



Royal College
of Physicians

Our **future** health

Talking about dying:

How to begin honest
conversations about
what lies ahead

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Our Future Health

In its 500th year, the Royal College of Physicians (RCP) is taking the opportunity to reflect on day-to-day dilemmas facing physicians and patients within the current healthcare system. Our Future Health is a year-long campaign of events and multimedia outputs that will lead the debate and raise awareness of the impact of these challenges on patients, healthcare professionals and the NHS. This campaign has focused on three main areas: clinical resources, innovation and research, and investment. The data captured are informing policy positions and documents that will drive improvement in health and healthcare through advocacy, education and research.

Join in the discussion

#OurFutureHealth @RCPFuture



Foreword



In recent years, healthcare has become increasingly politicised, with an increased focus on affordability and system-wide problems. These,

together with stories of low-quality care, make the headlines all too frequently. If you speak to clinicians involved in the direct delivery of today's healthcare, their overwhelming concern is with the quality of the care and the compassion with which they interact with their patients, in increasingly difficult circumstances. When asked, clinicians agree that #medicineisbrilliant, but the system in which we work is not. The Our Future Health campaign refocuses on the needs of the patient, on the importance of the relationship between clinician and patient, and on addressing some of the dilemmas that we meet so frequently in daily clinical practice.

Many of those dilemmas escalate as patients reach the last years of their lives, and have not been shared or addressed adequately. I am grateful to Dr Sarah-Jane Bailey and Kacey Cogle who have facilitated this high-quality and honest piece of work for the RCP, which focuses on the benefits of open and honest conversations with the people whom we are privileged to support during their illness.

Professor Dame Jane Dacre
President, Royal College of Physicians
August 2018

Contents

01	Foreword
02	Introduction
02	Methodology
03	The case for change
04	Barriers
	Culture
	Confidence
	Practicalities
08	Myths and mythbusters
12	Summary
13	Recommendations
	For physicians
	For the wider healthcare system
15	Resources

Introduction

The core mission of the Royal College of Physicians (RCP) is to drive improvements in health and healthcare through advocacy, education and research. Drawing on the diverse experience and expertise of our 35,000 members and fellows, the RCP seeks to support clinicians in addressing the challenges facing our healthcare system today.

This year the RCP began a multimedia campaign, Our Future Health, to shine a spotlight on the daily dilemmas that physicians face on the front line. An area of major concern to physicians was uncovered: end of life care. When asked ‘How can we empower doctors, patients and carers to make shared decisions about care and treatment that balance duration and quality of life?’, physicians revealed that starting these conversations with patients and family is challenging and, at times, impossible.

The role of doctors and their relationship with the patients they care for has changed from when the NHS was set up 70 years ago. There are fewer ‘transactional’ consultations about a single, curable illness or injury, and a much greater need for individualised management of symptoms and conditions. For people to live as well as possible despite long-term and terminal illnesses, integrated and whole-system care is required. We all need to be equipped to offer patients honest conversations about what they can expect in the future, to give them choices and control over the remainder of their lives. This is not just about high-quality palliative care in the last weeks or days, but about holding conversations much earlier after diagnosis of a progressive or terminal condition, including frailty.

This report seeks to offer advice and support for any doctor to meet these challenges when caring for patients with a diagnosis of a serious, potentially life-limiting illness. It highlights some of the barriers, and busts common myths that might hamper a successful conversation between doctor and patient. We have also collated a series of resources and best practice to aid doctors to develop and improve in confidence when discussing their patients’ preferences and values, as they approach the end of life.

Methodology

Our Future Health supported discussions on end of life care with a diverse audience, both internally within the RCP and externally with professional and lay stakeholders in this area across a number of multimedia formats. In this report, we have summarised our findings alongside the evidence base, which is limited.

Firstly, and throughout this project, members of the RCP’s internal committees were consulted. This included several meetings and workshops with the Student and Foundation Doctor Network, Trainees Committee, New Consultants Committee, chief registrars, Joint Specialty Committee for Palliative Care and the RCP’s own Patient and Carer Network. The feedback we received from these groups assisted us in campaign strategy, purpose and design, and gave us a sounding board for proposed next steps. It also provided us with an opportunity to speak with both patients and healthcare professionals from a variety of specialties and career stages.

Externally, a stakeholder round table chaired by Professor Bee Wee, national clinical director for end of life care for NHS England, was held to discuss how we can empower doctors, patients and carers to have conversations that facilitate shared decision making about care and treatment that balances potential duration and quality of life. This round table was well attended, with representatives from the Association for Palliative Medicine of Great Britain and Ireland, the Faculty of Intensive Care Medicine, Breast Cancer Care, Macmillan Cancer Support, the Second Conversation Project, the Royal College of Nursing, St Christopher’s Hospice, the RCP Committee on Ethical Issues in Medicine, the RCP New Consultants Committee, NHS England, the Point of Care Foundation and the Alzheimer’s Society, along with representatives of palliative medicine, general internal medicine, geriatrics, gastroenterology, intensive care, foundation doctors, core medical trainees, medical registrars, nurses and policy professionals. The discussions from this round table were continued with attendees after the event, and supported by further communications with the British Geriatrics Society, the Royal College of Surgeons, the British Lung Foundation and Hospice UK.

Finally, to access an even wider audience, a conversation was conducted online. A podcast discussing end of life care was recorded and released, along with several pieces in the RCP’s member magazine and supplementary blogs (accessible at <http://ourfuturehealth.rcplondon.ac.uk/>). All these online outputs were supported by a social media push to encourage discussion with patients, healthcare professionals and policymakers online on Twitter and other social media.

One in three adults admitted to hospital through the acute take are in their last year of life.

The case for change

The UK has an ageing population, with more people than ever living longer with chronic diseases and multiple comorbidities. One in three adults admitted to hospital through the acute take and 80% of care home residents are in their last year of life.¹ This is often not obvious at first point of contact.

