



CARING FOR
PATIENTS
NEARING THE
END OF LIFE

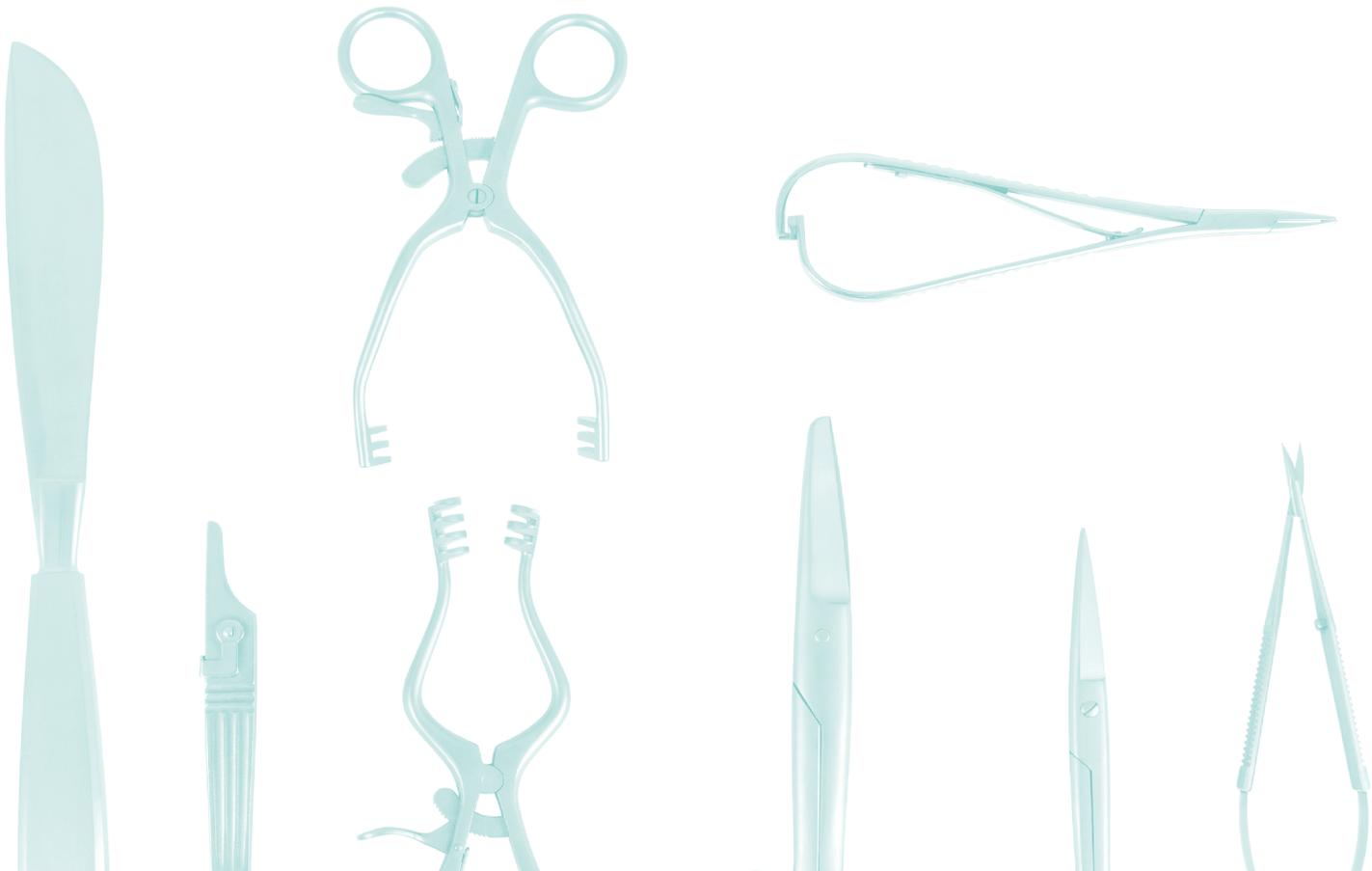


Royal College
of Surgeons

ADVANCING SURGICAL CARE

CARING FOR PATIENTS NEARING THE END OF LIFE

A Guide to Good Practice



The document was developed with the contributions of:

Miss Susan Hill
Mr Peter Lamont
Miss Clare Marx
Ms Katerina Sarafidou
Professor Keri Thomas
Miss Victoria Twigg

The College would like to thank Miss Victoria Twigg for drafting the document.

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Foreword

*‘To cure sometimes, to treat often,
to comfort always’.*

Hippocrates

I greatly welcome this new guidance from Royal College of Surgeons, applaud its intention and hope it may embolden and resource surgeons to play their part in caring for all those in their final years of life. It marks a line in the sand, in recognition of the subtle complexity and importance of care for those nearing the end of their life, and reaffirming the vital and irreplaceable role of surgeons in this care.

Surgeons play a crucial role in caring for people approaching the end of their lives. While patients are under your care, your guidance, your decisions, your technical expertise and your words of support are critical and have a huge impact on the care of people at this most important time. Yet sometimes it is easy to forget the wider context of these decisions within the person’s life beyond the hospital doors, their particular context, personal priorities and their own trajectory of illness. And perhaps on occasions, amidst the importance of correct surgical practice and technical expertise, the human element of care for the person beyond the patient can be overlooked. Your surgical expertise is vital but also your words of comfort and care will be appreciated and remembered for years to come.

Doctors can sometimes see death as failure but, in fact, the truth is that death in itself is not failure but a bad death can be. A surgeon’s care extends beyond his or her technical ability with the scalpel, important as that is, to care for the person behind the patient. This includes guidance as to when surgery is not necessarily the right decision towards the end of life (see Appendix 2), and when it might be right in the context of palliation or as prioritised by the patient,

while retaining that sense of perspective, humanity and support that is core to best medical practice.

Why is this so important now? The startling figure is that on average one in three hospital patients are in their last year of life,¹ even though many will not die on your wards, but later at home, care home or elsewhere. About half of all patients die in hospital,² most have 2–3 admissions in the final year of life and along with increasing longevity, mortality rates are set to rise by 25% by 2040. This has a real impact on the decisions for optimal care when seen as part of the wider context, not in withdrawing any particular treatments but in determining what may be best for this person to ensure quality of life in their remaining time. It is not about giving them less, but may be actually about offering them more, but different, care. With the end of the single disease era,³ with increasing longevity, cumulating complexities of frailty dementia and multi-morbidities along with increasing availability of possible interventions, this is a good time to reconsider and reframe care for people in the last years of life and the vital role of surgeons.

The term ‘end of life care’ is defined as care for people in the last year of life, rather than just the last days of life,⁴ and this is about 1% of our population as a whole, but 30% of people in hospital. In our experience through our GSF work in over 80 hospitals,⁵ every single ward has some patients in their final year of life, with audits showing an average of 9–35% on surgical or orthopaedic wards who die within the year, and about two thirds on care of the elderly, stroke or oncology wards and in community hospitals.

¹ Clark D, Armstrong A, Allan A, et al. Imminence of death among hospital inpatients: prevalent cohort study. *Palliat Med* 2014; **28**(6): 474–479.

² Public Health England National End of Life Care Intelligence Network: www.endoflifecare-intelligence.org.uk/home (cited August 2018).

³ Tinetti M, Fried T. The end of the disease era. *Am J Med* 2004; **116**: 179–185.

⁴ See, for example, General Medical Council. *Treatment and Care Towards the End of Life: Good Practice in Decision Making*. London: GMC

⁵ Gold Standards Framework. Acute Hospitals Training Programme. www.goldstandardsframework.org.uk/acute-hospitals-training-programme (cited August 2018).

Lifespan now exceeds health span, and although many age wonderfully, for some quality of life can diminish. Peoples' priorities can change as they near the final stage of their life, with a shifting balance of focus from cure to care, from life-extending heroics to life-sustaining comfort; from 'What's the matter with me?' to 'What matters to me?'. With potential over-medicalisation as access to complex interventions increases, we face a new tipping point in care for people towards the end of life: just because we can, doesn't mean we should. There is now a delicate balancing act in orchestrating appropriate care, avoiding both over-use of interventions and under-provision of care and support.

So what can surgeons do? A few constructive suggestions are included here and later in this guidance.

First, we need to face mortality, acknowledging that we are frequently dealing with seriously ill patients, many of whom are in their last chapter of life, and that recognising this can be a positive step towards helping them live out this final stage of life as well as possible. Many older people welcome such honesty, gently offered, as their fears may be even worse than the reality, although for others this can be too much to handle and denial can be their way of coping. But it is likely that for everyone, especially younger patients, such reconfiguring takes time to sink in – from being a person who will live forever to someone whose life is limited. If we can be more proactive and recognise potential decline earlier, to allow people (if they choose to consider this) more time and space to realistically clarify wishes, plans and preferences, which might often include less time in hospital and more at home, with consequent economic implications,⁶ then possibly better life decisions might be made. It is our experience working with care homes residents, that they would often choose fewer interventions and 'heroics' and more comfort care, given the opportunity to express their choice. Studies of renal patients suggest that many prefer to live with 'realistic hope' rather than delusions of false affirmations, and such discussions can in fact increase not decrease the sense of hope.⁷

So is it possible to identify patients earlier? Although prognostication is intrinsically difficult and flawed, current evidence suggests it is possible to anticipate decline earlier than we are currently doing and to identify more patients in their last year of life,^{8, 9} using tools such as the GSF Proactive Identification Guidance.¹⁰ So, somehow, wherever possible, (and it is not always possible during the crises of emergency surgery) it would be helpful to identify patients earlier, recognise possible decline, create a 'pause button' in the rollercoaster of care and help create space to consider the appropriateness of surgical interventions, enabling patients and families to discuss the best way forward in their final stage of life.

