

Guidance to support compassionate visiting arrangements for those receiving care at the end of life during the COVID 19 pandemic

Introduction

This guidance is focused on supporting compassionate visiting arrangements for those receiving care at the end of life during the COVID 19 pandemic.

It provides advice on how visiting at the end of life can be safely facilitated. This guidance advocates for people dying from COVID-19 and other diseases and illnesses in our hospitals in NHSGGC to be treated humanely, compassionately and with dignity and to ensure they receive care, which is person centred at the end of their lives.

This guidance applies to all patients dying from COVID-19 and other diseases and illnesses and is consistent with [NHSScotland Coronavirus \(Covid-19\): hospital visiting guidance](#) which allows patients at end-of-life to have essential visits from relatives and friends; the [Academy of Medical Royal Colleges and Faculties of Scotland](#) guiding principles to allow families equal access to visit dying relatives and wider [government advice on physical distancing](#).

Background

Deaths from COVID-19 and other diseases and illnesses occur across the entire range of care facilities in NHSGGC.

When patients are judged to be dying within days or weeks, the presence of family 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.

Being able to share time with friends and family at the end of life contributes, not only to the wellbeing of the patient, but also to those who matter most to them. Where possible all visiting requests should be met with compassion, sensitivity and understanding, particularly during the last days and hours of life.

Risk Assessment

Risk assessment should be balanced against:

- the benefits to individual wellbeing of having visitors at end-of-life
- the extent of harm experienced by a patient or by a visitor from a lack of visitation, particularly for people in the final days or weeks
- the provisions, wishes and needs outlined in an individual's care plan.

The considerations set out here aim to minimise the risk of infection whilst also allowing close family members or friends to accompany and say goodbye to their loved ones at the end of their life and for visits from faith leaders (including chaplains) if desired. The considerations assert the rights of those nearing end of life to see their loved ones and/or to receive religious support. They also aim to reduce the adverse impact on close family or friends of not visiting their loved one before death.

Ethical Framework

Concerns about visiting are legitimate but responses to them should be governed by principles of infection control at local and population level and by moral and ethical principles.

The [Academy of Medical Royal Colleges and Faculties of Scotland](#) suggests the following simple ethical framework to support family presence at end-of-life.

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. All staff have a responsibility to ensure they are aware of and engage with the rationale for 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 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.

Guiding Principles

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

1. It is very important for the health and wellbeing of patients and staff that people **do not visit** if they are feeling unwell in any way or have symptoms of Covid-19. This includes:
 - Feeling generally unwell
 - New/continuous cough

- Sickness or diarrhoea within the last 48 hours
 - Change in body temperature
 - Change in normal sense of taste or smell
 - If they are self-isolating because they have been in contact with someone suspected as having, or has tested positive for Covid-19, in the past 14 days
2. All essential visitors should be asked at each visit if they are well (checklist above) to visit and their contact details checked to assist Public Health, **Test and Protect** colleagues should there be a need to contact them.
 3. In all cases, essential visitors must be compliant with all Personal Protective Equipment (PPE) requirements in accordance with the situation of the patient they are visiting and undertake all other relevant hygiene requirements. Support should be provided to doff and don equipment as necessary.
 4. All patients who are considered by the MDT, Consultant or most senior informed decision makers available at the time, to be dying and are within days or weeks of the end of life are entitled to receive essential visits from family and friends.
 5. Where possible, the patient should verbally 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 and should be documented in the patient's care record.
 6. An individualised and flexible approach must take into consideration a patient's wishes, proximity to death, rights, family needs and any cultural or religious needs. Patients should be involved in this approach as far as possible. These discussions should be documented within the patient's care record.
 7. When patients are in the last days or weeks of life **the number of people, visiting (although the number at any given time will be in line with local guidelines) and the frequency of visits should not be limited as long as** this is in accordance with the requirements described from the same/extended household. If visitors not from the same household or not part of an extended household, they should visit the bedside separately and maintain distance when they are outside of the clinical area.
 8. The term "family" should be interpreted as flexibly and broadly as possible acknowledging the many different forms a family can take and should include all those who matter to the patient including close friends.
 9. Supporting children to visit loved ones at end-of-life can be a key part of their grief and bereavement experience. There should therefore be no age restrictions imposed to ensure children are supported to visit, be present and say goodbye to the people who are important in their life and who contribute to their wellbeing.