End of life – the GMC definition

A patient is defined as approaching the end of life when they are likely to die within the next 12 months.² This includes patients whose death is imminent (expected within a few hours or days) and those with:

- > advanced, progressive, incurable conditions
- > general frailty and coexisting conditions that mean they are expected to die within 12 months
- > existing conditions if they are at risk of dying from a sudden acute crisis in their condition
- > life-threatening acute conditions caused by sudden catastrophic events.

The General Medical Council (GMC) defines patients as approaching the end of life when they are likely to die within the next 12 months (see box above). This definition includes patients meeting several criteria, such as those with chronic disease and frailty and those at risk of sudden acute deterioration.² People receive better, coordinated end of life care if they are identified early as being in the last year of life and included on the GP palliative care register,³ yet only 25% of such patients are captured on this register, and those with a non-cancer diagnosis – such as heart failure, chronic obstructive pulmonary disease (COPD), dementia and frailty – are particularly less likely to be identified.⁴

The NHS constitution enshrines the importance of a patient's right to be involved in planning and decisions about their health and care, including end of life care,⁵ and the Ambitions for Palliative and End of Life Care emphasise the importance of having 'honest, informed and timely conversations' with both the individual and the people caring for them.⁶

There are many potential benefits to early introduction of palliative care and advance care planning in a patient's treatment.^{7,8} They can improve quality of life and mood,^{9,10} reduce the use of aggressive care at the end of life,⁹ improve clinicians' documentation and delivery of the patient's preferences¹¹ including place of death,^{10,12,13} improve pain control towards the end of life,¹³ reduce emergency hospital admissions¹⁴ and even extend life expectancy of certain groups.⁹ However, despite these benefits, the National End of Life Care Audit¹⁵ revealed that only 4% of patients had documented evidence of any sort of advance care plan or discussion of their preferences prior to admission to hospital. It is unclear whether this is due to a lack of discussions, a failure of documentation or poor sharing of information between services. A 2016 report by the Care Quality Commission (CQC) also highlighted that the experience of end of life is often poor for people in late old age, and that communication with patients and their families across the system needs improvement.¹⁶ This is reflected in the experience of our members:

Too many patients are being admitted to hospital without ever having discussed serious issues like DNACPR (do not attempt cardiopulmonary resuscitation) or their ceiling of treatment despite chronic, life-limiting conditions and frailty. We act on default because we don't know what the patient wants. Carers and healthcare staff in the community think the safest thing to do is to send someone to hospital but it isn't always necessary, especially if it's not what the patient wants. **Medical registrar**

Nearly half of all deaths in England occur in hospital^{17,18} and nearly 25% of those who die in hospital have been there for over a month.¹⁹ Despite this wealth of in-hospital experience of caring for people at the end of life, the 2015 National Survey of Bereaved People¹⁷ showed that there were significantly higher rates of poor communication and poor understanding of information reported by relatives of people treated in hospital than in other settings. Indeed, in 2012 more than half of all hospital complaints related to end of life care.²⁰

Timely identification and honesty where there is uncertainty are key to the quality of care – all else follows. National Palliative and End of Life Care Partnership

Conversations around prognosis, palliative care and end of life can be challenging for both the doctor and the patient, but are important for improving patient experience.^{13,21} Such open conversations are often welcomed by the patient or their family as a chance to gain more information about their prognosis and treatment options, and to exercise some choice and preference.²² Research by Macmillan Cancer Support has shown that only 8% of people with cancer who said that they had thoughts and feelings about their death had shared these with their healthcare team. Of those who had, only 19% of the conversations were initiated by the healthcare professional,²³ suggesting an unmet need.

*There could be a whole population of people who, even at 60 years, may not want resuscitation. If we don't ask them, they'll just get it. This should be a routine conversation with every single person. **Trainee***

Many physicians still find these conversations difficult²⁴ and there are not enough palliative medicine specialists to see every patient as demand increases. In 2016, there was a median of 1.08 specialist palliative medicine consultants and 5.08 clinical nurse specialists (whole-time equivalents) per 1,000 general adult hospital beds.¹⁵ If recent mortality trends continue, 25–42% more people in England and Wales will need palliative care by 2040.²⁵ Providing good palliative care is not solely in the remit of specialist palliative care teams; many of the other physician specialties already support people who are gradually or rapidly approaching death, and this will need to become a part of normal practice for all in the future.

There are multiple opportunities in a patient's healthcare journey to start honest conversations about future goals and limits of treatment. Initially, it may be recognised by primary or social care that a person has a life-limiting or progressive condition(s), and appropriate care planning in the community can begin in conjunction with the patient and their loved ones. However, hospital physicians also have the opportunity to intervene early: at outpatient appointments, as well as during every inpatient admission (patients in the last year of life are admitted to hospital an average of 3.5 times²⁶). Such early conversations allow patients choice and control over the remainder of their lives. The final set of difficult conversations occurs further down the line, when it has become clear that treatment is not working or would be futile, and the patient has a high chance of dying in the next few hours to days.

This should change focus to symptom management and discussions about preferred place of death and required support. However, as our RCP chief registrars highlighted, these important discussions currently often take place in crisis, out of hours in hospital and can seem unexpected to unprepared patients and carers. Ceiling of treatment decisions are being made in an emergency setting by clinicians who have not had time to build a relationship with the patient, sometimes with patients too unwell to contribute and relatives on the phone or out of contact, which is far from best practice.^{5,6}

We need to consider how we – as a society, as a medical profession, as individual clinicians and as patients – can open up more timely discussions about priorities at the end of life and improve understanding of the many different benefits of timely palliative care. The RCP has set itself and the physician workforce a challenge to do this better.