Second, earlier identification can lead to more proactive needs-based care, including initiating or signposting these important 'advance care planning' discussions of their priorities and wishes, putting the person at the centre of care, to enable them to live out the final stages of their life in the way that's right for them. This could also possibly prevent some understandable family conflicts and pressures, as some family members urge further surgical treatment at all costs.

These discussions are not necessarily just with you as surgeons – in fact, it might be a relief to hear that quite often you might not always be the right people to have very in-depth discussions. Surveys suggest that most people wish to have such discussions within a longer relationship, such as with their GP, physician or nurse involved in their long-term care and when that are back in the safety of their home. However, your recognition of the seriousness of their condition could be the first step in triggering this discussion and alerting others, leading to more open conversations with family, carers, or other healthcare provider, who can help clarify preferences that determine future decision making. But your role in horizon-scanning, initiating and triggering this discussion is of great importance.

⁶ Dixon J, Matosevic T, Knapp M. The economic evidence for advance care planning: systematic review of evidence. *Palliat Med* 2015; **29**(10): 869–884.

⁷ Davison SN, Simpson C. Hope and advance care planning in patients with end stage renal disease: qualitative interview study. *BMJ* 2006; **333**: 886.

⁸ Milnes S, Orford NR, Berkeley L *et al*. A prospective observational study of prevalence and outcomes of patients with Gold Standard Framework criteria in a tertiary regional Australian hospital. *BMJ Support Palliat Care* 2015; pii: bmjcare-2015-000864.

⁹ Thomas K, Armstrong Wilson JA, Tanner T. 1. Evidence that use of GSF improves early identification of patients in different settings. GSF Update on Evaluations and Evidence no. 1, Sept 2016. <https://tinyurl.com/h8xvpkz> (cited August 2018).

¹⁰ Gold Standard Framework. *Proactive Identification Guidance*, 6th ed. Shrewsbury: GSF; 2017. www.goldstandardsframework.org.uk/PIG (cited August 2018).

Advance Care Planning (ACP) is now an internationally recognised concept and process that is gaining weight in every developed country.¹¹ The new international consensus definition of ACP helpfully clarifies its aims as being more to do with ensuring people receive care consistent with their values, goals and preferences. Further resources and videos that stimulate discussions can assist eg 5 Steps to ACP,¹² Dying Matters¹³ and evidence confirms the positive experience of others, reduction of family distress¹⁴ and economic benefits¹⁵ of such advance care planning discussions.

Third, this guidance affirms the continuing role of surgeons even when further surgery is not appropriate, and the need for continued active supportive care of the person. 'End of Life Care is everybody's business'¹⁶ and it is important that surgeons feel confident in their non-surgical contributions and play their part to the full. No longer is it right for a surgeon to pass by the bed of a dying patient because they are under the care of the palliative care team or they feel there is little more surgically that can be done. Where appropriate, this could also include referral to palliative care specialist advice, but if a third of all patients are in the last year of life, most care will be provided by the usual hospital team. In our experience palliative care specialists might only be able to see about 12% of those in their last year of life, while about 88% of all hospital patients would be under the care of generalists, including surgeons. Teamwork with nurses and other colleagues and seeking views of the wider MDT are important here. In our experience, we find, supported by the wider nursing teams, that surgeons can give excellent care and guidance for people in their last stage of life, recognising the importance of continued care beyond invasive surgical interventions.

And finally, end of life care has been said to be a litmus test for our society. As doctors we meet death and dying more often than most. Premature death can be particularly distressing for all and reducing avoidable deaths will always be critical. We must never deny the possibility of life conserving treatments to people at any age and yet for some the 'be-tubed, pyjama-ed' highly medicalised inpatient existence is a diminished life – which option might we consider for our own parents or even ourselves?

Maintaining compassionate care, ensuring we bring our humanity to work, can be tough at times but ensures a deeper connectedness and also leads to greater personal and job satisfaction. It is hard sometimes to find the right words, and yet something important can be transmitted in other ways– the personal human touch is never wasted and always valued. Life for many is measured less in quantity of time but more in quality of life lived, and it is our responsibility to ensure this is as good as possible.

In the light of current and future challenges, with a reframed, population-based yet person-centred approach to this area, meeting the challenges of the 21st century, facing our mortality, we can affirm the importance of living well to the very end and when the time comes, dying well too.

This guidance is a crucial step forward in achieving this.

'You matter because you are you, and you matter to the end of your life. We will do all we can not only to help you die peacefully, but also to live until you die'
Dame Cicely Saunders

**Professor Keri Thomas OBE MB BS MRCGP
DRCOG, MSc Pall Med**

Founder and Clinical Lead for the National Gold Standards Framework Centre in End of Life Care and Hon Professor End of Life Care University of Birmingham

¹¹ Thomas K, Lobo B, Detering K, eds. *Advance Care Planning in End of Life Care*, 2nd ed. Oxford: Oxford University Press; 2017.

¹² Gold Standards Framework. Advance Care Planning in 5 Simple Steps [video]. www.goldstandardsframework.org.uk/advance-care-planning (cited August 2018).

¹³ Dying Matters. www.dyingmatters.org (cited August 2018).

¹⁴ Detering KM, Hancock AD, Reade MC, Silvester W. The impact of advance care planning on end of life care in elderly patients: randomised controlled trial. *BMJ* 2010; **340**: c1345.

¹⁵ Dixon J, Matosevic T, Knapp M. fn6.

¹⁶ Prof Sir Bruce Keogh, Former Medical Director NHS England. NHSE End of Life Care Strategy Board.



A. Introduction

‘Good surgeons know how to operate, better surgeons know when to operate, and the best surgeons know when not to operate’.

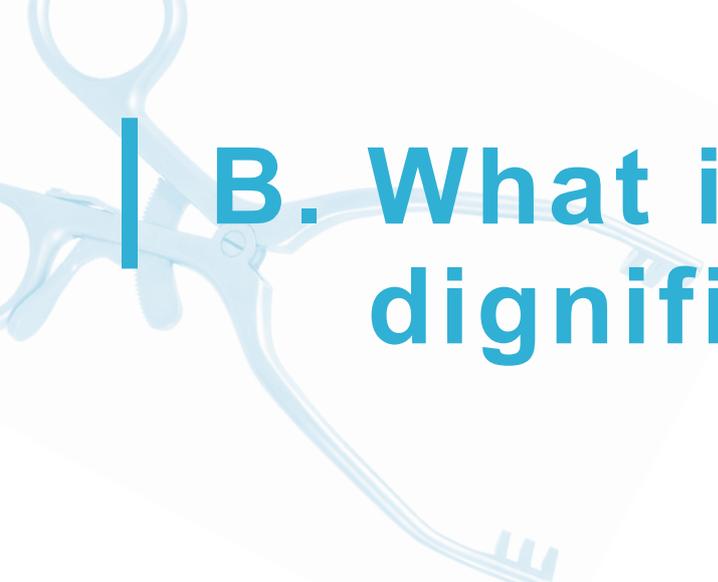
Dame Clare Marx, Past President of the RCS

Providing end of life care is a duty for all registered medical practitioners. Many doctors and perhaps surgeons in particular find this care a difficult and onerous duty. Instinctively we feel that we should be doing all in our power to preserve life.

Nevertheless, death is finally inevitable for us all and there comes a time when extending life through surgery or other therapeutic intervention is not in a patient’s best interests. Often attempts to prolong life can have a negative effect on its quality. Such considerations are relevant not only for older patients nearing the end of their life. Even when the patient is a younger person, the quality of time they have left may be more important to them than prolonging their life.

WHAT CAN I LEARN FROM THIS GUIDE?

This document provides advice, guidance and support to surgeons and service providers on many important aspects of end of life care. Most importantly, it covers the steps surgeons can take to ensure that patients nearing the end of life experience a ‘dignified death’. It covers a framework for communication and decision making, the important care planning documents in use at the end of life and how to work together as a team to ensure high-quality end of life care.



B. What is a dignified death?

Adapted from: National Palliative and End of Life Care Partnership's *Ambitions for Palliative and End of Life Care: A National Framework for Local Action 2015–2020*;¹ and Leadership Alliance for the Care of Dying People's *One Chance to Get it Right*.²

We all only get one death. Surgeons can help to ensure that when the time comes their patients experience a dignified death, in line with their wishes, preferences and beliefs, just as we would wish for ourselves or our loved ones.

