avoid unnecessary distress, caution is urged about virtual communication when someone is dying (Selman et al, 2020)
- How do we facilitate people with hearing or visual impairment? Can we create some extra privacy for the patient? Does a frail, elderly relative have someone to support them with the use of technology and with the information they may hear during the exchange?
- Can the organisation facilitate visual contact at the window or balcony? Such visualisation may help family to appreciate changes for example, in terms of frailty etc.
- Some people may not engage well with technology. The use of photographs of family and friends or other memorabilia may be appropriate and may serve as a useful 'trigger' for meaningful conversations.
- If using audio-visual technology, this can be helpful for family to visualise the person and understand changes in health over time as a preparation for dying
- While the primary purpose of using electronic technology may be to give patients and family time together in a visual space, it may also help the family to 'see' the space where the patient is being cared for and to see who is caring for them.
- We must be aware in all our communication with family that relationship between family and team is more important than ever in order for family to have confidence in the process which they now only experience remotely.

- Be mindful of the importance of the 'feedback loop'. Check in with patient and family about the experience of communication with the team generally and about their experience of specific communication experiences and strategies.
- Assessment and support over the 'phone is not new to social work but it is usually supplemented by face to face contact. Now a very high percentage of work is remote without the same potential to assess body language and to interpret non-verbal communications. It is a particularly intense way to work and extra attention is required to ensure that the information being exchanged is understood by all concerned.
- Social workers must pay specific to the communication needs of vulnerable and/or absent family members – people living abroad who cannot travel, those being cared for in nursing homes or residential care centres, children, those with intellectual disability or mental health issues, prisoners, or those who are 'cocooning' because of their own health concerns. In many of these situations, we will likely be working through others. This raises challenges of support and respecting privacy and confidentiality

**Exploring the Unfolding Grief Narrative**

Social workers, as part of their psychosocial assessment, are generally alert to ways in which families narrate their experiences and understanding of the current situation.

- It is incumbent on social workers, as part of the multi-disciplinary team in these difficult times, to help families to find or focus on aspects of the narrative that will help them in the weeks and months after the death. Families have continued to care for and support their relatives despite all the challenges and decisions were made in difficult circumstances.
- We also need to acknowledge the real and sometimes difficult experiences in an empathic way but also help them reframe their understandings and perceptions, where appropriate, in order to assist them in developing a coherent narrative for the future.
- Social workers, may empathise with families about the experiences and challenges of recent months which may have been complicated by COVID-19 restrictions and protocols. We must, however, be mindful of colleagues in our own and in other institutions and services, both hospital and community who

are also working in a restricted way. It is important to maintain a respectful discourse when speaking with patients and families about other professionals and services and to demonstrate an appreciation of the different roles and functions of each. These are difficult times for all concerned.

## II. Around the time of death

- Social workers advocate for family in a way that adheres to protocols but aims to ensure meaningful contact between staff and family and between family members and the patient. Enabling family members to say goodbye in person where possible can help mitigate against poor bereavement outcomes (Selman et al, 2020). Where this is not possible, relative's perception of whether a patient received emotional support at end of life and whether they were treated with dignity and compassion, including whether they were alone or not can impact bereavement outcomes (Selman et al, 2020). The social worker, in collaboration with the multi-disciplinary can have a role in communicating such information to the family.
- Social workers and pastoral care colleagues will explore ideas about funeral rituals in order that the experience can be as meaningful as possible under the circumstances.
- 'Remind families that there is no single correct way to memorialize a life. It's okay to be creative: talking about ways to note their loved one's passage can be a connective, healing experience' (Cann et al, 2020)
- Some families may want mementoes or keepsakes, for example a lock of hair or a handprint. These can be taken just after a death, being mindful of any infection control procedures that need to be observed.

## III. Bereavement support after the death of a patient

- Social workers link with members of the multi-disciplinary team to assess the families' perception of the restrictions and communication strategies before the death and their perception of the death itself.
- There may be a need for reach out to the family after the death. Consider carefully whether they need some bereavement support and/or information about the care coming towards the end of life. This will determine who in the

organisation may be best placed to respond to the family or any queries they may have. The social worker may chair the review of care meeting

- The impact of social distancing, cocooning and isolation on people due to the COVID-19 restrictions cannot be underestimated. Loss of social and community networks and living alone are known to exacerbate psychological morbidity in bereavement (Selman et al, 2020). It can be important to offer people additional bereavement information that includes information on the new context and ways to cope (IHF, 2020)

**Caring for self**

The context of the pandemic has raised the issue of fear and worry for many people in relation to their own health and the health of friends and family. For people working in healthcare, it may also raise the possibility of the virus transmitting from healthcare worker to patient, with potentially life threatening consequences. This concept of “Second Victim” can have a significant impact of staff (Casey, 2020; Selman et al, 2020). Social work teams and agencies will also be affected by staffing changes due to the impact of the virus. Considering the emotional needs and self-care needs of social workers and other staff is important, but requires an organisational and systemic response (Selman et al, 2020). There are many resources available to help support this, including a module on Northern Ireland Social Care Council new resource ‘Hopes, Hints, “How To”- Helping you to respond to respond to living and dying issues during COVID-19’ (2020). We have a responsibility to regulate our own emotions before communicating with others and create an emotional climate that encourages empathy and hope. During this challenging time, it is even more important that we acknowledge the support we can offer to and receive from our colleagues (SSSC, 2020).

**Conclusion**

This guidance acknowledges the new and potentially complex context that we now live in as a result of the impact of COVID-19. It provides some information, guidance and considerations to enhance and support social workers working with people who are dying and their families, and working with bereaved relatives in a specialist palliative care setting.

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