Barriers

During 2017–18, the RCP conducted five workshops with medical students, foundation doctors, core medical trainees, registrars, chief registrars and new consultants, with approximately 100 attendees in total. Through these conversations, we identified three main barriers to discussing quality versus longevity of life: culture, confidence and practicalities. Our findings are detailed below, alongside relevant literature.

Culture

Physicians we spoke to perceived a culture among the public to avoid discussing death and to expect modern medicine to cure all ailments. However, the evidence would suggest that this is not the case for all patients,²³ and 77% of the public in England stated they would want to know if they had less than a year to live.²⁷

We released a podcast²⁸ earlier this year in which Claire, a patient with metastatic breast cancer, told us that 'talking about it really helps manage emotions – not holding it inside actually makes me feel better'.

Case study

The Conversation Project

Royal United Hospitals Bath NHS
Foundation Trust

Background – starting the conversation

Caring for people nearing the end of life is one of the most important things we do in hospitals. Over the past 5 years, the Royal United Hospital has developed an initiative called The Conversation Project. This was initially a quality improvement project with the King's Fund and The Point of Care Foundation Patient and Family-centred Care Programme. The aims are:

- > to support earlier recognition of patients with end of life needs or whose recovery is uncertain
- > to improve communication and advance care planning (ACP)
- > to improve documentation of conversations with patients and their families about their wishes for future care
- > to improve sharing of information related to these conversations on transfer of care.

Intervention

The Specialist Palliative Care Team has continued to lead on this initiative. In the past year, a grant from the Health Foundation has supported the team in developing resources, including:

- > 'Planning ahead' information leaflet for patients and their families
- > 'Planning ahead – my wishes' ACP document for patients
- > intranet resource for staff
- > The Conversation Project CHAT Bundle (Consider, Have, Advise, Transfer)
- > a series of short films for staff on having ACP conversations with patients and families.

Results

Evaluation has shown improvements in identification of patients with end of life care needs and compassionate conversations with patients and their families around their wishes for future care. The trust is now piloting an electronic record to document ACP discussions and monitor outcomes in care. The principles of The Conversation Project will continue to be embedded across the hospital to support all wards with providing compassionate, individualised patient care to those nearing the end of life.

Point of contact

Helen Meehan, helenmeehan@nhs.net

She talked about the power of 'honest answers to difficult questions' and wants to know how treatments will impact her quality of life versus the possibility of life extension. She wants to be supported to balance these factors herself before making choices. She wants to know what to expect as her health deteriorates so that she can organise how and where she will be cared for and by whom. Claire wants to have frank conversations about how she can achieve a 'good death'.

Clearly this will not be the case for every patient: for some patients and their families, not talking about death and 'not giving up' is how they want to approach life, even at the end. However, they should still be given the opportunity to have a conversation. A YouGov plc survey commissioned by Macmillan in 2017 found that 20% of patients who had not shared their worries about death with anyone felt uncomfortable talking about it, but 22% had not shared because they did not want to bother anyone.²⁹ We know that, despite the difficulty that can be associated with talking about death, people want repeated opportunities to consider whether to engage in such honest conversations about their future.²²

Physicians we spoke to also felt that there remains a culture within the healthcare profession itself to see death as a failure, and a desire to 'always do something to help' that can result in unnecessary, aggressive treatment.^{23,30} Inappropriate interventions near the end of life have been identified as a common problem in cancer care in the UK^{31,32} as well as non-cancer care, for example with the futile insertion of percutaneous endoscopic gastrostomy tubes.³³ There is a sense that this will be an increasing phenomenon as UK healthcare becomes more litigious; however, overtreatment is not the answer, as our round-table experts vehemently protested:

It is morally wrong to waste a dying person's time. You shouldn't give futile treatment. We need to articulate this to doctors. Fundamentally, we are dealing with people not pathologies.

Medical director

Finally, in the context of a system under pressure, the clinicians we spoke to highlighted that healthcare management targets do not currently prioritise clinic or ward round time for communication or advance care planning:

There is no time to have these discussions in clinic; outpatient nurses and other patients get annoyed having to wait if I overrun. Even if I start the conversation, there is no time to do the paperwork. Managers won't extend clinic times to allow for advance care planning with follow-up patients. It doesn't seem to be valued by management.

New consultant

Every on call, there will be a patient referred to ITU who the doctors don't have the confidence to say 'you're dying' to, so people aren't prepared. They come to ITU by default. Intensive care consultant

Confidence

Our discussions revealed that confidence remains low among doctors at all levels. From medical students to consultants, many of those we spoke to told us that they feel uncomfortable initiating conversations about the future with patients.²⁴ Junior doctors complained of a paucity of role models, and highlighted the range of good and bad practice demonstrated by different consultants and specialties encountered during their training rotations.

Many medical students only have experience of talking to simulated patients about prognosis and end of life care, with their first real experience of witnessing or leading these conversations delayed until after qualification. In medical school curricula, great emphasis is placed on seeing a set number of births and engaging in other procedures – there should be an equivalent for end of life care training.

Junior doctors also said that they had few opportunities to practise these conversations with feedback. It was felt that observation by another staff member was unlikely in a healthcare system under pressure, but also that current postgraduate education models and training objectives still do not prioritise teaching and evaluating these 'softer' skills.^{34,35}

Prognostic uncertainty in complex patients was frequently cited by registrars and consultants as a reason to avoid these conversations.^{36–38} Nevertheless, we would encourage clinicians to share this uncertainty in honest discussions with patients.

Case study Implementing mandatory end of life care training

Worcestershire Acute Hospitals NHS Trust

Background

In line with many acute hospitals, Worcestershire Acute Hospitals NHS Trust experiences perceived delays in patient flow, with timely discharge of patients being a prominent theme. This online case study describes how having early conversations with people and their families around prognosis, their choices and their preferences for care can bring many benefits.