For patients that may be nearing the end of their life, decisions should be made early as to whether or not to undergo surgical or other interventions. These decisions should be made by the patient in conjunction with their healthcare team.

The appropriateness of high intensity treatments, escalation of treatment and admission to intensive therapy wards should be discussed. The dying person's wishes must take priority and should be regularly reviewed and revised.

The patient's wishes should be clearly documented so that all members of the healthcare team are aware of them and care is well coordinated. Each patient's care should be individualised and delivered with dignity and compassion; it should include consideration of nutrition, hydration, symptom control and psychological, social and spiritual support.

Once a patient has died, their bereaved friends and family should be provided with support appropriate to their needs.

C. Definition and recognition of the end of life

DEFINING 'END OF LIFE'

There can be confusion about the term 'end of life care'. Patients in the last 12 months of life meet the common definition for 'end of life',³ although the term is often used on the ward to denote care in the final days of one's life.

The scope of this guidance includes both:

- care for people who are likely to die within 12 months
- care for people in the final days only – the imminently dying.

Clarifying terms can be important, especially in conversations with patients and families. Nevertheless, both possible death in the coming months and weeks and imminent death are often very difficult to predict. In some people, conditions that will end their life begin many years before the end, whereas for others end of life care may start only in the preceding seconds, minutes or hours before death. Preparation for death will clearly differ between an individual who has been given a terminal diagnosis where a chronic course is expected and a patient presenting with an acute unsalvageable catastrophe.

RECOGNITION OF THE 'END OF LIFE'

Recognising that a patient is approaching the end of their life can be difficult and not just for surgeons; the patient themselves may not realise their situation and may need to be made aware of it in a compassionate way. This recognition is important to allow patients to plan the final stages of their life, including appropriate decisions about their treatment.

Surgeons may use the surprise question as guidance when considering whether a patient may be nearing the end of life, as pioneered by the Gold Standards Framework *Proactive Identification Guidance*:⁴

'Would you be surprised if this patient were to die in the next few months, weeks, days?' is a useful starting point.

Good Medical Practice recommends the following range of situations to guide when end of life care should be considered:⁵

- a. advanced, progressive, incurable conditions
- b. general frailty and co-existing conditions that mean death is expected within 12 months
- c. existing conditions where there is a risk of dying from a sudden acute crisis in that condition
- d. life-threatening acute conditions caused by sudden catastrophic events.

Surgeons should be familiar with the specific clinical indicators that patients are likely to be in their last year of life, available from the *Proactive Identification Guidance*⁴ or the Supportive and Palliative Care Indicators Tool⁶ for cancer, organ failure and frailty/dementia, to guide the discussions that they have with patients or their supporters about care.

D. Communication with patients and decision-making at the end of life

Guidance is based on: the General Medical Council's *Good Medical Practice*;⁵ *Treatment and Care Towards the End of Life: Good Practice In Decision Making*;⁷ the Royal College of Surgeons of England's *Good Surgical Practice*;⁸ and *Consent: Supported Decision Making A Guide to Good Practice*.⁹

The following guidance should be used by surgeons looking after patients at the end of life. Decisions may be needed not only over when to and when not to operate or when to and when not to admit to intensive care, but also when to stop and start other treatments such as antibiotics and cardiopulmonary resuscitation.

Decision making must be in line with the *Mental Capacity Act 2005*.

PATIENTS WITH CAPACITY

Where patients have capacity, the decisions they make about the care they receive should be facilitated by the surgeon, including decisions about the end of life. Surgeons should make an assessment of the patient's priorities before discussing the potential investigations and treatment available to them.

The surgeon should explain:

1. The likely/known diagnosis, prognosis and course of the condition.
2. Lifestyle changes that may moderate the disease process.
3. The right of the patient to refuse treatment and to make their own decisions about their care.
4. The possible options, including the benefits, burdens and risks of each option. There should be a focus not only on the procedural risks but also on the associated functional outcomes and how these outcomes may align with the patient's priorities. There should be a discussion about:

- the purpose and expected benefit of the treatment options
- the nature of the treatment
- the likelihood of success
- the clinicians involved in the treatment
- potential follow up treatment
- the option not to undergo treatment.

It is important for surgeons to note that patients should be made aware of all risks and benefits that may be material to them for all treatment options, in line with the Montgomery ruling and explained in further detail in *Consent: Supported Decision Making*.⁹

Of particular note in decisions that may involve hastening or delaying the end of life, patients must be made aware that they can withhold their consent or change their mind about treatment at any time, but in time-critical conditions this may change their prognosis and the options available to them because of the nature of the disease process. A patient with capacity has the right to refuse a treatment without reason, even if this may be dangerous or fatal, and this refusal must be respected by the surgeon.

Surgeons must not assume that patients will have the same set of values, wishes or life priorities as the surgeon would have in a similar situation and the patient's views must be respected. Time should be taken to learn and understand the priorities of the patient, which may affect their treatment choice. Surgeons should encourage discussion of the options with supporters, but must be sure that any decision the patient makes is voluntary and is not coerced either by the supporters or by the surgeon.

In cases where life may be threatened, it is important for the surgeon to ascertain whether the patient has made any advance care plans, advance statements, advance decisions to refuse treatment or has appointed someone with a lasting power of attorney. Where the patient has not made any of these advance arrangements, they should be sensitively urged to consider what care they may prefer should they lose capacity in the future and to communicate these preferences to the surgeon. The patient's wishes should be well documented and shared with any other healthcare professionals involved in the patient's care with the patient's permission.

PATIENTS WHO LACK CAPACITY

If a patient lacks capacity to make a decision, despite the best efforts being taken by the healthcare team to maximise their ability to understand, retain, use or weigh up information to make a decision and communicate their wishes, the surgeon should act in the best interests of the patient. The decisions that you or others take on the patient's behalf must be based on whether the treatment would have overall benefit to the patient.

In the situation where the patient lacks capacity, decisions over end of life care can be challenging, particularly so if such decisions affect the quality of the patient's remaining life. Ultimately, the decision for what is in the best interests of the patient lies with the treating clinician, but this decision should be informed by considering what you know of the patient's preferences. You should consult the opinions of other healthcare professionals who know the patient well in addition to supporters such as relatives, friends and carers of the patient. In England and Wales, if there is no one willing or able to represent the patient, an Independent Mental Capacity Advocate (IMCA) must be appointed to do so as required by law (Mental Capacity Act 2005).

If you or another health care professional have discussed with the patient their preferences for end of life care, you must refer to these preferences. Of particular importance are any advance care plans, advance statements, advance decisions to refuse treatment or lasting powers of attorney. These will be addressed in more detail in section E.

The steps that you should take in reaching your decision, based on guidance provided by the General

Medical Council's *Treatment and Care Towards the End of Life: Good Practice in Decision Making*,⁷ are as follows.

1. Be clear which decisions about treatment and care have to be made.
2. Check the patient's notes for any information about whether the patient has made a potentially legally binding advance statement or advance decision to refuse treatment or has appointed a lasting power of attorney. An advance care plan, made when the patient had capacity, is useful to guide clinicians on what the patient's preferences may be and should be used to inform decisions regarding treatment that is in the patient's best interests.
3. You should make enquiries of healthcare professionals and supporters to ascertain whether any of the above documents exist or if the patient has appointed a lasting power of attorney. The office of the public guardian keeps records of the latter. If so, you should bear in mind that the lasting power of attorney may not have the power to make decisions for all aspects of healthcare. If there is an appointed lasting power of attorney with the power to decide the matter at hand, you should explain all of the options to them as you would a patient with capacity. The surgeon can offer them support, but similarly cannot pressurise or coerce.
4. When no lasting power of attorney or advance decision exists, the responsibility for decision making rests with the doctor responsible for the patient's care. You must consult an advance care plan or advance statement, if one has been made, and those close to the patient including other healthcare professionals to make your decision. You must not give others the impression that they are making the decision. Where possible seek affirmation from a consultant colleague. The decision that you make should be in the patient's best interests and align with their personal preferences, wishes and beliefs and not your own.
5. If there is no lasting power of attorney, close relative or friend who is willing or able to represent the patient, then the surgeon must approach their employing or contracting organisation to appoint an Independent Mental Capacity Advocate (IMCA). An IMCA has the power to make enquiries on behalf of the patient and contribute to the decision by representing his or her best interests, but cannot make a decision on behalf of the patient.

The surgeon should be careful in these circumstances not to rely on their personal views about a patient's quality of life and to avoid making non evidence-based and biased judgments.

As a surgeon you must ensure that your decisions are informed by your knowledge of the patient's priorities, which can be drawn from an advance care plan, previous discussions between the patient and yourself or other healthcare professionals or from those relatives, friends and carers that understood the patient's priorities and values.

All discussions that the surgeon has, including with patient's supporters and other healthcare professionals, should be clearly and contemporaneously documented in the patient's case notes.

After death, surgeons should ensure that the patient's friends or relatives have the opportunity to ask questions, that they are provided with information on sources of support and the next steps they should take, for example, in registering the death. This will likely involve directing bereaved friends or relatives to the bereavement team.

