

How to have urgent conversations about withdrawing and withholding life-sustaining treatments in critical care – *including phone and video calls*

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Professor Ruth Parry

**Professor of Human Communication and Interaction Loughborough University
NIHR Career Development Fellow**

Dr Kath Mannix

Palliative Care Physician and author of “With the End in Mind”

Professor Natalie Pattison

**Florence Nightingale Foundation Clinical Professor of Nursing
University of Hertfordshire and East & North Herts NHS Trust**

This rapidly produced guidance encompasses urgent phone or video call conversations about withholding, or withdrawing life-sustaining treatments in critical care, in the context of the COVID-19 pandemic, between professionals and people close to the patient – usually family members. This guide is based on existing best practice guidance¹ and research.

Daily review of goals and preferences of treatment, in the context of the patient’s ongoing clinical condition should take place with the team, and should be a multi-disciplinary discussion.

Context

This guidance is specifically drawn up with reference to the COVID-19 pandemic and is UK specific. These are guidelines only, drawing on best practice principles in the literature and using best practice exemplars. They are not meant to be exhaustive, and there are limitations and setting-specific considerations.

The guidance developed here supplements existing guidance published in 2019 [Faculty of Intensive Care Medicine, Care at the end of life: A guide to best practice, discussion and decision-making in and around critical care]¹, NICE COVID-19 cg159², NHS HEE³ and the broader

BMA ethical guidance⁴ The aim is to provide a rapid access document to support phone and video calls, although many points also apply to face-to-face conversations.

We offer some suggestions for wording of statements and questions. Use this as a guide, but it is best to use your own skill and judgement in wording things in ways that work for you and the person you are talking to. Keep your language simple, even if you are speaking to a fellow professional: this is their loved one, not their patient.

Legal position

This brief overview summarises key considerations. Please see FICM, 2019¹ for in-depth guidance

- If a Lasting Power of Attorney (LPA) health and welfare is not in place

In UK law, only a competent adult or their LPA can make a treatment-limitation decision. In all other circumstances, if it is a medical decision, the Decision Maker (legal term under the Mental Capacity Act, 2005,⁵ applicable in England and Wales only) is the clinician in charge, who is bound by the Act to make a Best Interests decision that takes the person's known wishes and preferences into account.

Only a person with LPA for Health and Welfare, including permission for decisions relating to life-sustaining treatment, can make a decision that may have life-limiting consequences on behalf of a patient (Mental Capacity Act, England and Wales). There is a similar arrangement in Scotland¹. Northern Ireland has not yet enacted the Powers of Attorney for Health and Welfare included in the Mental Capacity Act (NI)⁶ so any prior discussions should be taken into account when reaching a Best Interests decision.

- If an LPA is in place

The key issue is to assess if the LPA, or Advance Decision to Refuse Treatment (ADRT) is valid. Please see summary diagram in Appendix 1¹ and FICM guidance¹ for more advice.

Although LPAs apply to children over 16 years of age only, and this guidance focuses on adults. In an emergency surge situation, it is unlikely you will have to treat children within an adult ICU setting.⁷ The BMA have produced guidance on supporting ethical decision-making with children and young adults.⁸

'Advance Care Plans'

There is actually rarely a document called an 'Advance Care Plan. ACP is the process, but it leads to, for example, a ReSPECT form, an ADRT, a LPA, an Emergency Health Care Plan, a document of wishes and preferences, an 'All About Me' booklet, a dementia pathway passport. Thus you may encounter a wide variety of documents.

People with learning disability may well be carrying a paper booklet that introduces them, their preferred ways of communicating, and their wishes about ceilings of intervention or acceptable/unacceptable environments for care. Their Carer and their LD team should always be consulted. All UK hospitals now have an LD Liaison nurse specialist, who should be involved as early as possible in the person's admission.

The hospital team/ICU team needs to ascertain whether the GP, the family, or any other team previously managing the patient (COTE; LTCs; oncology; diabetes team; etc) has had discussions about preferences for care in the future and if so, where they are documented.

