



Discussions about goals of care

(adapted from RCP, 2018)

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. (Clark *et al*, 2014) Despite such facts, few have ever had discussions about ceilings of treatment or resuscitation.

Timely honest conversations about the person's preferences and priorities, including advance decisions to refuse treatment, is part of advance care planning for anybody who has a progressive life-limiting illness. In the context of people who have severe COVID-19 disease, honest conversations about goals of care and treatment escalation planning should be initiated as early as is practicable so that a personalised care and support plan can be developed and documented. This will need to be revisited and revised as the situation changes. Families and those close to the person should be involved in these discussions as far as possible and in line with the person's wishes. This is standard good practice in palliative and end of life care.

However, in the context of COVID-19, the person is likely to have become ill and deteriorated quite quickly so the opportunity for discussion and involving them in decision making may be limited or lost. Families and those close to them may be shocked by the suddenness of these developments and may themselves be ill and / or required to self-isolate. There may be multiple members of the family ill at the same time. But as far as possible it remains important to offer these conversations. Being kept honestly informed helps to reduce anxiety, even if the health care professionals do not have all the answers and even if the conversations need to be conducted behind PPE or, in the case of families who are self-isolating, by telephone or by using other technology solutions.

It should be acknowledged that talking to patients and those close to them about prognosis, ceilings of treatment and possible end of life care is often challenging (Brighton & Bristowe, 2016) 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. This is not only 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 (DoH, 2015; NPEoLCP, 2015), honest conversations are often what patients and those close to them actually want. (Choice, 2015)

Key points to consider when discussing ceilings of treatment

□ don't make things more complicated than they need to be; use a framework such as SPIKES:

- **S**etting / situation: read clinical records, ensure privacy, no interruptions
- **P**erception: what do they know already?; no assumptions
- **I**nvitation: how much do they want to know?
- **K**nowledge: explain the situation; avoid jargon; take it slow
- **E**mpathy: even if busy, show that you care
- **S**ummary / strategy : summarise what you've said; explain next steps

□ should ceilings of treatment conversations include ethical issues, for example where 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

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.