



Irish Association of Social Workers: Submission on HPSC Visiting Guidance.

'We had to watch her die through a glass window, in the wind and rain and just look at her lying there taking her last breath' (Relative of a family in Ballynoe Nursing Home, as reported in the Irish Examiner 20/02/20)

The IASW appreciates the work, collaboration and effort which has underpinned the development of the current HPSC guidance, developed in the extraordinary circumstances of a pandemic. We also recognise the unique challenges posed in delivering visiting guidance for a sector over which the State lacks oversight. The Expert Panel on Nursing Homes Report clearly identified social work as an essential service within the nursing home sector. Given the complexities of our nursing home sector, with known gaps in clinical oversight, it is essential that we work systemically to ensure residents, families and service providers maximise visiting opportunities.

Social workers have witnessed the harm and suffering caused by visiting restrictions. The IASW calls for a revision of the current HPSC visiting guidance, to reflect lessons on safe, managed visiting practice in other jurisdictions and to ensure that residents rights to family life are protected.

The guidance should be informed by the following principles:

Visiting Guidance must be evidence informed:

A review of international literature¹ on safe and managed visiting highlights the following:

1. Blanket visitor and family caregiver bans should not be used to prevent COVID-19 infections in care homes
2. Safe on-site visiting practices should be used, with options chosen based on local levels of community transmission and in discussion with residents, families and staff and health authorities
3. 'Family caregivers' should be designated as essential partners in a resident's care during the pandemic and be able to have more frequent, longer hands-on visits if they can be supported to do so safely

¹ Low L-F, Hinsliff-Smith K, Sinha S, Stall N, Verbeek H, Siette J, Dow B, Backhaus R, Devi R, Spilsbury K, Brown J, Griffiths A, Bergman C, Comas- Herrera A (2021) Safe visiting at care homes during COVID-19: A review of international guidelines and emerging practices during the COVID-19 pandemic. LTCcovid.org, International Long-Term Care Policy Network, CPEC-LSE, 19th January 2021

4. Care homes should receive additional government funding and support to implement safe visiting practices
5. Regulators should be ensuring that care homes meet residents' rights to have visitors and that safe visiting practices are being used

The IASW calls for a revision of current visiting guidance to reflect evidence informed practice around nursing home visits.

Visiting Guidance must be based on rights to family life, rather than subjective grounds of compassion:

In the current guidance, fundamental and protected rights to family life are diluted as something to be measured on the basis of subjective compassionate grounds. Visits granted on compassionate grounds are highly subjective, paternalistic and are neither evidenced informed or rights based. Evidence from frontline social work practice suggests that interpretations of compassion vary significantly from one nursing home to the next. Some families have reported excellent practice, where creative efforts were made to facilitate a sense of connection and safe managed visits were arranged. Others report the continued refusal of window visits and end of life visits, some only granted when the dying person was no longer aware of their presence. Others stood outside windows watching their relative die alone. This after a prolonged period of separation, shows little compassion to either the dying person or their family members. It is important to note that these experiences are reported from multiple settings, only some of whom are experiencing outbreaks.

One of the compassionate grounds in the current guidance advises visits may be granted based on "circumstances in which a resident is significantly distressed or disturbed and although unable to express the desire for a visit there is reason to believe that a visit from a significant person may relieve distress." This core ground has been very distressing for families to understand and accept. Social workers also object to it. Given family connection is known to be vital for well-being, waiting for signs of significant distress before sanctioning visits is both ethically and morally unacceptable. It ignores the fact that residents also respond to high levels of distress caused by family separation in different ways, some are overtly upset, while in others, it may prompt a slow and equally harmful decline over time. Visiting can either be safely managed or it cannot, attempting to subjectively test the human need for love and connection is neither acceptable or evidence based.

The IASW propose that references to compassionate grounds are removed and replaced with rights based language, such as visits granted on 'residents right to family life' consistent with the rights to family life afforded in Article 16 of the UN Declaration of Human Rights and Article 8 of the European Convention on Human Rights.

Visiting Guidance must recognise the irreplaceable safeguarding and protection afforded through family life:

Safeguarding is inextricably linked to family life and the guidance must reinforce the irreplaceable protective role families play in the lives of residents. The HSE National Safeguarding Office, HIQA and the IASW have been explicit about the limitations of current regulation and adult safeguarding policies. In 2019, HIQA received 711 concerns from members of the public about the quality of care offered in nursing homes. 159 established concerns of institutional abuse were reported by the National Safeguarding Office in the same year, with a further backlog of 1000 concerns related to institutional abuse reported in CHO7 alone. Safeguarding and Protection social workers continue to

receive concerns in relation to institutional abuse and a wider social work investigation is underway in relation to the rape of a cocooned resident.

Residents usually confide concerns about experiences of low quality care, neglect or abuse during private visits with trusted family members. Family members monitor and address issues related to quality of care. Window visits or use of technology are not suitable for many, including those with communication difficulties. There is often less opportunity to speak privately with families during cocooning. The prolonged removal of vital protective eyes and ears of families is of significant concern in an inadequately regulated sector, which lacks safeguarding legislation.

Current guidance views nursing homes as universally benign care settings. Investment in safe visiting spaces, such as visiting pods, ensures that families can sight their relatives during any further periods of high community transmission, when some visiting restrictions may be required.

The IASW proposes the visiting guidance supports the development of safe visiting spaces, i.e. high quality, heated visitor pods and all relevant testing, infection control, staff and visitor education etc. measures required to support safe visiting spaces, to ensure that all residents have consistent private, face to face communication with their families.

Guidance on challenging Visiting Refusal must be provided:

The current guidance is weighted in favour of the service provider. While the guidance highlights the residents right to decline visits, it fails to advise residents of their rights or ways to respond should the nursing home fail to grant visits. IASW members, in a voluntary capacity, developed resources to support families & residents in exerting their rights to challenge unreasonable visiting refusal, highlighting the range of procedures and agencies which support rights to family life. Following use of this rights-based resource, families have consistently reported that nursing homes were able to reverse visiting refusal and facilitate safe visits. Families and residents should not require voluntary efforts to obtain this vital information.

Plain English visiting guidance, which includes information on challenging visiting refusal, must be provided to residents themselves and to their families. Efforts must be made to share this information with residents who may have difficulty reading. Nursing homes must document the means in which they shared information on visiting and visiting rights to residents and families.

The IASW propose visiting guidance provides clear information on resident and family rights in the event of visiting refusal. The IASW is available to provide support and assistance around this.

For Further Information email: administrator@iasw.ie or call 086-0241055