Principles: The framework for these conversations and its rationale

PREPARE⁹

- Clarify – including through discussion with colleagues - what is the key propose of this conversation?
- Make sure you know whether whether a Lasting Power of Attorney or ADRT is in place [Figure 1]¹
- If possible, find a comfortable and private place so you are not interrupted
- Prepare in advance for how you will end the conversation:
 - What advice or referral for support can you offer to the person?
 - What will happen next for them?
 - Who will contact them next and when?

START THE CONVERSATION WITH SIGNPOSTING

- Check they are in a safe place to take the call (not driving/doing unsafe activities)
- If possible and appropriate, start with a clear outline of what is going to follow (e.g. an update, a decision to be made, etc.)
- Much of what is said may well not be remembered – ideally offer to record and/or write down key points, and offer to summarise again at the end

SHOW COMPASSION AND EMPATHY THROUGHOUT

- Use an empathic, soft tone of voice, and by saying particular things that attend to emotion [theirs, and yours too]
- Try to speak slowly throughout, even though you may be feeling under pressure and rushed
- Say things that show you know this is difficult, that you are sorry, sad

- You can also say things that convey the difficulty for both of you: saying something like “*I know this is difficult for both of us*”. And more broadly, where it works to do so, use ‘we’, not just ‘I’. Remember you are speaking on behalf of your whole team
- Use terms like: “*I guess this must be very hard....*” and/or “*I cannot imagine what it must be like for you to have a conversation like this over the telephone.*”

Compassion and empathy involve balancing showing some understanding about another person’s emotions without overly claiming that you can possibly know what they are going through¹⁰. Explicitly refer to the difficult emotions the person may be feeling¹¹. But do so with some tentativeness - show you do not know for certain what they are feeling, for instance ‘I guess this must be very hard....’. It is also empathic to tell the person you cannot imagine what they are going through – this shows you recognise the uniqueness of their experience.

Saying something like “*I know this is difficult for both of us*” recognises the likely position of the person you are talking to, but also makes it clear that it is not easy or comfortable for you either. And using ‘we’ rather than ‘I’ can help to convey that the unwell person has been managed by a team, making joint decisions. This can help you and the person you are talking to understand that you’re not individually responsible for this bad news and for this conversation.

FORECAST

- Forecast what is to come by describing what has happened to the patient, and asking the family member for their understanding and knowledge of this. For example:

“We need to talk about your [‘family member’]’s condition. Can you tell me what you have been told so far and what you understand by it?”

This works to share views, knowledge and perspective, and can work to enable recognition without inducing shock.^{12, 13, 14, 15, 16}

PROVIDE A COMMENTARY FROM YOUR CLINICAL PERSPECTIVE

- Give commentary, that is, describe what you can see and feel regarding the patient’s condition, share evidence which conveys the seriousness of the condition
- Include information on current circumstances and on what you and the team anticipate is likely to happen in future

Like forecasting, this builds understanding and recognition. It provides an opportunity for family members to contribute to the decision process. It conveys that a decision is coming up and that their view and understandings are important within that.¹⁵

- When a patient is clearly dying, plainly convey that fact, and that starting or continuing life-sustaining treatment would prolong but not prevent suffering and dying

- Do not leave ‘wiggle room’ for overly optimistic prognostic expectations as this can lead to prolonged withdrawal and protracted dying for patients.¹⁷ Convey where there is uncertainty but do not build up hope unnecessarily. Examples:

“Your ...[family member]... has deteriorated further and is no longer responding to the intensive care treatments we are supporting them with. As a team, we need to talk about what we do next with their treatment and care and we need your input on this.”

OR

“We’ve consulted as a team and it’s clear that everything we’ve done and are doing is no longer capable of saving their life. They are now dying.”¹

OR

“Your [family member] has been transferred here because they became very unstable. We are trying to stabilise their condition but they are very poorly. We hope things turn around but things are likely to continue to be very uncertain in the hours/days ahead.”

ARE THEY WITH SOMEONE, CAN THEY TALK TO SOMEONE AFTERWARDS?