Appendix 1 provides a checklist summarising the important steps that should be taken when decision making at the end of life.

THE IMPLICATIONS OF SURGERY

Surgery near to the end of life can be appropriate either because it will provide palliation or if the patient's priority is to prolong life at all cost. But as surgeons we have a duty to ensure that these decisions are well informed, based on realistic expectations of the course of the disease and take into account the limitations of the operation. Careful deliberation is required when considering invasive treatments that will directly impede the patient's quality of life, but with no additional value to the patient.

Some serious illnesses and acute surgical conditions that put elderly patients at risk of non-beneficial surgery, which could also be relevant for those younger patients who are nearing the end of life and require extra consideration, have been highlighted in **Appendix 2**.

Surgeons have a duty to facilitate decision making in patients with capacity, and to make decisions in the best interests of patients who lack capacity. As the expert, the surgeon should present information to the patient to inform their decision in an un-coercive, realistic and understandable manner, using professional interpreters where necessary. At the end of life, providing this information can be difficult for many reasons, including making assessments of the unknown at a time of high emotion. The instinct of the surgeon is often to operate even though surgery may not always be appropriate.

There is evidence that for patients at the end of life, avoidance of aggressive interventions is associated with less physical and psychological distress at the time of death.¹⁰⁻¹² It is also important for surgeons to be aware that most high intensity treatments are not delivered in line with the patient's personal goals for the end of life.^{10,13} Realistic discussion with patients about the likely outcomes, including a description of the likely functional impact, results in fewer patients undergoing aggressive medical interventions and more patients experiencing a death in line with their personal priorities.¹⁰

Patients should be provided with an accurate picture of the likely outcome of any potential surgery with a focus on the functional states and quality of life, in addition to the expected survival rates and associated procedural risks. Surgeons should explain how the different options may align with the patient's own priorities, using their own knowledge and experience and information from the literature. Where operations are associated with a stay in intensive care, surgeons should explain what this stay involves for the patient and for their functional outcomes afterwards in a realistic manner. Different options may be acceptable for different patients, depending on their priorities, but it is important that each patient is treated as an individual and facilitated to make decisions appropriate for them.

E. Planning for care at the end of life

This section has been adapted from guidance in *Treatment and Care Towards the End of Life: Good Practice in Decision Making*⁷ and Age UK's *Advance Decisions, Advance Statements and Living Wills*.¹⁴

Surgeons should be familiar with the planning processes and documents described below that may be involved in end of life care, so that they understand their duties in acting within them as well as the guidance to give to patients and their supporters and who to seek for further advice where required.

DISCUSSING CARE WITH THE PATIENT

Discussing death is a difficult task and many people, both medical and non-medical, avoid discussions about death. Nevertheless, it is a duty for medical practitioners to discuss care sensitively with patients that may be approaching the end of life to ensure that they receive the right care for them. Advance care planning discussions are a means of clarifying the patient's wishes at the end of life.

According to the international consensus definition of advance care planning,¹⁵ it is:

'a process that supports adults at any age or stage of health in understanding and sharing their personal values, life goals, and preferences regarding future medical care. The goal of advance care planning is to help ensure that people receive medical care that is consistent with their values, goals and preferences during serious and chronic illness.'

The patient should be made aware that in making their wishes known verbally to the healthcare team responsible for their care, these wishes would be taken into account if they lose capacity to make decisions but are not legally binding.

Areas that the surgeon could discuss about future care of a patient if they lose capacity, adapted from *Treatment and Care Towards the End of Life: Good Practice in Decision Making*,⁷ include:

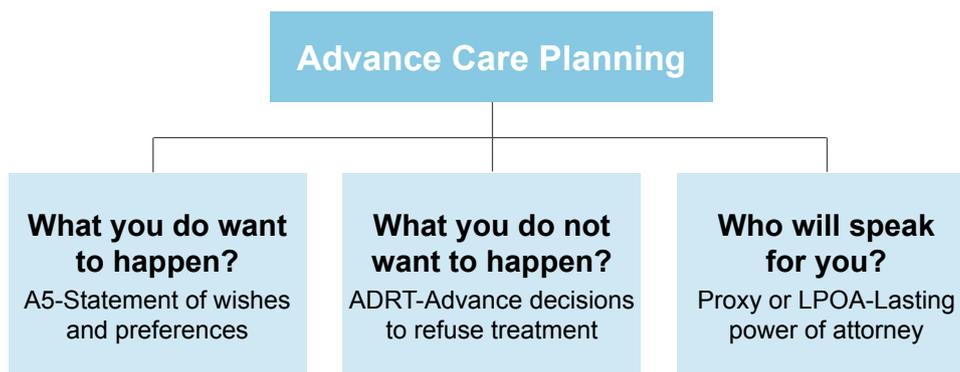
- the patient's wishes, preferences or fears in relation to their future treatment and care
- the feelings, beliefs or values that may be influencing the patient's preferences and decisions
- what elements of care are important to them and what would they like to happen in the future
- what would they not want to happen or worry about happening in the future
- what would be an unacceptable health state for the patient?

The family members, others close to the patient and if there is an appointed person with lasting power of attorney who they would like to be involved in decisions about their future care

- interventions they may or may not want to be undertaken in an emergency, eg operations, cardiopulmonary resuscitation, admission to an intensive care unit, prolonged mechanical ventilation, clinically assisted nutrition and hydration
- the patient's preferred place of care
- the patient's need for religious, spiritual or other support.

Within the Mental Capacity Act, these areas for discussion are summarised as follows:

In line with the UK Mental Capacity Act
ADVANCE CARE PLANNING DISCUSSIONS



What you do want – An advance statement of preferences – a simple discussion that is recorded and reviewed, that is not a legally binding document, but a guide to the patient’s wishes and preferences to inform later decision making including future treatment options.

What you don’t want – This can be included in the advance statement but some require specific refusal, eg with an advanced decision to refuse treatment or ADRT. This also will include resuscitation discussion or DNACPR or respect.

Who will speak for you? – This includes the nominated proxy spokesperson (not always the next of kin) or lasting power of attorney where present.

In the case where surgeons are unable to answer questions that patients may ask, for example, issues related to palliative care medications or legal documents at the end of life, they should signpost to appropriate healthcare or legal professionals with this expertise.

Where a patient lacks capacity (in the case of dementia, cognitive failure or reduced level of consciousness) and has not previously recorded their preferences, a best interest discussion is undertaken with the family or the nominated spokesperson.

ADVANCE CARE PLANS

Advance care plans are the formal documentation of the patient’s wishes, preferences and fears at the end of life, often made in conjunction with a healthcare professional. Such a plan might be known by other names such as advanced directive or living will. These are designed to be used to ensure that ongoing care takes the patient’s views into account, especially if

they lose capacity. There are several structured areas that are recorded, usually done in conjunction with a health professional in palliative care, GPs or community nursing teams. An example from the Good Standards Framework is given in **Appendix 3**.

As a surgeon it is important to know if the patient has already made an advance care plan. Where the patient has not done so and wishes to formalise their wishes, the surgeon should assist patients with making one, including direction to other healthcare professionals or sources of information where necessary.

Advance care plans are not legally binding but are a reflection of a patient’s wishes, preferences and beliefs and so should be used when the surgeon is deciding on the best interests of a patient lacking capacity.

ADVANCE STATEMENTS

An advance statement is similar to an advance care plan but is written by the patient independent of a healthcare professional and voices the patient’s wishes and preferences should they lack capacity in the future. It does not *need* to be signed by the patient and witnessed, but often is. An advance statement is not legally binding, but once again if it does exist it is a reflection on the wishes and preferences of a patient and should be taken into account when the surgeon is deciding on the best interests of a patient lacking capacity.

ADVANCE DECISION TO REFUSE TREATMENT (ADRT)

The ADRT is a written statement refusing specific treatments in future circumstances should the patient lose capacity, signed by the patient and a witness as a minimum. It is legally binding in England and Wales if it is clearly applicable to the patient's circumstances, but this has not yet been tested as case law in Scotland. For ADRTs at the end of life, they must include that the decision still applies even if life is at risk or shortened as a result and should have been updated recently to be considered truly valid (preferably within the last two years).

A valid ADRT will ensure that:

- the patient was an adult when the decision was made (16 years old and over in Scotland, 18 years old and over in England, Wales and Northern Ireland)
- the patient had capacity at the time the decision was made
- the patient was not subject to undue influence in making the decision
- the patient made the decision based on adequate information about the implications of their choice
- if the decision relates to treatment that may prolong life it must be in writing, signed and witnessed and include a statement that it is to apply even if the patient's life is at stake
- the decision has not been withdrawn by the patient
- the patient has not appointed an attorney since the decision was made to make decisions on their behalf
- more recent actions or decisions of the patient are clearly consistent with the terms of their earlier decision and there is no indication the patient has changed their mind.

If there are any concerns over the validity of an ADRT, it is advisable to seek legal advice.