Intervention

This case study illustrates how staff, engaged in blended education with partnership working, can improve their communication skills and confidence around such dialogues, and adopt AMBER care bundle language in their case note documentation. The study also demonstrates how the AMBER care bundle tool, supported on introduction by a comprehensive education package, encouraged staff to recognise and talk about uncertain recovery during the hospital admission at an earlier stage than they may have done previously.

Results

This proactive approach has had a positive impact on length of stay. Completion of a comprehensive electronic discharge, based on AMBER care bundle-directed conversations and communicated to the GP, has resulted in significantly fewer avoidable readmissions. Our bereavement surveys, which include cross-reference to questions about discussion of uncertain recovery, show year-on-year improvement.

Top tip

Invest to change behaviours and processes in order to reap long-term benefit.

Point of contact

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www.nhsemployers.org/-/media/Employers/Documents/Workforce-supply/End-of-life-care/EoLC-case-study---Worcestershire-Acute-NHS-Trust.pdf

Conversations are two-way interactions that take place over time. We need to be prepared to have ‘opportunity-based conversations’. Palliative medicine consultant

Practicalities

Our consultation showed that confusion remains as to who should be having these conversations. Should it be the person who knows the patient best, perhaps the GP? Or the specialist who has all the answers regarding treatment options? Given changing population needs and the pressure in our healthcare system, hospital physicians cannot assume that patients will always have a relationship with their named GP, as has traditionally been the case. Similarly, patients with multiple comorbidities and frailty will no longer have one condition, under one specialist consultant, with one set of treatment options. These are general medical patients with uncertain disease trajectories, and all healthcare professionals along the journey need to be adequately equipped to support them. As several patients told us, the patient will choose with whom and when they are happy to talk about the future, and our job is to offer them the chance.

Staff admitted that they were reluctant to start conversations around prognosis and advance care planning if they could not finish them with a patient themselves.²³ Given current fragmented care pathways and poor continuity, it is less likely that one practitioner will be able to build a relationship with a patient. Similarly, junior doctors rarely have the opportunity to meet the same patient in clinic twice, owing to job rotations.

Other practical barriers include how best to record these conversations, especially given the need to share records across the secondary care and community interface, with multiple providers and different record and IT systems. Given the strain that the health service and its workforce are under, time is a precious resource, with competing priorities at every patient encounter. Discussing prognosis and the future can seem less pressing in a busy outpatient clinic, and there is little privacy on the ward if the patient is confined to bed. Finally, there are challenges for physicians to learn about and be sensitive to different cultural and religious beliefs when having these discussions. ■

Case study

The Poor Prognosis Letter Project University Hospitals Bristol Supportive and Palliative Care Team

Background

In 2013, our local GPs told us that they needed prognostic information from secondary care specialists to help them identify patients approaching the end of life.

Intervention

- > We asked our GP colleagues what information they wanted.
- > We asked our physician colleagues to develop disease-specific indicators of poor prognosis.
- > We asked IT colleagues to design an electronic letter, the Poor Prognosis Letter (PPL), within our existing Integrated Clinical Environment (ICE) system.
- > We repeated the audits several times over the past 2 years to assess progress.

Results

- > Use of the PPL has increased steadily; around 30–50 PPLs are generated each month.
- > Qualitative feedback from GPs was very positive, suggesting that the PPL acted as a prompt for them to visit patients to have a conversation about future care.
- > We ascertained place of death for 187 patients who had a PPL completed between April and October 2015. Only 36% of these patients died in hospital. This was lower than the proportion of deaths in hospital for the whole Bristol CCG population at that time, which was 46%.

Top tips

This initiative was a culture change and so took a great deal of time. Using ward doctors as champions helped embed the process.

Point of contact

Dr Karen Forbes, k.forbes@bristol.ac.uk

Myths and mythbusters

‘Palliative care means that time is up’

Palliative care is not giving up, doing nothing, or resigning oneself to death. Palliative care is not just for when a person is close to death, but can be given earlier, even from diagnosis. It can be a change in focus, or exist in parallel with disease-targeted treatments. It can offer assistance in management decisions, symptom control, psychological support and practical issues, and help patients to understand their illness better. It is relevant to all conditions from which a patient may die in the foreseeable future, not just to those with cancer diagnoses. It is about making the absolute most of living when time is limited. In some cases, early palliative care input can even offer a survival benefit.⁹

‘CPR will always save a life’

Cardiopulmonary resuscitation (CPR) is not as portrayed in popular culture; there are risks, complications and a low likelihood of success.^{39–41}

Average survival to discharge after in-hospital cardiac arrest is 15–20%, but long-term cognitive impairments are present in half of these survivors.^{42,43} Average survival to discharge after out-of-hospital cardiac arrest is lower, at 5–10%.³⁹ In non-shockable rhythms or when the arrest is not witnessed, it is <10%.³⁹

NB Individual circumstances, such as comorbidities and the cause and circumstances of the arrest, should be taken into account. When a person is in the final stages of an incurable illness and death is expected within a few hours or days, in almost all cases CPR will not be successful. CPR cannot reverse the person’s underlying condition and it may prolong or increase suffering. In end-stage advanced cancer, the success of CPR is <1%, with survival to discharge close to zero.⁴¹

Risks include:

- > rib or sternal fractures
- > hepatic or splenic rupture
- > subsequent requirement for artificial ventilation and admission to intensive care
- > subsequent need for renal replacement therapy and/or circulatory support with inotropic drugs and/or an aortic balloon pump
- > brain damage and resulting disability, especially if there is delay in CPR initiation
- > CPR attempts are unavoidably physical and potentially traumatic; as a result, death may occur in a manner that neither the person affected nor people close to them would have wished.

‘Whether to have CPR is the most important decision in advance care planning’

For most people, CPR is completely irrelevant and other decisions are much more important (which disease-related treatments to accept or not, for instance).