- At this point, find out who is with them or who they could talk to afterwards.

“Is anybody with you now? Who do you have you can talk to? How can they support you?”

The presence or absence of support is relevant, but if asked right at the start it could easily be heard as very bad news. A more gradual move towards implying then telling news reduces the risk of sending the person on the receiving end into severe shock.⁹

ASK THEM ABOUT WHAT THEY THINK THE PATIENT WOULD WANT, ABOUT THE PATIENT’S BELIEFS, VALUES, WISHES AND PERSPECTIVES, AND ABOUT RELEVANT PAST CONVERSATIONS

- Ask the family member’s assessment of the patient’s perspective on the situation

“What do you think your [family member] would want in a situation like this?”

- If they hold LPA, help them to realise they are acting on the person’s behalf: so not ‘what do you think we should do?’ but something like:

“Which of the available options would X choose?”

- Give them space and encouragement to talk, for instance by leaving some silence after your question, and adding to or rephrasing it if they do not manage to answer at first¹²
- If it seems they have not previously discussed such things with the patient, ask about the patient's beliefs, values, wishes and perspectives, for instance:

“As someone who knows her the best, what is your view about what she would want?”

Eliciting and showing you have heard the family member's views shows you are treating their insights about the patient as important.¹⁸⁻²⁰ Also, asking about the patient's views works to gently build recognition that a decision is coming up, and what it might be – rather than announcing something bluntly e.g. *‘We have to decide whether to take her off the ventilator’*. As far as we can see from current evidence, seeking and showing you have heard their views, reduces the likelihood of resistance, anger, shock.^{12,20}

Also, be mindful that family members' wishes may not accurately reflect patients wishes,^{21,22} also that they should not be left feeling as if they have to make decisions themselves.

In some cultures, shared decision-making is not an easy concept to navigate.^{1,23-25} It may not be appropriate to push for a shared-decision making model and some families in critical care (where patients cannot contribute to decisions) may prefer to defer all decision-making to clinicians; equally some families place higher emphasis on patient autonomy and wish to be highly involved.^{1,32-25}

CONFLICT

Conflict can often arise at end of life, and clear communication is an obvious strategy to mitigate this. However where it does arise, de-escalation mechanisms that can be helpful¹ including:

- Avoiding firm predictions (positive or negative)
- Be sure to convey empathy
- Consider mediation, for example use a clinical ethics committee, a senior consultant from a different health care team, or pastoral/palliative care input
- A second opinion from another specialist from critical care can also be helpful

VOICE THE DECISION SENSITIVELY, STEP BY STEP, MONITORING THE FAMILY MEMBERS' RESPONSES, AND ENCOURAGING THEM TO RESPOND

- If possible, incorporate their views, understanding, and the terminology they have used^{14,15}
- If appropriate, explain why starting or continuing would be futile

For instance:

"We are concerned that placing him/her on to a ventilator to try to support breathing would not work, given his underlying problems with.....[e.g.COPD/heart problems], and that he might die in even greater discomfort if we start these treatments."

- Where an LPA is not in place for the patient, state the decision, explaining how it takes the person's known wishes and preferences into account. For this reason, say something like:

"I'm not asking you to make this decision: it is my [and my team's] responsibility to make it, because it's about a medical treatment. But we need you to help us understand what would be important to them in this situation."

- Now clearly articulate your treatment recommendation
- Provide support for the family to help them understand the decision, whether the decision is to withdraw, withhold or to continue life support

DEALING WITH CRYING

During the conversation, the person you are speaking to may start to show distress, which you might hear or see in different ways – more pauses, changes in voice quality, quietly speaking, a creaky or tremulous voice or even full on sobbing.