Even if the ADRT does not fit the criteria to be legally binding, it should still be taken into account as a reflection of the patient's wishes and preferences by the doctor making the decision in the best interests of a patient that lacks capacity.

For further clarification, see the Mental Capacity Act 2005 and the GMC's *Treatment and Care Towards the End of Life: Good Practice in Decision Making*.⁷

LASTING POWER OF ATTORNEY (LPA), OR NOMINATED SPOKESPERSON

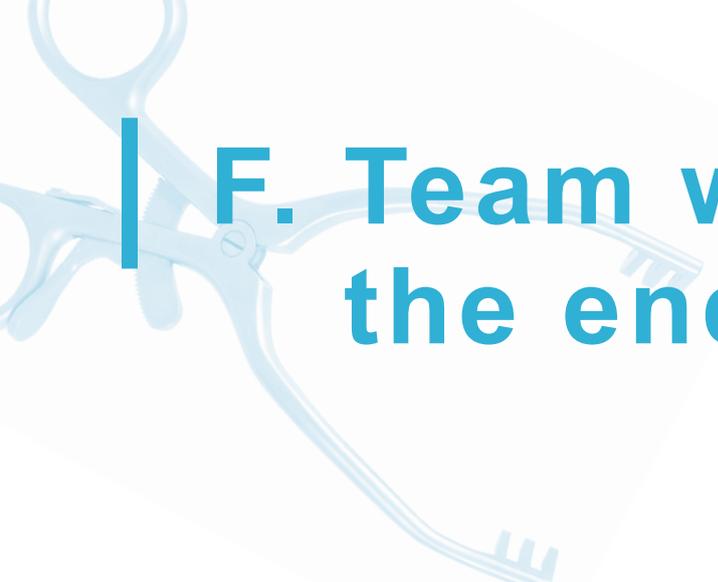
Formerly called a legal proxy, a health and welfare lasting power of attorney is a legally binding document entitling the patient, otherwise known as the 'donor' to grant an appointed 'attorney' the power to make decisions about their health and welfare should they lose capacity. It is important to note that in some cases restrictions will be in place and some 'attorneys' will not be authorised to make decisions about life-sustaining treatment. If this is the case, these decisions will be in the hands of the surgeon/clinician responsible for the patient's care to act in their best interests.

An LPA must be registered with the office of the public guardian to be valid. Surgeons should also be aware that another form of the LPA exists, which gives attorneys the power to make decisions over property and financial affairs, but not health and welfare decisions.

When communicating with an LPA, you should inform them of the risks, benefits and burdens of all available options as if they were the patient, as detailed in section C. You must ensure that you do not coerce them into making a decision.

Although the proportion of patients with LPAs is increasing, many still do not have such arrangements, so seeking and recording the name of the person they wish to nominate as their proxy spokesperson (who often might not be their next of kin) is important for future decision making. This is often included on the advance statement and within the Mental Capacity Act, such views should be taken into account.





F. Team working at the end of life

WITHIN THE IMMEDIATE SURGICAL TEAM

Non-consultant grade surgeons

As a non-consultant grade surgeon you should support patients to make decisions within the framework described in Section D with the support of the consultant surgeon responsible for the care of the patient. All significant decisions made in the best interests for patients lacking capacity should be made in conjunction with the responsible consultant surgeon, for example, decisions to undergo or not to undergo potentially life-prolonging surgery.

Consultant surgeons

As a consultant surgeon, you should provide adequate supervision and support to junior and non-consultant grade surgeons. The best interests of the patient should always be put first while facilitating the education of junior surgeons in dealing with the ethical issues faced at the end of life. You should ensure that the opinions of the team are taken into account when supporting patients with decision making. In particular, when making decisions for patients lacking capacity at the end of life, you should always seek the opinions of others involved in the care of the patient as they may have different insights into what could be in the best interests of the patient.

You should ensure that when you are not available there is a full and explicit handover for the assessment, treatment and continuing care of patients. This handover should include the patient's wishes and preferences for the end of life, where it is expected.

WITH OTHER MEMBERS OF THE HEALTHCARE TEAM

Surgeons have a duty to ensure that they communicate effectively with other members of the healthcare team to avoid fragmented care, which can be a source of frustration to those nearing the end of life. When considering appropriate treatment in the context of the likely prognosis and preferences of patients, such communication may include seeking guidance from the specialist palliative care team. However, it's important to ensure that referral to palliative care is not a replacement for continued support from surgeons and that surgeons should continue to be involved in communication and decision making.

The multidisciplinary team meeting (MDT)

For surgeons, many of the patients they see nearing the end of life may be eligible for discussion at an MDT meeting. In the context of surgery, this MDT is likely to be a cancer one but many other MDT types exist and should be used where appropriate.

In line with *The Characteristics of an Effective Multidisciplinary Team*,¹⁶ members of an MDT should be familiar with the patient's history, views and preferences when making recommendations for treatment. In ascertaining the views and preferences of the patient prior to the MDT, it is the recommendation of the RCS that advance care planning documentation can be useful to formalise these views and ensure that documentation is preserved for future decision making, should the patient lose capacity. The MDT should also ensure that the patient's views and wishes are documented when making recommendations. It is important that the MDT members' specialist knowledge is used when communicating the treatment options and prognosis to the patient.

The MDT can also be consulted at times where patients lacking capacity require decisions to be made in their best interests. The MDT can not only provide insight into the appropriate treatment options given the patient's condition, but also advice on what may be in the patient's best interests given their wishes, preferences and beliefs.

The wider multidisciplinary team

In many cases, a formal MDT meeting will not be the appropriate forum to discuss a patient's care and treatment options at the end of life, perhaps because of an emergency presentation or alternative diagnosis not represented by a formal MDT. The surgeon should seek to discuss the patient's case with relevant professionals to ascertain:

- the appropriate treatment options at the end of life available to the patient
- the patients' wishes, preferences and beliefs to inform their best interests.

A formal consultation with the palliative care team is particularly useful in this context but the wider team will also include anaesthetists, intensivists, physicians, care of the elderly physicians, other members of the surgical team, specialist nurses, general practitioners and any other healthcare professional that may have spent time with the patient to understand their wishes, preferences and beliefs.

Where patients have made decisions about their care, these decisions should be communicated to all healthcare professionals directly caring for the patient, so that the patient does not receive conflicting information.

Where patients are under the care of an intensive care unit or high dependency unit, surgeons should continue to participate in the care and decisions of patients.