You can help patients and their loved ones to understand that:

- > cardiorespiratory arrest is part of the final stage of dying
- > CPR is unlikely to be successful when someone is dying from an advanced and irreversible or incurable illness
- > healthcare professionals may start CPR inappropriately when someone dies unless a DNACPR (do not attempt cardiopulmonary resuscitation) decision has been made and recorded.³⁹

‘DNACPR forms are legally binding’

Occasionally, a person for whom a DNACPR decision has been made may develop cardiac or respiratory arrest from a readily reversible cause, eg choking. In such situations, CPR could be appropriate while the reversible cause is treated, unless the person has made a valid refusal of the intervention in those specific circumstances.

Unless there is a valid and applicable advance decision to refuse treatment, which specifically refuses CPR, a DNACPR form itself is not binding. As with any clinical decision, healthcare professionals must be able to justify their actions. In particular, clinicians should be cautious of overriding a DNACPR decision where the form records that the patient has expressed a clear wish not to receive attempted CPR.³⁹

‘Patients with a DNACPR won’t receive other treatments as a priority’

Patients with DNACPR orders can, do and should receive other active treatments as appropriate. DNACPR is not synonymous with stopping treatment. An emergency call can be put out for a patient with a DNACPR order if they are unwell and you need help urgently.

‘Families or patients can demand CPR even if it will be futile’

CPR remains a clinical decision, and physicians are not required to offer interventions that are futile or inappropriate.^{39,40}

If CPR is unlikely to be successful

When a person is dying as an inevitable result of advanced, irreversible disease or a catastrophic event and there is no realistic prospect of a successful outcome, then CPR should not be attempted.

If the patient declines CPR

Patients, of course, can decide to refuse CPR even if the clinical team thinks that it might be of benefit. This should be discussed as a matter of routine when patients are admitted to hospital with a foreseeable (even if remote) risk of cardiac or respiratory arrest.

Communication of DNACPR decisions

Patients should be included in discussions about DNACPR. The courts have stated that there should be a presumption in favour of patient involvement and that there need to be convincing reasons not to offer the opportunity to patients. If explaining a DNACPR decision will impose such distress that the patient suffers harm, then the reasons for not involving them must be documented fully.

If CPR may be successful but is likely to result in significant disability

30% of survivors of in-hospital cardiac arrest will be left with clinically significant neurological disability.^{42,43} However, where attempting CPR has a reasonable chance of successful return of spontaneous circulation

for a sustained period and a person has decided that the quality of life that can reasonably be expected is acceptable to them, then their wish for CPR should be respected. A second opinion should be offered in cases of disagreement.

When to involve family

With the patient’s consent, it is best practice to involve the patient’s loved ones in conversations about CPR.

If the patient does not have mental capacity, then every effort must be made to contact a legal proxy or those close to them. The courts have ruled that staff must attempt to inform those close to the patient of a DNACPR decision, even if it may be inconvenient or undesirable at a particular time. However, if attempts to make contact have failed, the decision should not be delayed inappropriately and the senior clinician should:

- > record fully their reasons for not explaining the decision to those close to the patient at that time
- > ensure that there is ongoing active review of the decision
- > ensure that those close to the patient are informed at the earliest practical and appropriate opportunity.

If the patient does not have a legal proxy with relevant authority, those close to the patient have an important role in advising the healthcare team about the patient. However, it is not their responsibility to decide whether CPR will be of overall benefit.^{39,40}

‘Attention to saving life is a priority; we should avoid mentioning death to acutely unwell patients’

Physicians meet patients who are sick enough to die every day. While assessing the potential for recovery and instituting appropriate life-saving treatment, we should also ask ourselves whether the care covers all the requirements for managing death well if the patient does not respond. If the patient does not survive, what family members or friends should be with them? Would they be comforted by any religious rites? Would they want to say important or personal things to anyone?

Explaining to patient and/or family that the patient is ‘sick enough to die’ won’t make them sicker, but it will enable everyone to understand the gravity of the situation and to respond appropriately.

‘People, patients and healthcare professionals do not want to talk about death’

Confronting one’s own mortality can be difficult. However, when supported, many people do want to talk about death.^{22,23,27,28} There is evidence that disclosing a diagnosis of a terminal illness will help patients to feel more empowered about care and decision making, rather than diminish their hope.⁴⁴

Professionals are often reluctant to initiate conversations about the end of life because they are not sure that the patient will die within the next 12 months. You do not have to be sure of a timeframe to initiate the conversation. Evidence suggests that doctors are much more inclined to overestimate the time a patient has left than to underestimate.³⁶

'A ceiling of treatment has an implication on a patient's individual worth'

Setting a ceiling of treatment is not a value judgement on a patient's worth as a person. It is based on the likelihood that the intervention will work. This needs to be discussed sensitively with the patient and their loved ones to avoid misunderstandings. Less treatment at this point should go hand in hand with more care.

'Doctors can give precise prognoses when pushed'

Healthcare professionals can only give an indicative range of life expectancies, based on overall probability using population data with some consideration of an individual's comorbidities and frailty. A more precise prognosis is almost always wrong, and mistakes can be harmful. Patients can feel cheated (if a prognostic guess was too long and they die sooner than expected), or sometimes burdened (if it was too short and they feel they are 'lingering' and die later than predicted). Timeframes need to be reviewed; as death approaches, it often becomes easier to prognosticate.

Be aware that patients can conflate 'a possible range' with a precise prognosis. It is more helpful to give a timeframe of 'many months', 'weeks to months', 'only a few weeks', 'could be as short as days or as long as a couple of weeks', and to avoid numerical answers.

'Every patient who is dying should be made aware'

Everyone will have their own individual preferences. In certain cultures, talking about death remains taboo. Healthcare professionals need to respect this while offering patients the opportunity to discuss their future.