- Modify your own delivery to be softer and more lilting
- Allow silence
- Offer sympathy – *"I'm so sorry"* - may need to be repeated
- Acknowledge the distress before moving on with further information delivery
- In the event of full on sobbing give the person you are speaking with time – repeated phrases such as *"it's ok"* and *"take your time"* are fine

- The person crying may well apologise – just reassure them it is fine: *“please don’t worry”, “it’s perfectly understandable to be upset”*
- Allow time, and check as you go on to see whether they are following or whether it is OK to carry on^{18,19}

MOVING TOWARDS THE END OF THE CONVERSATION WITH ‘SCREENING’ – ARE THERE THINGS THEY WOULD LIKE TO ASK, THAT I HAVE NOT SAID, OR EXPLAINED ENOUGH

- *“Are there things I have not covered or explained enough?”* is a way of checking understanding that avoids the implication that the person has not understood things, and lessens the burden on them
- *“What else would you like to ask me?”* can be a useful question

Try to avoid the phrase ‘anything else’ because in some circumstances, we know this can be heard as conveying you’re not expecting there to be anything else.²⁸

MOVING TOWARDS THE END OF THE CONVERSATION WITH WORDS OF COMFORT AND ATTENTION TO WHAT HAPPENS NEXT

- Try to take some burden off the person with whom you are talking – that is, don’t leave them wondering what happens next²⁹
- Give them advice on who they can call for support. Be very clear on where they can find information
- Assure them that the patient will not be abandoned by the clinical team prior to death
- Assure them that the patient will be kept comfortable and not suffer prior to death

“Our intention now is to do everything we can to ensure [patient’s name] is free from pain and distress and to focus on comfort. We may not be able to remove all the tubes and machines as this in itself may sometimes cause discomfort, but we will review as we go along.”³¹

“We can reassure you that someone will be with them at all times and we will continue to care for them at all times.”

- Explain how pain or other symptoms will be controlled. If the person is sedated, or so ill as to be unconscious, it can be helpful for family to understand that they are not aware of their surroundings and not lonely, awake and afraid

- Check local policy about being able to view the body, offering locks of hair/fingerprints/ ECG mementoes. These usual practices are highly unlikely given the risk of cross-infection, and usual mortuary and funeral arrangements will also differ; the person who has died may be placed in a temporary mortuary

The VALUES framework^{8,17} can also help here, it is a 5-step mnemonic to improve ICU clinician communication with families:

V = Value comments made by the family

A = Acknowledge family emotions

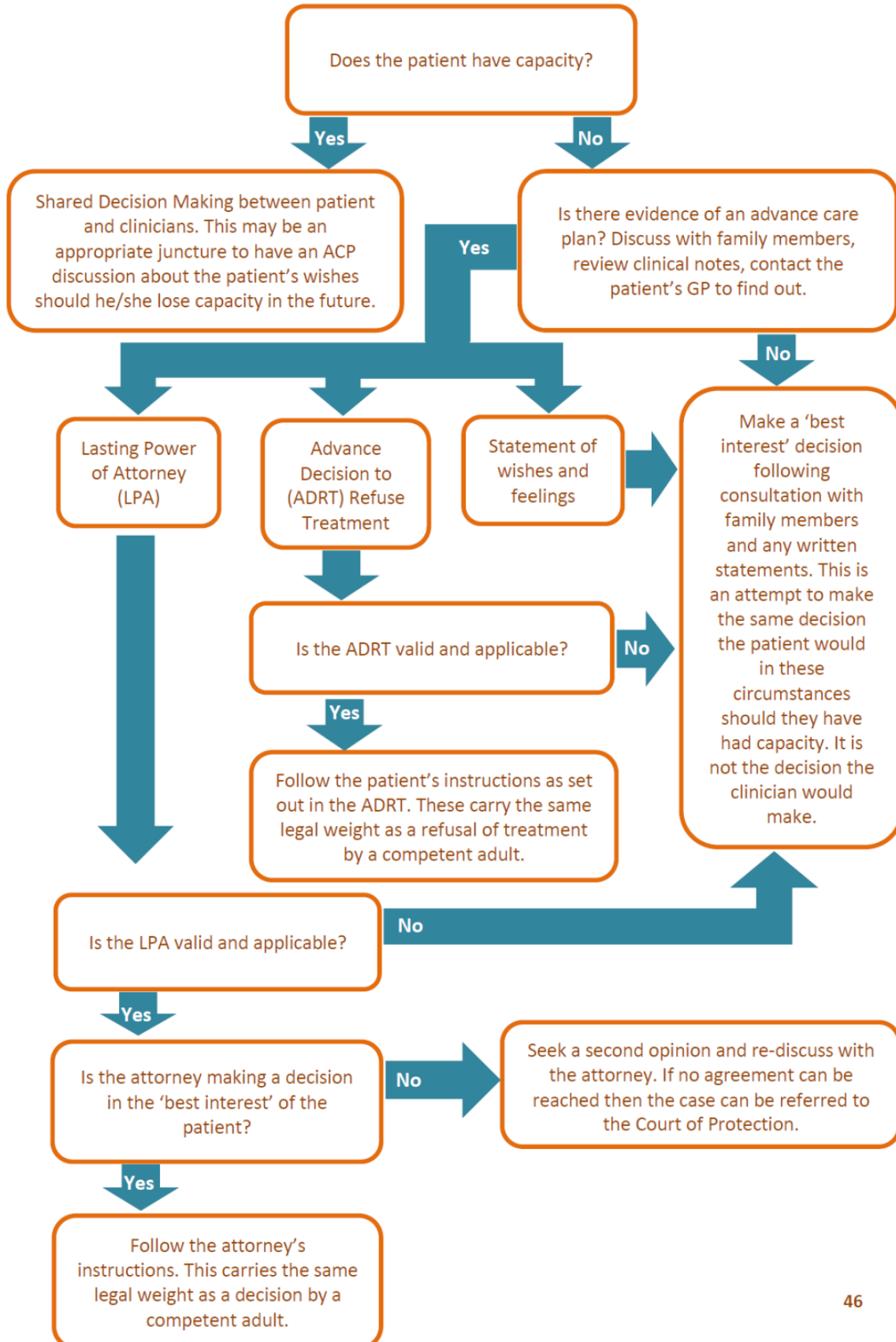
L = Listen

U = Understand the patient as a person

E = Elicit family questions

Appendix 1. Figure 1.

Aide memoire for assessing and responding to a patient's Advance Care Plan



REFERENCES

1. Faculty of Intensive Care Medicine. [2019]. Care at the end of life: A guide to best practice, discussions and decision-making in and around critical care. London: FICM. (www.ficm.ac.uk/eolc)
2. National Institute of Clinical Health and Excellence (NICE), [2020] COVID 19: Rapid Guidance for Critical Care. <https://www.nice.org.uk/guidance/ng159> Accessed 29.3.20
3. Health Education England (HEE) [2020] Available at: https://portal.e-lfh.org.uk/Catalogue/Index?HierarchyId=0_45016_45128_45654&programmeld=45016 Accessed 09.04.20
4. British Medical Association [BMA] [2020] Covid-19: Ethical issues. Available at: <https://www.bma.org.uk/advice-and-support/covid-19/ethics/covid-19-ethical-issues>. Accessed 3.4.20
5. Department of Health. [2005] Mental Capacity Act [2005]. London HMSO
6. Department of Health and Social Care. [2005] Mental Capacity Act [Northern Ireland] 2016 [2016].
7. Paediatric Intensive Care Society [PICS] Modelling of minimum UK PICU beds. Available at: <https://picsociety.uk/wp-content/uploads/2020/03/Modelling-of-minimum-UK-PICU-beds-v5.0-dt25Mar20.pdf> Accessed 1.4.20
8. British Medical Association [BMA] [2018] Children and Young People Ethics toolkit. Available at: <https://www.bma.org.uk/advice-and-support/ethics/children-and-young-people/children-and-young-people-ethics-toolkit> Accessed 09.04.20
9. Maynard, D. [2003] How to tell the news. In: Bad news, good news: conversational order in everyday talk and clinical settings. Chicago: University of Chicago Press. Available at: https://www.academia.edu/1881622/Bad_news_good_news_Conversational_order_in_everyday_talk_and_clinical_settings Accessed 09.04.20
10. Kuroshima, S., & Iwata, N. [2016] On displaying empathy: dilemma, category, and experience. *Research on Language and Social Interaction*, 49(2), 92–110. <https://doi.org/10.1080/08351813.2016.1164395>
11. Ford, J., Hepburn, A., & Parry, R. [2019] What do displays of empathy do in palliative care consultations? *Discourse Studies*, 21(1), 22–37. <https://doi.org/10.1177/1461445618814030>
12. Pecanac, K. E. [2017]. Communicating Delicately: Introducing the Need to Make a Decision About the Use of Life-Sustaining Treatment. *Health Communication*, 32(10), 1261–1271. <https://doi.org/10.1080/10410236.2016.1217455>
13. Anderson, R. J., Bloch, S., Armstrong, M., Stone, P. C., & Low, J. T. [2019] Communication between healthcare professionals and relatives of patients approaching the end-of-life: A systematic review of qualitative evidence. *Palliative Medicine*, 33(8), 926–941. Available at: <https://journals.sagepub.com/doi/10.1177/0269216319852007> Accessed 09.04.20