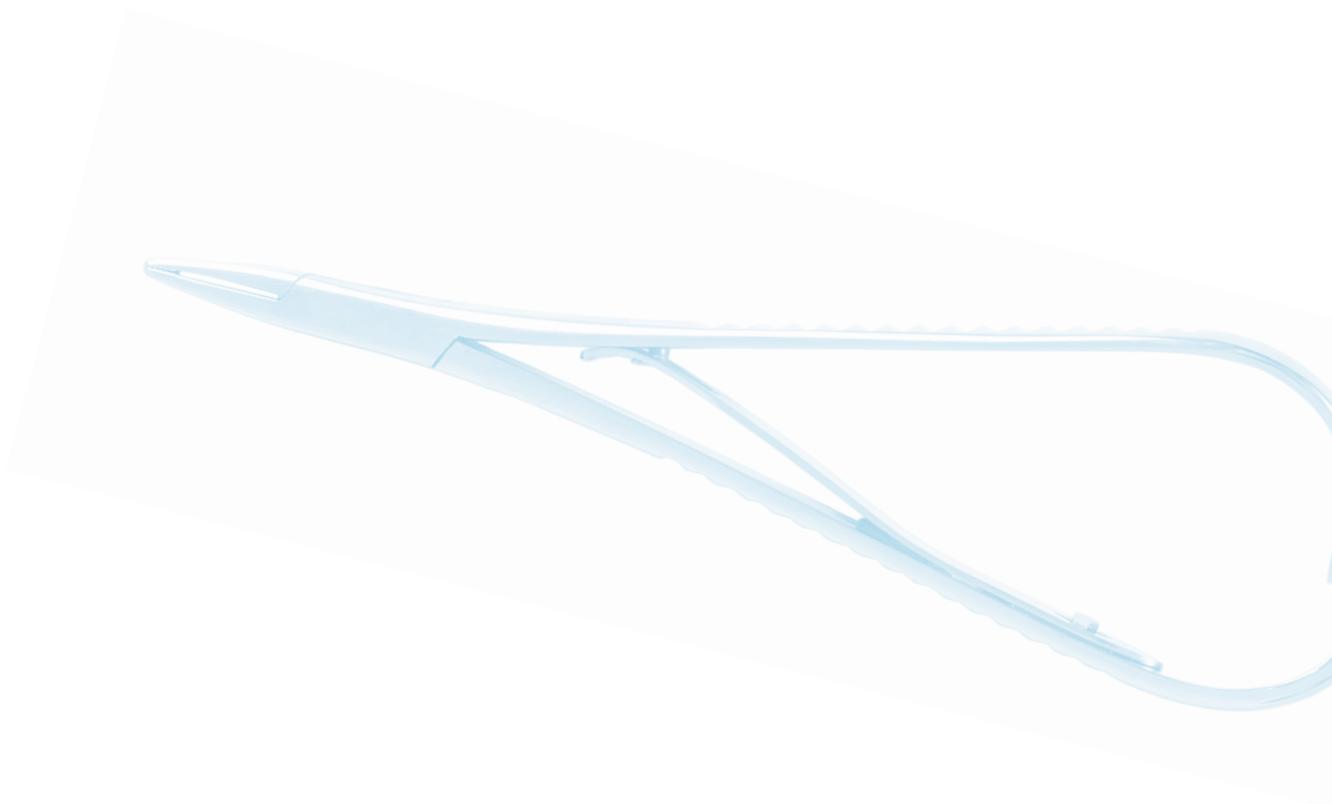
Handover

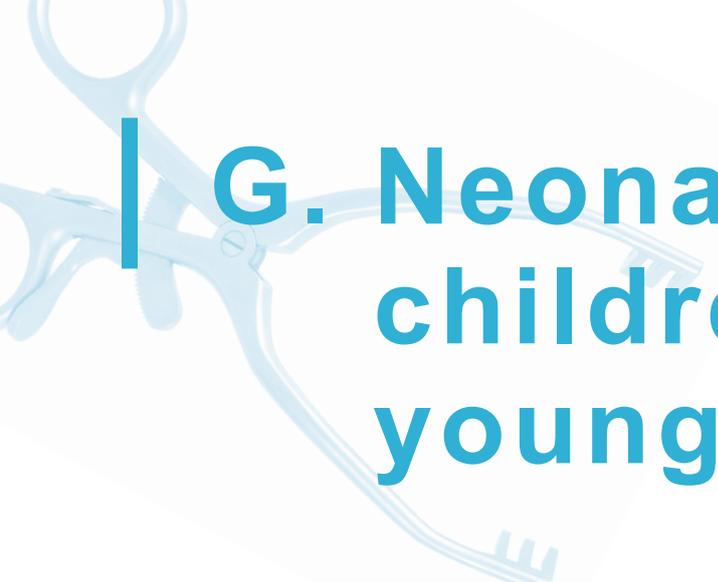
There are likely to be occasions where it is appropriate to handover the care of the patient to other teams more appropriately equipped to care for the patient given their circumstances, for instance, GPs or palliative care services. Surgeons should conduct a thorough verbal or written handover and ensure that all important information required to provide safe, effective and timely care is provided.

Surgeons should communicate with GPs and healthcare professionals in the community, with the patient's consent, to hand over important information to allow them to give the patient safe, effective and timely care. This should make use of any available electronic handover or sometimes it is appropriate for the surgeon to speak to the GP over the telephone.

Advance care plans, advance statements, ADRTs and the presence of a lasting power of attorney and DNACPR decisions should be handed over, and placed in a prominent position, clearly visible at the front of any case notes.

When patients are discharged, they are sometimes readmitted in an emergency situation. Surgeons should ensure that case notes offer a precise overview of the decisions that have been made in conjunction with the patient to guide treatment in the case of an emergency.





G. Neonates, children and young people

DECISION-MAKING AT THE END OF LIFE

This guidance is adapted from the GMC's *Treatment and Care Towards the End of Life: Good Practice in Decision Making*,⁷ *0–18 Years: Guidance for All Doctors*¹⁷ and the National Institute for Health and Care Excellence's (NICE) standard *End of Life Care for Infants, Children and Young People with Life-limiting Conditions: Planning and Management*.¹⁸

At the end of life, indeed as with other decisions over their health, decision making in children depends on their capacity to consent. All surgeons should be familiar with the available published guidance on consent in children, for example *0–18 Years: Guidance for All Doctors*,¹⁷ including the implications of Gillick competency.

If children are able to express a view, you should listen and respect this. At the end of life, children and young people should be encouraged to discuss decision making, including their wishes and preferences, which should be taken into account when deciding the child's best interests, even if they lack capacity.

TREATMENT AND CARE AT THE END OF LIFE

Similar to dealing with adult patients, the surgeon should use guidelines, where these exist, to guide treatment for patients who may be nearing the end of life and decisions on the available treatment options should be discussed with the multi-disciplinary team. The surgeon should ensure that children who may be nearing the end of life are under the direct care of a named medical paediatric consultant, who should lead and coordinate their care. Specialist paediatric palliative care teams should be able to advise on matters of palliation for neonates, children and young people, and advice should be sought where required.

PLANNING FOR FUTURE CARE AT THE END OF LIFE

Similar to adults, children, young people and their parents/supporters should be encouraged to take part in advance care planning to formalise their preferences and wishes for treatment at the end of life. Advance care plans should be shared with appropriate members of the multidisciplinary team and be easily available in the patient's medical notes.

COMMUNICATING WITH CHILDREN, YOUNG PEOPLE AND THEIR FAMILIES

When discussing care with children, young people and their parents you should ensure that the information given is provided in the most appropriate way and in a sensitive manner. Ensure that the healthcare professional discussing matters around end of life is the most appropriate person, depending on the subject matter, their expertise and ability, their availability and the views of the child, young person and their parents/carers. Bear in mind that the method of information giving may be different depending on the age and understanding of the child or young person and could involve one-to-one discussions, play, art and music, written materials, pictures and digital media.

You should support parents during the decision-making process and inform them of the part they play. It is also important to provide support to siblings who will undoubtedly be affected by the death of their brother or sister and the grieving of their parents.

H. Cardiopulmonary resuscitation

Guidance adapted from the GMC's *Treatment and Care Towards the End of Life: Good Practice in Decision Making*.⁷

Cardiopulmonary Resuscitation, (CPR) embraces all the procedures, from basic first aid to the most advanced medical interventions, that can be used to restore the breathing and circulation in someone whose heart and breathing have stopped (Resuscitation Council, 2017). The resuscitation status should be discussed with all patients at risk and the decision whether or not to perform CPR formally recorded in the patient's medical notes, with regular reviews of that status according to clinical progress.

DECISION MAKING IN CPR

When making a decision about whether a patient should be provided with CPR should their heart stop beating, it is important for the surgeon to remember that CPR is a treatment. As such, the decision-making guidelines provided in Section 2, in *Consent: Supported Decision Making*⁹ and in *Treatment and Care Towards the End of Life: Good Practice in Decision Making*⁷ should be followed, taking into account whether the patient has capacity or not.

There are two important factors in particular for surgeons to take into account.

1. If a cardiorespiratory arrest is expected to occur as part of the dying process and CPR will not be successful, this treatment does not need to be offered to the patient even if they have capacity. The surgeon should offer to discuss the decision with the patient and offer a second opinion where there is disagreement. The surgeon should also offer to discuss this decision with the patient's supporters, subject to consent of the patient with capacity or in the best interests of a patient lacking capacity.

2. In cases where CPR may be successful, the surgeon should discuss the use of CPR with the patient with capacity, or make a decision in the patient's best interests if they lack capacity (by following the steps laid out in section B, or RCS's *Consent: Supported Decision Making*).⁹ If the surgeon believes it may be successful but clinically inappropriate, they should discuss this view with the patient. If, after discussion, the surgeon still believes that CPR is clinically inappropriate, they are not obliged to offer the treatment but should explain to the patient options for their next steps, including a second opinion and legal advice.

OTHER TREATMENTS AT THE END OF LIFE IF A DNACPR DECISION HAS BEEN MADE

When a DNACPR decision has been made, the surgeon must ensure that other treatments are not withheld unless a separate decision has been made to do so. The DNACPR order applies only to CPR.

It is good practice for surgeons to review the appropriateness of other treatments such as administration of regular medication, antibiotic treatment or the appropriateness of escalation to high dependency or intensive care at this point. These decisions should be made in conjunction with the patient where they have capacity, or in line with their best interests when lacking. Where these decisions have been made, they should be well documented.



I. Clinically assisted nutrition and hydration

This guidance is adapted from the GMC's *Treatment and Care Towards the End of Life: Good Practice in Decision Making*⁷ and *Care of the Dying Adult in the Last Days of Life*.²⁰

Patients, paediatric and adult, should be encouraged to take nutrition and hydration orally and assisted to do so (eg by spoon feeding) wherever possible, even at the end of life. Where patients are unable to take food and drink orally, patients with capacity (or their LPA, if one is appointed) should be assisted in making the decision over whether they wish to receive nutrition and hydration intravenously or enterally, for example via a nasogastric (NG) tube or a percutaneous endoscopic gastrostomy (PEG) or similar.

All the risks, burdens and benefits should be explained to the patient and the decision should be regularly reviewed. In those patients lacking capacity, where no advance decision or LPA is in place, the treating surgeon should weigh up the risks, benefits and burdens and consider what is in the best interests of the patient using the framework in section B, or in *Consent: Supported Decision Making*.⁹ Advance statements and advance care plans may assist the clinician in discerning the best interests of the patient.

Surgeons must consider that clinically assisted nutrition and hydration may improve the patient's quality of life or prolong the life they have left, but may have other burdens such as discomfort or distress. These treatments should only be provided if there is overall benefit for the patient.