'Clinicians know what patients want without asking them'

Healthcare professionals sometimes assume that a patient will not want further aggressive intervention. However, while clinicians may be better placed than others to judge prognosis, illness trajectory or success rates of possible treatments, they cannot possibly know a patient's individual priorities without asking.

'Plans made in advance are binding'

People can and do change their minds about their priorities, including preferred place of death. Care plans can be deviated from, in conjunction with discussions between the patient, family and medical team. Equally, a small but significant proportion of patients who are thought to be dying do improve. If treatment has been scaled back and symptom relief prioritised, then this can always be reversed.

Advance care planning is a process by which future care is negotiated and recorded in anticipation of future loss of mental capacity. As long as the patient has mental capacity, their contemporaneous wishes override any prior wishes they may have stated. Advance decisions to refuse treatment (ADRTs) are legally binding if the patient has lost mental capacity and the ADRT is valid and applicable to the current situation. Statements of wishes are not legally binding, but they do provide a useful guide to the patient's priorities and preferences if they are too acutely unwell to discuss, or have lost mental capacity.

Any decision about treatment that is made when a patient has lost mental capacity must comply with the Mental Capacity Act 2005 (England and Wales).

'Opioids are dangerous, addictive and shorten life'

Opioid drugs are safe and effective for cancer pain management and to relieve other symptoms associated with cancer and non-malignant diseases.⁴⁵ Opioid abuse and addiction are rare in people with advanced illness when prescribed under close medical supervision. Therapeutic use of opioids for palliative care of people with a history of opioid addiction should involve a specialist in palliative medicine.

Correct opioid use at the end of life does not shorten life, but uncontrolled pain can.⁴⁶ At the end of life, drug route and doses may need to be adjusted to maintain comfort and avoid loss of pain control.

'Sedation shortens life'

Side effects of sedative drugs may include impairment of safe swallowing, reduced respiratory drive and reduced ability to eat and drink.

Rarely, dying patients may experience distress when symptoms cannot be controlled despite expert advice. In these circumstances, some patients may require sedating medication to diminish awareness of their suffering. If medication is sedating in its effect, the dose should be monitored in order to ensure that it is the minimum required to relieve distress. Medication used in this way does not shorten life.^{47,48}

‘The doctrine of double effect justifies poor practice in end of life prescribing’

The doctrine of double effect states that ‘the risk of a potential, known (foreseen), unintended consequence or side effect of treatment is justified only if all the following criteria are met:

- > the intended effect is good in itself
- > the clinician’s intention is solely to produce the good effect
- > the intervention is proportionate to the situation
- > the good effect is not achieved through the bad effect.’

There is currently no credible research evidence to suggest that a patient’s life is shortened by either opioids or sedatives when used in line with specialist palliative care guidance.^{49,50} The prescriber should use the lowest possible dose that relieves distress, review the patient regularly, adjust dosage as needed, and record decision making in the case notes. Professionals who are concerned that they are shortening life by use of these medications should contact their local specialist palliative care services.⁵¹

‘Hydration is inappropriate at the end of life’

The hydration status of all patients at the end of life should be assessed and reviewed regularly. Those who can take nutrition and hydration orally should be encouraged and assisted to do so. However, it is a natural part of dying and preterminal deterioration for people to lose interest in food and fluids.

The role of clinically assisted nutrition and hydration via intravenous or enteral replacement is not clear-cut. While it may improve a patient’s quality of life or prolong the time they have left, it may cause discomfort and distress.^{52,53}

‘Patients don’t want to die in hospital’

Preferred place of death varies among patients. Many patients do want to be at home, but there are some who want to be in hospital when they die. Faced with the reality, people often only realise that death is close once they or a loved one is in hospital, and they often choose to stay when offered alternatives. 74% of respondents in the National Survey of Bereaved People felt that hospital was the right place for the patient to die, despite only 3% of respondents stating that patients wanted to die in hospital.¹⁷ Death at home can provide familiarity, dignity and comfort in some cases, but it can also create anxiety and challenges depending on what community resources are available.

‘If healthcare professionals support patients to remain at home for end of life care, they put themselves at higher risk from the CQC, GMC or NMC’

If a healthcare professional can demonstrate that good end of life care, tailored to the patient’s needs and requests, has been discussed and provided, there should not be a problem. However, conveyance to hospital is often emergency responders’ default, sometimes because there is no alternative care provision out of hospital for that patient at that time. Recording preferences of plans made in advance is important, and often supports people to remain at home.



Case study

Introducing supportive palliative care nurses to care homes

Salford Royal NHS Foundation Trust

Background

Across Salford, a formal programme in palliative and end of life care education has existed since 2010; this training is accessible to all local health and social care staff. In 2012, it was supplemented by delivering a formal training programme across care homes. A training needs analysis identified that greater impact could be gained by implementing an innovative coaching model, and substantive funding from Salford Clinical Commissioning Group (CCG) was secured to create a team of supportive palliative care nurses for care homes.

Intervention

- > Building relationships with the care home carer, primary care and nurses
- > Supporting the staff standing side by side at the point of need
- > Empowering staff to deliver a high standard of care
- > Role modelling clinical and effective communication skills
- > Formed strong links with CCG
- > Became integral to other stakeholders (eg NHS-funded care, safeguarding teams, community services)
- > Building relationships with clinical hospital-based teams as well as community-based teams
- > Involvement in region-wide projects (eg integrated care organisation)

Results

- > Engagement from all homes, including those whose residents have specific cultural and religious needs
- > 90% of care home residents who died in January 2018 had a completed advance care plan
- > Results from a bereavement questionnaire illustrated an improvement in the quality of end of life care
- > In one quarter, 88 residents died; 75% of these died in the care home, and 81% were supported by the team.

