

Collated for the Northern Care Alliance NHS Group and the Association for Palliative Medicine of Great Britain and Ireland by:

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Please note

The COVID-19 outbreak currently being experienced around the world is unprecedented and requires everyone to work together to contribute to the health and well-being of populations as well as ensure that appropriate guidance and sharing of good practice occurs. This is essential in order to support the care of patients at the end of their lives or who are significantly unwell as the result of both COVID-19 or other possibly life-limiting illnesses.

This guidance, which is been prepared for secondary care initially and is not intended to be comprehensive, has been prepared and collated locally by the Northern Care Alliance NHS Group and the Association for Palliative Medicine of Great Britain and Ireland. While it is not nationally endorsed by the National Health Service, it may be useful to colleagues throughout the country when preparing their own guidance.

Please feel free to use, adapt and share this guidance appropriately, acknowledging where specific individuals have been identified as contributing to discrete parts of the guidance.

This will be a 'live' document that will be updated, expanded and adapted as further contributions are received and in line with changing national guidance. The most current version of the guidance document will be available on the public-facing pages of the Association for Palliative Medicine website (<https://apmonline.org/>). It is advised that you always check that you are referring to the most current version. **Please do not share the guidance on social media, as it contains some information that may be distressing to the public if not presented in a sensitive way with appropriate opportunity for discussion and explanation.**

Staff should be aware that this guidance is subject to change as developments occur. Every effort will be made to keep this guidance up to date. Additional information can be found at <https://www.gov.uk/government/topical-events/coronavirus-covid-19-uk-government-response>. The Swan Bereavement team, site Bereavement Offices, mortuary teams and Coroners' Offices can be contacted for additional support and guidance.

The utmost consideration and care must be given to the safety of other patients, visitors and staff by maintaining infection control procedures at all times.

As far as is possible in such a short period of time, the information contained within this document has been checked by experts from across the palliative care profession. However, neither the Northern Care Alliance NHS Group nor the Association for Palliative Medicine of Great Britain and Ireland can accept any responsibility for errors or omissions in this document.

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Talking to patients and those close to them about prognosis, ceilings of treatment and possible end of life care is often challenging but, in the current COVID-19 outbreak, such conversations with the population described may become even more difficult, as health professionals may have to triage patients, often in emergency or urgent situations, and prioritise certain interventions and ceilings of treatment.

Background

The UK population is ageing and many more people are living with chronic illness and multiple comorbidities. A third of patients admitted unexpectedly to hospital (rising to 80% in those living in 24-hour care) are in the last year of their lives. Despite such facts, few have ever had discussions about ceilings of treatment or resuscitation.

Such conversations, which constitute advance care planning, are useful during normal times, but even more so during the COVID-19 outbreak. Open, honest discussions regarding ceilings of treatment and overall goals of care are not only essential to ensure that those with significant potential to recover receive appropriate care, but also that those who are very unlikely to survive also receive appropriate, end of life care.

Such decisions may have to be made when health professionals have not had the opportunity to get to know their patient as well as they would usually like, or may involve discussion with those close to the patient over the telephone or via internet-based communication facilities. While this is less than ideal, honest conversations are often what patients and those close to them actually want.

While palliative, end of life and bereavement care professionals cannot take over responsibility for this aspect of care and have the conversations for you, they should be able to support, advise and provide follow up care.

Consider

- don't make things more complicated than they need to be; use a framework such as SPIKES:
 - **Setting** / situation
read clinical records, ensure privacy, no interruptions
 - **Perception**
what do they know already?; no assumptions
 - **Invitation**
how much do they want to know?
 - **Knowledge**
explain the situation; avoid jargon; take it slow
 - **Empathy**
even if busy, show that you care
 - **Summary** / strategy
summarise what you've said; explain next steps
- should ceilings of treatment conversations include ethical issues, for example where escalation to Level 3 care is thought not to be appropriate due to frailty, comorbidity or other reasons, health professionals should be prepared for anger / upset / questions
 - these are usually not aimed directly at you, but you may have to absorb these emotions and react professionally, even if they are upsetting / difficult at the time
 - patients or those close to them may request a 'second opinion' – this should be facilitated wherever possible
- be honest and clear
 - don't use jargon; use words patients and those close to them will understand
 - sit down; take time; measured pace and tone; use silences to allow people to process information
 - avoid using phrases such as "very poorly" on their own – is the patient "sick enough that they may die"? If they are – say it