Please note that in the case of a patient in a persistent vegetative state for whom decisions are being made about withdrawal of nutrition or hydration, courts must be approached by the clinician responsible for the patient's care for a ruling (In England, Wales and Northern Ireland. Seek legal advice in Scotland).

J. Care in the final days of life

This guidance is based on the NICE guideline *Care of Dying Adults in the Last Days of Life*.²⁰

The following advice applies to patients in the last moments, hours or days of life.

As with all decisions, the guidance from the RCS's *Consent: Supported Decision Making*⁹ should be followed when deciding which treatments to implement. Recommendations are made to:

- identify and document when patients may be in the last days of life. Indications that patients may be entering the last days of life are;
 - agitation, Cheyne-Stoke's breathing, deterioration in consciousness, mottled skin, noisy respiratory secretions, progressive weight loss
 - fatigue and loss of appetite
 - changes in communication, mobility, performance status, social withdrawal.
- Where you have determined that the patient is dying, you should sensitively communicate this status to both the patient and, with consent, their family.
- Limit investigations that are unlikely to affect care unless there is a clinical need to do so.
- Monitor the patient for changes to their condition at least every 24 hours and update their care plan.
- Communicate with patients appropriately.
- Ensure there is a named healthcare professional responsible for the care of the patient.
- Ensure care is individualised.
- Maintain hydration where possible (see below).
- Provide appropriate non-pharmacological measures for comfort where possible eg positioning to relieve pain.
- Review medications to stop any that are not providing symptomatic benefit or that may cause harm.
- Consider alternative routes for administration of medication if an oral route is not being tolerated, eg subcutaneously or intravenous using a syringe pump where necessary.
- For symptoms such as pain, breathlessness, nausea and vomiting, anxiety, delirium and agitation review and consider treatment of reversible causes. Attempt non-pharmacological interventions first, and treat pharmacologically where persistent.
- If distressing to the patient, noisy rattling breathing can be treated pharmacologically and should be monitored. However, the harms and benefits of these therapies should be weighed up, as the anticholinergic agents used in this case can cause excessive dry mouth and other side effects, about which the patient is unable to complain.
- It is often appropriate to prescribe anticipatory medicines to ensure there is no delay in administering medicines to provide maximum comfort for the patient when needed.

K. Organisation of surgical services to support patients, surgeons and surgical teams to deliver high-quality end of life care

ORGANISING SERVICES

Service planners can support surgeons to meet the quality standards identified by NICE in *End of Life Care for Adults*²¹ by ensuring the following.

Training

- Regular mandatory training of all healthcare professionals, including doctors, in how to provide high-quality end of life care and care planning should be provided. An example of this is the [GSF Acute Hospitals Programme](#) or the [free online e-learning](#) provided by Health Education England.

Diagnosis and planning

- Upon referral to the surgeon, service planners should ensure that GP referrals include whether the patient is considered to be nearing the end of life, which may be indicated by the patient being named on a supportive or palliative care or end of life care register, or flagged in another digital record such as a local EPaCCS (Electronic palliative care coordinating system). If so, the existence of an advance care plan, advance statement, ADRT or LPA should be communicated to the surgeon. It may be appropriate to include this as part of a proforma.
- There should be appropriate availability of information (including verbal, written and electronic) for patients approaching the end of life and their

supporters on what to expect and on planning for the future.

- Advance care planning proformas are available, for example from the [GSF](#), and service planners should ensure that these are accessible to healthcare professionals for use.
- Ensure that there is appropriate provision to facilitate advance care planning for surgical patients nearing the end of life. This provision includes ensuring appropriate training to surgeons and allied healthcare professionals and may be included in the job plan of an appropriate member of the surgical team, for example a cancer specialist nurse.

Ongoing care in the final days of life

- Specialist palliative care support and advice should be available 24/7 for patients nearing the end of life, as well as the availability of regular holistic assessments and spiritual support in line with existing End of Life Care guidance.
- MDT discussions should ensure that they cover aspects of advance care planning, such as patient's wishes, preferences and beliefs when discussing treatment and ongoing care.

- Service planners should support the provision of well coordinated care, for example through the Electronic Palliative Care Coordination Systems (EPaCC). All clinicians should be able to access any available, electronic, up to date summary document of disease, prognosis, decisions made and planned treatment, with access to the Advance care plan/Advance statement/ADRT or details on the LPA. Where these EPaCC systems do not yet exist locally, the patient's GP will be able to switch on, with the patient's consent, their enhanced summary record, which can include such details.
- There should be clear guidance to staff and a streamlined method to support clinicians to start the process of appointing an independent mental capacity advocate (IMCA) for patients without capacity and no friends or family to act as an independent body to support the patient.

Handover

- Arrangements should be in place for expedited transport and discharge for patients in the final days of life, to facilitate dying in the environment that the patient wishes and which is recorded in their advance care plan.
- There should be appropriate facilities and IT infrastructure in place for rapid information sharing with the GP and other community providers. Discharge letters should include information on whether patients are being discharged at the end of life, and if an advance care plan, advance statement, ADRT or LPA exists. Along with details of these documents, more comprehensive information should be available to all healthcare professionals on the current condition and prognosis of the patient, and what has been discussed with the patient, along with any contingency planning arrangements that have been agreed.
- Services must be designed to support patients with an end of life care diagnosis in the case of an emergency. A concise overview of the patient's diagnosis, prognosis, recent treatments, decisions made and patients' preferences should be clear to those treating patients in an emergency and any contingency plans and the content of any advance care plan, statement, ADRT, LPA or DNACPR decision should be effectively communicated. In some areas, the [ReSPECT](#) forms are being trialled and, where available, should be used. An electronic summary document accessible to all clinical staff should be available and kept up to date.

After death

- Service planners should ensure that there are appropriately trained and available healthcare practitioners to verify and certify the death in a timely manner.
- There should be support provided to families, friends and carers who are bereaved. This should include immediate and continuing practical, emotional and spiritual support appropriate to them. The National Palliative and End of Life Care Partnership recommends the inclusion of the community and volunteers for the best bereavement support.²³
- Service planners should actively seek feedback from supporters and, where appropriate, from patients about the end of life care they have received, to ensure constant improvement in the quality of care provided. Service providers should also provide appropriate support to healthcare professionals who have been affected by the death, which includes access to counselling where required.

Ensuring consistent quality

- Surgical units should audit their own performance. National audits into the care provided at the end of life do exist, for example the Royal College of Physician's *National Care of the Dying Audit for Hospitals*.²⁴ However, this audit focusses on performance at a trust or individual hospital level and purely in the final days of life, and does not give performance measures for surgical units.
- Suggested key indicators that surgical units should audit regularly and discuss at governance meetings are:
 - documented recognition of the end of life
 - relevant review of medications
 - documented communication with families
 - advance care plan in place before death and whether this is adhered to (unless death is sudden)
 - whether DNAR forms are in place, when they were signed and whether there was senior clinician input/signature
 - bereaved relatives' views (eg from the VOICES survey).²⁵
- End of life care should be discussed at regular morbidity and mortality meetings to highlight and reward where good quality care was provided, to learn lessons where it was not, and discuss how to implement future improvements where required. See **Appendix 4** for a recommended framework.

Supporting the surgical team

- Members of the surgical team may need additional emotional support following cases where their patients have died. Services should consider providing support by:
 - developing structured peer-support programmes including one-to-one discussion with experienced peers following episodes where difficult decisions have been made, or treatment has not gone according to plan (this may be in the form of a Schwartz Round,²⁶ a structured forum for staff to discuss the emotional and social aspects of working in healthcare)
 - providing structured opportunities for mentoring and open discussion
 - providing counselling should be available to those surgeons that need it
 - ensuring appropriate training for surgeons will enable surgeons to make well informed decisions
 - use of Incident Analysis, both within a medical or wider clinical team, can be helpful after a death or a critical event to ensure a positive approach to continued quality improvement.

PROVIDING INFORMATION FOR PATIENTS, THEIR SUPPORTERS AND THE BEREAVED

An important aspect of the care that patients receive at the end of life involves making sure that they have the appropriate support that they require at all stages.

Service providers should ensure that all patients have access to the following information, which may be as part of a leaflet or digital media:

- information and contact details for local and national support groups for those diagnosed with life-limiting conditions
- access to advance care planning discussions, including to charities and support groups that can offer the patient advice
- signposting on the steps to take to create a legally binding advance directive to refuse treatment
- advice on appointing a lasting power of attorney for health and care, including how to access the Office of the Public Guardian
- the role of the Independent Mental Capacity Advocate (IMCA) including how and when a patient will be appointed one
- encouragement to flag up early on if they feel their care could be improved or they have questions to ask
- how to complain if they feel that they are receiving inappropriate care.



