

Tip Sheet on Dignified End-of-Life Care

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**Produced by: Frontline Collaboration Against COVID-19
Humanitarian Analysis, Guidance and Support for NHS Workers**

Situation

A recent study by the Intensive Care Audit and Research Centre found that 47.9 percent of all patients admitted to critical care in the UK passed away.¹ In the context of COVID-19, a patient admitted to hospital may deteriorate rapidly, so the opportunity for discussion and involving them in decision making may be limited or lost.² It is therefore of critical importance to engage in such discussions early on during a patient's care.

“During this crisis, it is important to reflect on what is most important for patients and their families. Although as health practitioners we may not be able to do all we would want given the exceptional circumstances, we can provide and insist on dignified care by appreciating the holistic needs of our patients.” Mohammed Rahman, GP and Chair of the NHS Emerging Needs Group, Frontline Collaboration Against COVID-19.

However, infection control measures, quarantine and self-isolation often means that families are not able to communicate with, be with, or be a part of a patient's last living moments. Families face the prospect of separation from their loved ones and of being unable to comfort one another.

Who is this advice for?

This tip sheet is aimed at all professionals and carers in the hospital setting who are supporting patients with COVID-19, and their families, when decisions around end of life care are being addressed.

This advice is complementary to, and does not replace any palliative care protocols that your health facility is using. It summarises some tips and key considerations.

Background

People have the right to live and die with dignity even during emergencies and crises. This entails more than physical well-being but respect for the whole person including values, beliefs and coping mechanisms³.

Dignified care recognises and addresses a person's individual physical, psychological, social, language and spiritual needs⁴. Palliative care incorporates the physical, psychosocial and spiritual needs of a patient in end of life care⁵.

Experiencing and witnessing unaddressed pain and suffering can be traumatic for patients, families/caregivers, as well as health care providers and adjusting mechanisms of providing dignified care in crisis settings is important.

Assessment

In response to patients with COVID-19 and with resources stretched, the rapid adoption of technology, innovative practices or working with wider stakeholders will play an increasing role in addressing a patient's emotional, psychosocial and spiritual needs. These issues are promoted as a 'dignified care' bundle outlined in this document.

Recommendations

1. Honest conversations are often what patients and those close to them want.⁶ Being kept genuinely informed helps reduce anxiety, especially if family members are away from the patient. These messages can still be of immense value, even if delivered from behind PPE (personal protective equipment), over the telephone or using other technology.⁴
2. If possible, aim to discuss care plans early on with the patient and their family. This should include understanding their psychosocial and spiritual needs and how these can be supported within the existing setting. The Recommended Summary Plan for Emergency Care and Treatment (ReSPECT) form helps to guide such discussions, in addition to being a part of the patient record.
3. Opportunities to form relationships with patients and their families will be limited. So ensure you record a primary point of contact to call and a secondary point of contact should the primary contact fail. Details should include a verified WhatsApp, Skype and FaceTime contact details. Note any details of whether their primary contact has any communication issues such as problems hearing. Ensure their families receive a contact number so that they can call to obtain updates.
4. Keeping loved ones connected can be a source of comfort for people who are dying. Enlist the support of medical students, volunteers or other people who may be otherwise present to help conduct telephone video calls with families and designated support services.

5. Spiritual care is a core element of palliative care.⁷ A formal spiritual needs assessment may not be possible, however we need to understand what is important to the patient and their family in terms of their culture, values and beliefs, and the impact this may have on their care. Although not validated for this setting, simple tools such as the HOPE or FICA spiritual assessment models may help.
6. Determine any language preferences and/or comprehension issues which may affect decision making and care delivery.
7. Enlist the support of chaplaincy and spiritual support where appropriate to promote dignified care.
8. Think about increasing linkages with community volunteer support groups either via the chaplaincy or directly through the department to support communications and needs of the patient and family.
9. Consider having team members oriented in psychological first aid. Psychological first aid is not a clinical intervention, but is a basic, humane and supportive response to suffering and includes listening carefully and trying to address basic needs and encouraging social support⁸. Healthcare workers, community leaders can provide psychological first aid after a brief orientation⁹.
10. Clarify your hospital's guidance for people visiting patients at the end of life. Hospital wards may allow one visitor for a specified time following discussion with the ward manager or nurse in charge on a case by case basis.
11. If requested by the patient or their family and it is appropriate, it is possible to virtually share a patient's last moments. This can help patients and their families enormously.
12. Have transparent conversations with the patient and family about handling the body of those who die within the hospital setting including the use of PPE, limits on visitation and funerals. Please refer to Public Health England for the latest advice¹⁰
13. Consider the practicalities of which member of staff may complete the Medical Certificate of Cause of Death (MCCD) to allow timely release of deceased.
14. Look after yourself. The stress and burden of providing care in such challenging circumstance can have an impact on your own well-being, and hence your ability to provide dignified care. Have compassion for yourself, and acknowledge the limitations of what you can do in such circumstances. Recognise the collective emotional experiences of other team members and discuss events where helpful. Seek external support if you feel you are struggling to cope.