Top tips

- > Strong links with care home management and primary care
- > Flexibility and reactivity within the team
- > Collaboration with stakeholders
- > Data collection to evidence impact
- > Form strong relationship with local CCG

Point of contact

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Summary

During our research, we identified that the timely, honest conversations about their future that patients want are not happening. Many physicians do not feel confident to initiate these conversations, to handle prognostic uncertainty or to discuss decisions about care and treatment that balance duration and quality of life.

Currently, attitudes within the profession and a culture of targets and pressure within our healthcare system do not support physicians to easily prioritise proactive conversations in clinic or on the ward.

Yet, these discussions are fundamental to effective clinical management plans, part of being a medical professional⁵⁸ and align with the aspirations of the RCP's Future Hospital Commission Report.⁵⁹ Given the increasing proportion of people living with one or more long-term condition, it is more important than ever that we do not shy away from these conversations. This is a challenging problem: it requires doctors, medical systems and societal attitudes to change.

This report begins to highlight and challenge professional reluctance to engage in conversations with patients about uncertainty, treatment ceilings, resuscitation status and death; we offer some 'mythbusters' to get physicians thinking; and we offer signposts to tools and educational resources to support physicians and other healthcare professionals. Getting care right at the end of life is a fundamental and important part of our work as physicians, a key component of Our Future Health and a skill set that will be increasingly relevant in our ageing population.

On the following pages are some recommendations that should help individual physicians and the wider healthcare system to take this forward. ■

Recommendations

Recommendations for physicians

- > All healthcare professionals reviewing patients with chronic conditions, multiple comorbidities or terminal illness should initiate and encourage shared decision making, including advance planning of care in line with patient preferences ('advance care planning'). This can and should be addressed in outpatient clinic, as well as on the wards.

- > All specialties treat and care for people who may be sick enough to die; therefore, it is the responsibility of all physicians to drive improvements in end of life care.

- > 'End of life' marks the last phase of life, which may be many months or sometimes years. Conversations about the future can, and should, be initiated at any point; they do not need to wait until the last weeks to days of life. When future loss of mental capacity is anticipated, early conversations become more pressing and physicians need to be proactive in initiating them.

- > A conversation is a process. Any professional at any time in the patient's healthcare journey, regardless of whether they are in the community, primary, secondary or tertiary care, should engage with a willing patient. It is not a one-off, tick-box event.

- > Conversations do not have to reach 'a conclusion' within the same sitting. There may need to be a number of discussions before any firm decision is made, and encouraging a patient to think about their preferences does not always need to end with a written plan. Documenting how far the dialogue has reached each time, eg in the notes, discharge summary or clinic letter, enables the threads of that conversation to be picked up next time, even if by somebody else.

- > Hospital physicians must ensure that such conversations begun in hospital clinics or prior to hospital discharge are communicated to a patient's GP in a timely way, to be picked up and explored further if necessary.

- > If you are unsure whether to have the conversation at all, ask the patient if it is something they would like to discuss and how much information they want. Even if they don't wish to discuss it at this point, you will have planted the seed to make it easier for them to raise the subject when they are ready.

- > Be aware of the language you use with patients, their loved ones and other professionals. Palliative care is not 'doing nothing'. There is no 'ceiling of care', and healthcare professionals never stop caring. The focus of care is to avoid the harms of futile, inappropriate or unwanted treatments and to help patients live as well as they can for as long as possible.

- > Ensure that all the relevant people take part in conversations about the future; this will depend on individual patient preference, but involving family/ friends, carers and health and care professionals from other sectors should be considered.

- > Consider using a structured tool, such as the ReSPECT process,⁶⁰ to support conversations and documentation.

- > Avoid giving erroneously precise prognoses.

- > Use local quality improvement approaches to get this right.

- > Consider including reflection in your mortality and morbidity meetings:
 - ~ was this death expected?
 - ~ were the patient's priorities for end of life care (such as place of care and death) known?
 - ~ were they adhered to?
 - ~ were there missed opportunities for advance care planning?
 - ~ could feedback from the bereaved inform practice in your department?

- > Offer feedback to team members, particularly junior doctors leading these conversations for the first time. Consider a structured workplace-based assessment using the Second Conversation Project tool.

- > Consider reading *Being mortal* by Atul Gawande and *With the end in mind* by Kathryn Mannix as part of your commitment to professional development in end of life care. ■

Talking about it really helps manage emotions – not holding it inside actually makes me feel better. I want honest answers to difficult questions. Claire, a patient with metastatic breast cancer

Recommendations for the wider healthcare system

- > Alongside evolving progress towards person-centred care, greater priority needs to be given to training, practice and support of undergraduate and postgraduate physicians to enable them to better discuss prognosis of life-threatening conditions and future options with patients and their loved ones.
- > Time needs to be allowed within outpatient clinic and ward rounds to allow physicians to hold and to document these important discussions. These conversations need to be valued in the same way as a physical therapeutic intervention.
- > Well-evaluated advance care planning tools and standardised processes and documentation for treatment plans, including CPR decisions, need to be promoted for use pan-region or nationally in the future, to reduce confusion and replication between sectors.
- > The RCP promotes the use of the ReSPECT process⁶⁰ to support advance care planning.
- > The RCP supports the implementation of the Ambitions for Palliative and End of Life Care⁶ as a national framework for local improvements.
- > It is also vital to invest in services, particularly community nursing and social care, to meet patients' evolving needs and to support those who care for them.
- > A public awareness campaign is needed to demystify some of the myths, fear and culture surrounding the end of life. ■

Extending death is worse than extending life.

Acute medicine registrar

Advance care plans are like birth plans. It's about the process and having the conversation. Things might not go to plan and people can change their minds.