14. Maynard, D. W. [2017] Delivering bad news in emergency care medicine. *Acute Medicine & Surgery*, 4(1), 3–11. Available at: <https://onlinelibrary.wiley.com/doi/pdf/10.1002/ams2.210> Accessed 09.04.20
15. Kawashima, M. [2017] Four ways of delivering very bad news in a Japanese Emergency Room. *Research on Language and Social Interaction*, 50(3), 307–325. Available at <https://onlinelibrary.wiley.com/doi/pdf/10.1002/ams2.210> Accessed 09.04.20
16. Parry, R., Land, V., & Seymour, J. [2014]. How to communicate with patients about future illness progression and end of life: a systematic review. *BMJ Supportive & Palliative Care*, 4(4):331-41. Available at: https://repository.lboro.ac.uk/articles/How_to_communicate_with_patients_about_future_illness_progression_and_end_of_life_a_systematic_review/9473396 Accessed 09.04.20
17. White DB, Carson S, Anderson W, et al. [2019] A Multicenter Study of the Causes and Consequences of Optimistic Expectations About Prognosis by Surrogate Decision-Makers in ICUs. *Crit Care Med*. 47(9):1184-1193.
18. Lautrette A, Darmon M, Megarbane B, et al. [2007] A communication strategy and brochure for relatives of patients dying in the ICU. *N Engl J Med*. 356(5):469-78
19. Stapleton RD, Engelberg RA, Wenrich MD, et al.[2006] Clinician statements and family satisfaction with family conferences in the intensive care unit. *Crit Care Med* 34(6):1679–1685.
20. Scheunemann LP, Ernecoff NC, Buddadhumaruk P, et al.[2019] Clinician-Family Communication About Patients' Values and Preferences in Intensive Care Units. *JAMA Intern Med*. 179(5):676–684.<https://jamanetwork.com/journals/jamainternalmedicine/fullarticle/10.1001/jamainternmed.2019.0027>
21. Hsieh, H.; Shannon, S.E.; Curtis, J.R. [2006] Contradictions and Communication Strategies during End-of-Life Decision Making in the Intensive Care Unit. *J. Crit. Care*, 21, 294–304
22. Kon AA, Davidson JE, Morrison W, et al. [2016] Shared Decision Making in ICUs: An American College of Critical Care Medicine and American Thoracic Society Policy Statement. *Crit Care Med*. 44(1):188–201.
23. Sprung, C. L., Maia, P., Bulow, H.-H., [2007] "The Importance of Religious Affiliation and Culture on End-of- Life Decisions in European Intensive Care Units," *Intensive Care Medicine* 33, no. 10: 1732–1739.
24. Blank, R. H. [2011]. End-of-Life Decision Making across Cultures. *The Journal of Law, Medicine & Ethics*, 39(2), 201–214.
25. Wong WT, Phua J, Joynt GM. [2018] Worldwide end-of-life practice for patients in ICUs. *Curr Opin Anaesthesiol*. 31(2):172-178.