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- 3.The Sphere Handbook, Humanitarian Charter and minimum standards in Humanitarian Response 2018, Palliative Care Standard, Page 346 [accessed 30th March 2020]
- 4.Health and care standards with supporting guidance, theme 4 Dignified Care, NHS Wales <http://www.wales.nhs.uk/governance-emanual/theme-4-dignified-care>
- 5.WHO Definition of Palliative Care, <https://www.who.int/cancer/palliative/definition/en/> [accessed online 3rd April 2020]

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9. IASC Reference Group on Mental Health and Psychosocial Support in Emergency Settings, February 2020. Addressing mental health and psychosocial aspects of Covid-19 Outbreak Version 1.5
10. Guidance for care of the deceased with suspected or confirmed Coronavirus COVID-12, <https://www.gov.uk/government/publications/covid-19-guidance-for-care-of-the-deceased/guidance-for-care-of-the-deceased-with-suspected-or-confirmed-coronavirus-covid-19> [accessed 5 April 2020]

Further Reading

1. WHO 2018, Integrating palliative care and symptom relief into the response to humanitarian emergencies and crises
2. Eric L Krakauer et al, November 2019 A field manual for palliative care in humanitarian crises
3. Humanitarian Health Ethics, Alleviating suffering and upholding dignity in the midst of CoVID-19 response: a place for palliative care https://humethnet.files.wordpress.com/2020/04/pallcarecovid_recommendations_final.pdf
4. Blaber M, Jones J, Willis D. Spiritual Care: Which is the best assessment tool for palliative settings? [Int J Palliat Nurs.](https://www.magonlinelibrary.com/doi/abs/10.12968/ijpn.2015.21.9.430?af=R&mobileUi=0&) 2015 Sep;21(9):430-8. Available from: <https://www.magonlinelibrary.com/doi/abs/10.12968/ijpn.2015.21.9.430?af=R&mobileUi=0&>

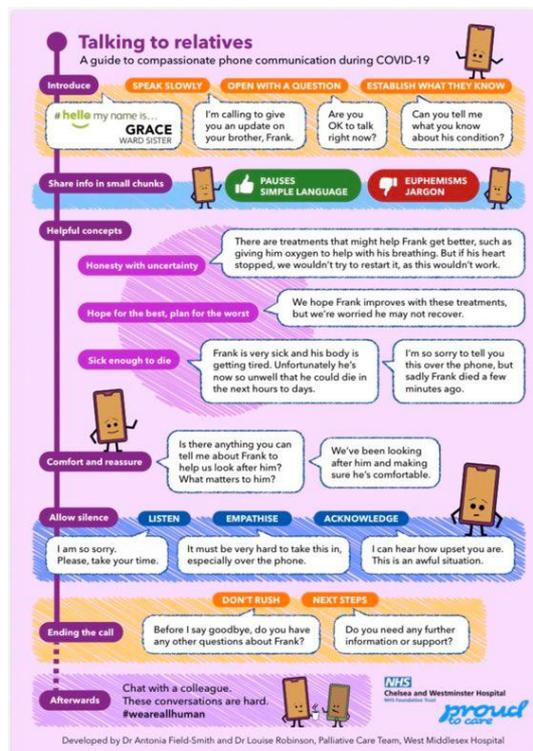
Appendix A

A Hospital Checklist for Dignified End-of-Life Care

- Have you documented two family contacts including a verified WhatsApp, Skype and FaceTime contact details?
- Have you checked language requirements and any additional communication needs?
- Has the Recommended Summary Plan for Emergency Care and Treatment (ReSPECT) form been completed?
- Have you provided the hospital guidance on visitation to the patients family?
- Have you assessed any spiritual or faith needs and contacted the relevant department?
- Have any preferences for the patients last moments been documented and handed over?
- Is there a nominated person to complete the Medical certificate of cause of death (MCCD)?

Appendix B

A Talking to Relatives poster produced by Chelsea and Westminster Hospital, NHS Foundation Trust, and developed by Dr Antonia Field Smith and Dr Louise Robinson, Palliative Care Team, West Middlesex Hospital



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About Us:

Frontline Collaboration Against COVID-19 We are a group of leading healthcare practitioners and humanitarian experts with frontline experience in the UK and around the world. We are communicating daily with NHS practitioners to understand the problems they are facing in responding to the COVID-19 pandemic. We have identified urgent, unmet needs in terms of knowledge and know-how.

We are rapidly responding to these needs with practical guidance and tools that draw on international humanitarian response and outbreak experience. At the same time, we are engaging the institutions and leadership of the overall response to lobby for system-wide improvements.

Our support is designed to complement the formal NHS system.

Our vision is of Leaders, Healthcare workers and Humanitarians Working Together Against COVID-19.

Feedback

We welcome your feedback and suggestions. Please contact us at info@beckhealthcare.co.uk

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