Palliative medicine consultant

The best physician is the one who has the providence to tell to patients according to their knowledge the present situation, what has happened before, and what is going to happen in the future. Hippocrates

Resources

NICE (National Institute for Health and Care Excellence) guidelines – End of life care for adults

www.nice.org.uk/guidance/QS13

This quality standard covers care for adults approaching the end of their life. This includes people who are likely to die within 12 months, people with advanced, progressive, incurable conditions, and people with life-threatening acute conditions.

www.nice.org.uk/guidance/ng31/chapter/Implementation-getting-started

There are also NICE guidelines on improving care for people who are in their last days of life.

General Medical Council (GMC) guidance

www.gmc-uk.org/ethical-guidance/ethical-guidance-for-doctors/treatment-and-care-towards-the-end-of-life

This guidance includes advice on topics such as:

- > making decisions with patients who have mental capacity
- > what to do if your patient doesn't have mental capacity
- > assessing the overall benefit of treatment
- > advanced care planning
- > meeting a patient's nutrition and hydration needs
- > CPR
- > the role of relatives, partners and others close to the patient
- > organ donation and care after death.

Decisions relating to CPR

www.resus.org.uk/dnacpr/decisions-relating-to-cpr/

Guidance from the British Medical Association, the Resuscitation Council (UK) and the Royal College of Nursing (previously known as the Joint Statement), updated 2016.

Talk CPR

<http://talkcpr.wales/>

These training tools encourage conversations about CPR for people affected by life-limiting and palliative illnesses.

ReSPECT: Recommended Summary Plan for Emergency Care and Treatment

www.respectprocess.org.uk/

ReSPECT is a process that creates personalised recommendations for a person's clinical care in a future emergency in which they are unable to make or express choices. It provides health and care professionals responding to that emergency with a summary of recommendations to help them make immediate decisions about care and treatment. ReSPECT can be complementary to a wider process of advance/anticipatory care planning.

The plan is created through conversations between a person and their health professionals and is recorded on a form. It includes their personal priorities for care and agreed clinical recommendations that could help to achieve the outcome that they would want, that would not help, or that they would not want.

ReSPECT can be for anyone, but will have increasing relevance for people who have complex health needs, people who are likely to be nearing the end of their lives, and people who are at risk of sudden deterioration or cardiac arrest.

Gold Standards Framework – Proactive Identification Guide

www.goldstandardsframework.org.uk/pig

This framework aims to enable the earlier identification of people nearing the end of their life who may need additional support. This includes people following the three main trajectories of illness for expected deaths – rapid predictable decline, eg cancer; erratic decline, eg organ failure; and gradual decline, eg frailty and dementia. Additional contributing factors when considering prediction of likely needs include current mental health, comorbidities and social care provision. It uses the surprise question: 'would you be surprised if your patient were to die in the next 12 months?'

There is mixed evidence to support this tool, with high false-positive rates in non-cancer patients; however, evaluation suggests that patients still benefit from the personalised care planning.⁵⁴

SPiCT: Supportive and Palliative Care Indicators Tool

www.spict.org.uk/

This tool aims to identify people with one or multiple advanced conditions who are at risk of deteriorating and dying. It offers case-by-case assessment and advice on communication and how to record plans for holistic, palliative care needs.

On evaluation, 50% of patients identified by this tool were still alive after 12 months, so its positive predictive value has been called into question by some.⁵⁵ It is better used as a guide to recognising that somebody has an advanced progressive illness, rather than as a prognostication tool.

AMBER care bundle

www.ambercarebundle.org/homepage.aspx

- > Assessment
- > Management
- > Best practice
- > Engagement
- > Recovery uncertain

AMBER is a hospital tool for managing uncertain recovery over the next 2 months. It has been shown to improve multiprofessional team decision making, give clarity around patient preferences and reduce readmission rate.

Serious Illness Conversation Guide

www.talkaboutwhatmatters.org/documents/Providers/PSJH-Serious-Illness-Conversation-Guide.pdf

This structured conversation guide, produced by the US Serious Illness Care Programme (www.ariadnelabs.org/areas-of-work/serious-illness-care/team/),⁵⁶ has flowcharts and patient-tested language to help start difficult conversations. There is now also a UK-based, NHS England-funded pilot.⁵⁷

The Second Conversation Project

www.rcplondon.ac.uk/projects/second-conversation-improving-training-around-end-life-care-conversations

This tool encourages junior clinicians to return to a conversation started by their seniors. It gives patients, carers and family members the time and space to reflect on information they have received, while providing doctors in training with a valuable educational opportunity that builds their skills and confidence in handling end of life care discussions.

E-learning programme: End of Life Care for All (e-ELCA)

www.e-lfh.org.uk/programmes/end-of-life-care

This e-learning programme aims to enhance the training and education of the health and social care workforce so that well-informed, high-quality care can be delivered by confident and competent staff to support people, wherever they happen to be.

Ambitions for Palliative and End of Life Care

<http://endoflifecareambitions.org.uk/>

This is a national framework for local action 2015–2020 to promote high-quality end of life care. The website is being developed into a knowledge hub of resources, such as assessment tools, useful information, best practice examples and case studies.

Deciding Right

www.necn.nhs.uk/wp-content/uploads/2014/05/Deciding-Right-v28-7May-20152.pdf

This range of guides and learning materials is available to help organisations, teams and individuals to understand the principles of key issues in end of life care:

- > advance care planning
- > Mental Capacity Act
- > CPR decisions
- > advance decisions to refuse treatment
- > emergency health care plans
- > Deprivation of Liberty Safeguards.

The Point of Care Foundation QI Collaborative on End of Life Care

www.pointofcarefoundation.org.uk/event/sweeney-programme-collaborative-improving-the-experience-of-patients-at-the-end-of-life-and-their-families/

The Sweeney programme is a patient-focused quality improvement collaborative to improve the experience of patients at the end of life and their families. The Point of Care Foundation will work with NHS teams to equip them with skills and support to carry out patient-centred service design to improve care at the end of life. ■

References are available online at:
rcplondon.ac.uk/talking-about-dying



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