- 26.** Hepburn A, Potter J. [2007] Crying receipts: Time, empathy, and institutional practice. *Res Lang Soc Interact*; 40: 89–116. Available at: https://www.tandfonline.com/doi/pdf/10.1080/08351810701331299?casa_token=7fLI3YFUTYUAAAAA:TVnexp3vXiUoDcOa8DTLvBvSGZR48hpiyJjHp_oE-e1gDhBNm9NlIttU9oEoL2ut5UTMmShN9giK2Sg Accessed on 09.04.20
- 27.** Hepburn A, Potter J. [2012] Crying and crying responses. In: *Emotion in Interaction*. Oxford: Oxford University Press. Downloadable at: https://www.academia.edu/1112952/Crying_and_crying_responses Accessed 09.04.20
- 28.** Heritage, J., Robinson, J. D., Elliott, M. N., Beckett, M., & Wilkes, M. [2007]. Reducing Patients' Unmet Concerns in Primary Care: the Difference One Word can Make. *Journal of General Internal Medicine*, 22[10], 1429–1433. Available at: <https://link.springer.com/content/pdf/10.1007/s11606-007-0279-0.pdf> Accessed 09.04.20
- 29.** Stokoe, E., Sikveland, R. O., & Symonds, J. [2016]. Calling the GP surgery: patient burden, patient satisfaction, and implications for training. *British Journal of General Practice*, 66[652], e779–e785. Available at: <https://bjgp.org/content/bjgp/66/652/e779.full.pdf> Accessed 09.04.20

Summary: Prompt list for phone and in person urgent conversations about withdrawing or withholding life-sustaining treatments in UK critical care

PREPARE	<ul style="list-style-type: none"> • Check LPA / ADRT status • Clarify what you are going to say, including arrangements and information you will provide at the end • If possible, find a comfortable, private place
START AND SIGNPOST	<ul style="list-style-type: none"> • Introduce yourself, your role, name the patient, check who you are speaking to • Are you able to talk? Are you safe to talk at the moment (e.g. not driving)? • If possible, signpost by explaining reason for call, for instance 'I'm going to give you an update on
EXPRESS EMPATHY	<ul style="list-style-type: none"> • Tone of voice, sorry statements, show understanding about emotion but don't overclaim you understand: Something like: 'We know this is really tough, I can't imagine how hard it is for you right now'
FORECAST, CHECK UNDERSTANDING	<ul style="list-style-type: none"> • Explain, in a way that forecasts what is to come, that you need to talk about the patient's condition • Find out what they know, understand already
CLINICAL COMMENTARY	<ul style="list-style-type: none"> • Be clear and honest about condition • If the patient is dying, use that word or a non-ambiguous alternative (e.g. will not survive) • Convey uncertainty if appropriate, avoid raising hopes unnecessarily
ELICIT PATIENT'S WISHES & CLARIFY WHO WILL ACTUALLY MAKE THE DECISION	<ul style="list-style-type: none"> • Check who is with them now, who they can talk to after • Ask about the patient's values, goals, and wishes, allowing time • Explain it's a medical decision, but that their views and their knowledge of the patient's views are important (unless LPA Health and Welfare in place – see full guidance)
VOICE THE DECISION	<ul style="list-style-type: none"> • Clearly summarise what they have said • Give the team's clinical opinion • Reiterate this is a collective clinical decision, in which the patient's views are taken into account • With empathic statements, check the need for further explanation, articulate the decision
SUMMARISE AND SUPPORT	<ul style="list-style-type: none"> • Check need for further explanation. Sensitively restate the decision, explain what will happen next • Emphasise care will continue, that the team is not abandoning the patient • Allow time for emotions to be expressed • Signpost to support and who will next contact them and when

V = Value comments made by the family **A = Acknowledge family emotions** **L = Listen** **U = Understand the patient as a person** **E = Elicit family questions**