

Patients and Family at the End of Life

Implications of COVID-19

When patients are judged to be dying within hours or days, the presence of family¹ at their side for short visits, or longer stays, is vital to palliative and end of life care and a timeless part of the human experience of life and death. It provides comfort not only to the dying patient, but also to those present, and the inability to be present is a source of anxiety, distress and moral injury that may be long-lasting.

The COVID-19 pandemic has created concerns relating to visiting. Visitors could contract infection from a patient dying of COVID-19 and thus come to physical harm themselves. They could also spread the infection to others outwith the care setting where the patient is dying. Limiting 'footfall' through any inpatient or residential care setting forms an important aspect of risk reduction for staff and other patients.

Limiting travel in the wider community has been an equally important aspect of Scotland's effort to reduce deaths from COVID-19 and so enabling visiting, even when limited to the end of life, sat at odds with that risk reduction measure. Although the national updated principles on visiting noted end of life visiting as [essential](#), Government guidance for the public on travel from home did not explicitly specify visits to a dying family member as permissible.

As a consequence, inconsistent interpretations of this guidance mean that variable policies are in place. Some are more stringent, and limit or may entirely exclude access of family to a patient dying of COVID-19. The risk of moral harm for care staff in being required to repeatedly enforce these restrictions and absorb the resultant distress of families cannot be underestimated, and this is not acknowledged in current ethical decision-making guidance.

Other approaches are more lenient and permit exceptions to be made apparently without explicit consideration of the wider implications of population harm or PPE limitations. Knowledge of this causes significant staff and family distress in facilities where more stringent restrictions are in place.

Importantly, such restrictions are in place in some settings for patients who are dying of diseases other than COVID-19. In this case there is no risk to family of contracting the disease from the patient, although risk may occur if the care facility has other patients with the disease. However, family could bring the disease into the facility, and thus increase the risk of other patients of contracting COVID-19.

Deaths from COVID-19 and other diseases and illnesses occur across the entire range of care facilities in Scotland. Patients die at home, in nursing and residential homes, in hospices, community hospitals, general wards of acute hospitals, emergency departments, and high dependency and intensive care units.

Concerns about visiting are legitimate but responses to them should not only be governed by principles of infection control at local and population level, but also by moral and ethical principles. We therefore

¹ Family in this context means those related by blood, through marriage, or close friends.

suggest how a simple [ethical framework](#) can be applied to the issue of family presence at the time of death.

1. Respect

All patients, wherever they are dying and whatever they are dying from, should be offered good quality and compassionate care.

2. Fairness

Family presence should be considered equally across all care settings, and for patients dying with and without COVID-19

3. Minimising Harm

Harm from visiting can occur to the visitor, to those they subsequently come in contact with, or to others in the care facility. The patient themselves may experience harm if they feel guilt about exposing family visitors to the infection.

That harm must however be balanced against harm to the dying person occasioned by absence of family, harm to family who are unable to be present (both immediate and longer term in bereavement), and harm caused to care staff who substitute themselves for absent family and undertake difficult telephone communication.

4. Working Together

A patient's current or previously known wishes about their own end of life care should be taken into account.

Clinicians should act with honesty and integrity in their communication with patients and should communicate and document decisions regarding visiting and the reasons behind them transparently.

Organisations have a responsibility to ensure that staff are aware of and engaged with the rationale for the local guidance. There must be transparency in how the competing factors of social responsibility, PPE resource, and direct and indirect risk of infection and of psychological harm are being balanced.

5. Flexibility

As the clinical situation evolves both at the individual and population level, decisions will need to be kept under review with clear guidance at national level.

6. Reciprocity

Where there are resource constraints, patients should receive the best care possible, while recognising that there may be a competing obligation to the wider population.

7. Capacity and Consent

The capacity of family to provide informed consent relating to the risks associated with visiting should be taken into account as should the capacity of the patient to receive visitors.

Practical Principles

The following practical principles emerge from this ethical framework.

These principles **do not represent a series of rules**, to be applied rigidly. They are simply principles, to be considered and applied flexibly, humanely and sensitively in the particular context of each patient and their family.

1. All patients who are judged to be dying from COVID-19 or other conditions within hours or days are entitled to receive visitors. That entitlement is however qualified by the following.
2. Visiting arrangements will aim to best serve the needs of patients and their families, but may need to change at short notice in light of local or national changes in COVID-19 related restrictions.

3. To the greatest extent possible, and recognising that visiting can be emotionally and physically exhausting, a limited number of family members should represent the family over the period of the patient's decline and death.
4. When possible, the patient should consent to receive visitors, if not, their previously known wishes or judgement of a legally appointed proxy decision maker or closest relative should be taken into account.
5. When possible, visitors should provide informed consent that they understand the personal risks associated with visiting.
6. In all cases, visitors must agree to undertake the subsequent isolation and quarantine restrictions appropriate to the contact that has occurred in association with their visits.
7. In all cases, visitors must consent to wear Personal Protective Equipment and undertake all other relevant hygiene requirements equivalent to that used by care staff in the specific care facility. Support should be provided to put on and remove equipment as necessary.
8. Anyone who is unwell and/or exhibiting symptoms of COVID-19 - a new, persistent cough and fever or high temperature - should NOT visit any patients in a hospital or other care facility.
9. Care facilities are entitled to limit the frequency of visits, duration of visits, or numbers of visitors in accordance with the risk to other patients, other care staff, or other practical considerations in the care setting. However, the reasons for this must be documented and be in accordance with the framework outlined above.
10. Clinical teams in more acute settings, particularly ICU and HDU, should receive support in family liaison from other staff members, including chaplaincy, bereavement and counselling services, thus enabling them to focus on direct patient care.
11. Care facilities should support family who cannot visit by providing access to and support in the use of mobile tablet or handheld communication devices to patient and family, particularly if a family cannot provide these for themselves.
12. For those managing visits in care home settings, reference should also be made to the Scottish Government's [guidance](#) on this topic.