



A Note About These Guidelines:

These are unprecedented times. There is no roadmap as yet. We are facing situations that we never expected or wanted to. Working together we can make it through with empathy, compassion and sense of service intact.

These guidelines have been rapidly assembled and should be seen as an acute response to a fast-moving pandemic. The situation is fluid, and best practice is likely to need to change quickly. As we learn more about the specific needs of people dying with COVID-19, these guidelines will be constantly updated, and we welcome your input and experience in helping to keep these as useful and relevant as possible.

Introduction and an approach to palliative management in a pandemic.

It is currently impossible to know what the effect of the COVID-19 pandemic will be on our population. The hope is that normal standards of care will be able to continue throughout. However, we also need to prepare for the very real possibility that this will not be so.

One of the characteristic features of a public health crisis is that “health needs overwhelm available human and material resources” (Thompson et al, 2006: 2). A move from our usual patient-centred practice to practice guided primarily by public health considerations can cause great tension for clinicians, because ensuring the health of the population often entails imposing limitations on the rights and preferences of individual patients (Berlinger et al, 2020: 1-2). In public health emergencies, for people needing palliative care and dying, resources may become insufficient to palliate to a degree that we may normally see as sufficient.

When someone is dying an overarching goal is to support that person and their whanau, reduce their suffering, and maximise wellbeing until death. In a pandemic, this may necessitate realising that our ‘normal standard of palliative care’ may need to be replaced by ‘crisis standards of palliative care’.

Crisis standards of care are based on the principles of fairness, duty to care, duty to steward resources, transparency, consistency, proportionality and accountability (Hicks et al, 2020: 2). Many of the norms of good care will still carry over into the transition to crisis standards of care however (e.g., respect, fairness, and appropriate communication with patients and families)

In practice this will mean constantly reviewing the standard of care it is possible to deliver and then justifying any different approach to the allocation of scarce resources (including clinical personnel) and how we approach specific issues: a shift from what we currently see as ‘best practice’, to ‘practice which is as good, equitable and fair as it possibly can be given the circumstance’.

For instance, if regular assessment of distress and breathlessness is curtailed because of staff shortages, it might be appropriate to use slightly higher than normal doses of opioids for breathlessness or benzodiazepines for anxiety or distress to ensure the highest likelihood of relief of suffering and distress, in the absence of the ability to titrate in a timely manner.



In this pandemic there will also likely be a large increase in people dying from respiratory failure compared to normal. In addition, if life sustaining resources are limited, people that may otherwise normally be ventilated with a goal of stabilisation and recovery, may instead need acute palliation if this resource is not available.

Furthermore, the management of acute respiratory failure can often be challenging, and for humane relief of distress and suffering, this may necessitate proportional use of medication at life's end with a view to sedation.

The symptom control guidelines will particularly address the palliation of symptoms focusing on respiratory illness – breathlessness, cough, anxiety, and secretions. In addition, they will also describe palliation of respiratory symptoms, including sedation, and where necessary describe alternative methods if normal approaches are not available.

Thompson et al (2006) "Pandemic influenza preparedness: an ethical framework to guide decision-making". BMC Medical Ethics, 7:12.

Berlinger et al (2020). "Ethical Framework for Health Care Institutions Responding to Novel Coronavirus SARS-CoV-2 (COVID-19)". The Hastings Centre. Available at: <https://www.thehastingscenter.org/ethicalframeworkcovid19/>

Hick et al (2020). "Duty to Plan: Health Care, Crisis Standards of Care, and Novel Coronavirus SARS- CoV-2". National Academy of Medicine

Some principles applying to COVID-19 guidelines produced by the Collaboration:

As with all guidelines, they are designed to support decision making and best practice alongside individual assessment and ongoing reassessment (where possible).

No one size fits all, and the guideline recommendations should be tailored to individual circumstances. If local guidelines are available, these guidelines can be used in addition as appropriate. In some instances, these guidelines may not necessarily be appropriate or fitting to the situation you are facing.

Whilst these guidelines are aimed specifically for people with COVID-19, the principles may also apply to people who are dying of other conditions too during a crisis.

Please do not share these guidelines on social media: the information may be sensitive to the public if not given the appropriate context.

Please feedback with your experience, and what else needs to be added or changed, as we learn more about how best to help people needing palliative care in a COVID-19 pandemic.

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