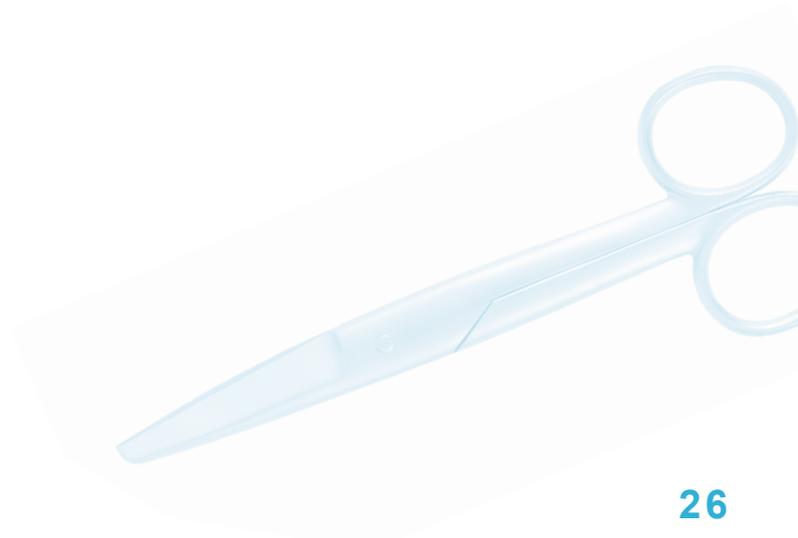
L. List of abbreviations

ADRT	Advance Decision to Refuse Treatment
CPR	Cardiopulmonary resuscitation
DH	Department of Health
DNACPR	Do not attempt cardiopulmonary resuscitation
GMC	General Medical Council
GPs	General Practitioners
GSF	Gold Standards Framework More information at: http://goldstandardsframework.org.uk
IMCA	Independent Mental Capacity Advocate
LPA	Lasting Power of Attorney
MDT	Multi-Disciplinary Team
M&M	Morbidity and Mortality
NHSE	National Health Service England
NICE	National Institute for Health and Care Excellence
PHE	Public Health England
RCP	Royal College of Physicians
RCS	Royal College of Surgeons
ReSPECT	Recommended Summary Plan for Emergency Care and Treatment More information at: http://www.respectprocess.org.uk/
SPICT™	Supportive and Palliative Care Indicators Tool. More information at: http://www.spict.org.uk/
VOICES	Views of Informal Carers – Evaluation of Services More information at: www.ons.gov.uk

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N. Appendix 1

CHECKLIST FRAMEWORK FOR DISCUSSION WITH PATIENTS WHO MAY BE NEARING THE END OF LIFE

PATIENTS WITH CAPACITY

Diagnosis

- Have you explained the diagnosis to the patient in terms they understand?
- Have you explained the natural course of the condition without treatment?
- Have you given the patient a leaflet on their condition/signposted them to somewhere to read more?
- Have you given the patient any information on available support groups for their condition?
- Have you involved any supporters of the patient, with the patient's consent?

Getting to know the patient

- Does the patient already have a valid advance care plan, advance statement, advance decision to refuse treatment or lasting power of attorney? If not, would they like support to make one?
- What are the patient's values in life? What is important to them?
- What elements of care are important to them and what would they like to happen in the future?
- What would they not want to happen or worry about happening in the future?
- What would be an unacceptable health state for the patient?

Treatment options

- Have you explained to the patient that they have the right to decide on whether to undergo treatment or refuse treatment?
- Have you discussed treatment options with the MDT, if appropriate?

- Have you explained all of the treatment options to the patient in a non-coercive manner including;
 - the purpose and expected benefit of the treatment options
 - the nature of the treatment
 - the likelihood of success including what the best case and worst case scenario of undergoing treatment and the effect on the patients quality of life
 - the clinicians involved in their treatment
 - potential follow up treatment.
- Have you explained the option of no treatment, or of palliative treatment?

Communication with colleagues

- Have you documented the outcome of your discussion contemporaneously in the patient's case notes?
- Have you ensured that, with the patient's consent, the GP is accurately informed about discussions had, the decisions made and why?
- If advance planning documentation has been made, including statements, ADRT and LPA, has the GP been made aware and a copy sent to them (with the patient's consent)?

Treatment at the end of life

- Are you delivering patient-focussed care?
- Where appropriate, have you sought input from palliative care specialists into the patient's treatment?
- Is the patient's treatment in accordance with any available ACP, advance statement or ADRT?

PATIENTS WHO LACK CAPACITY

Ascertaining who should make decisions

- Have you undertaken all reasonable steps to maximise the patient's capacity to make decisions?
- Has the patient appointed a lasting power of attorney registered with the Office of the Public Guardian?
- Is there a valid advance decision to refuse treatment?
- Where the patient has no independent friends or family to act as their advocate, has an independent medical capacity advocate been appointed?

Guiding best interests

- Have you examined any advance care plan, advance statement or ADRT to ascertain the patient's wishes, preferences and beliefs?
- Have you discussed the patient's care with supporters, including ascertaining what they believe are the patient's wishes, preferences and beliefs?
- Have you discussed the patient's care with other healthcare professionals that know the patient, including ascertaining what they believe are the patient's wishes, preferences and beliefs?

Making decisions in the patient's best interests

- Have you discussed the benefits and burdens of different treatment options, including doing nothing or palliative care with members of the MDT or other relevant clinicians?
- Have you weighed the benefits and burdens of the different options in line with what you believe are in the best interests of the patient?

Communicating

- Have you taken reasonable steps to inform the patient of treatment where applicable?
- Where you believe it is in the best interests of the patient, have you informed the patient's supporters of the diagnosis, prognosis and treatment plan?
- Have you handed over to the GP or other medical teams the decisions that have been made, as well as the content of relevant advance care plans, advance statements, ADRTs or whether there is a LPA?

Treatment at the end of life

- Are you delivering patient-focussed care?
- Where appropriate, have you sought input from palliative care specialists into the patient's treatment?
- Is the patient's treatment in accordance with any available ACP, advance statement or ADRT?

Appendix 2

ILLNESSES AND CONDITIONS WHERE BURDENS COMMONLY OUTWEIGH THE BENEFITS OF OPERATING IN THE ELDERLY

This table illustrates situations where there are many postoperative outcomes where the burdens outweigh the benefits of operating.¹ This is not a strict list of where surgery should not be offered, but an indicator to the surgeon that they should ensure the patient is aware that there may be a poor outcome associated with treatment and a poor postoperative expected quality of life, which may be below what the patient might value. This should inform the patient's own decision making.

Table 1. Serious illnesses and acute surgical conditions that put elderly patients at risk for non-beneficial emergency surgery

Serious Illnesses	Acute surgical condition
<p>General indicators</p> <ul style="list-style-type: none"> • Unplanned weight loss <10% in past 6 months • Permanent residence in a nursing home • Poor performance status, bed bound • Life expectancy < 6 months • ASA 4 or 5 	<p>General</p> <ul style="list-style-type: none"> • Small bowel obstruction • Large bowel obstruction • Malignant intestinal obstruction • Gastric or duodenal perforation • Intestinal perforation • Massive GI bleed • Infectious colitis • Necrotising soft tissue infection • Mesenteric ischaemia
<p>Cancer</p> <ul style="list-style-type: none"> • Worsening performance status • No longer candidate for chemo/radiotherapy due to disease progression • Persistent symptoms despite optimal therapy 	<p>Vascular</p> <ul style="list-style-type: none"> • Critical limb ischaemia • Acute limb ischaemia • Ruptured aneurysm
<p>Heart disease</p> <ul style="list-style-type: none"> • New York Heart Association Class 3 or 4 • Persistent symptoms despite maximal therapy • Cardiac cachexia • >2 hospitalisations for cardiac failure in 6 months 	<p>Cardiac</p> <ul style="list-style-type: none"> • Myocardial ischaemia meeting criteria for coronary bypass • Acute valvular insufficiency
<p>Respiratory disease</p> <ul style="list-style-type: none"> • Forced expiratory volume 1s <30% predicted • Meets criteria for long term oxygen therapy • Severe symptoms despite optimal tolerated therapy • Pulmonary hypertension • Pulmonary cachexia • >3 emergency admissions in the past 12 months 	<p>Neurosurgical</p> <ul style="list-style-type: none"> • Cerebral haemorrhage with midline shift

Serious Illnesses	Acute surgical condition
<p>Liver disease</p> <ul style="list-style-type: none"> • Ascites • Encephalopathy • Variceal bleeding refractory to medical therapy • Hepatorenal syndrome • Coagulopathy 	<p>Orthopaedic</p> <ul style="list-style-type: none"> • Acute spinal cord compression • Malignant fracture • Osteoporotic fracture
<p>Renal disease</p> <ul style="list-style-type: none"> • GFR < 30 mL/min • Worsening condition on haemodialysis • Refuses further dialysis 	
<p>Neurological disease</p> <ul style="list-style-type: none"> • Progressive deterioration in physical or cognitive function despite optimal therapy • Symptoms that are complex and difficult to control • Progressive dysarthria or dysphagia • Recurrent aspiration pneumonia 	
<p>Dementia</p> <ul style="list-style-type: none"> • Complete functional dependence • Unable to communicate meaningfully • Worsening eating problems • Recurrent aspiration pneumonia 	

¹Cooper Z, Courtwright A, Karlage A *et al.* Pitfalls in communication that lead to nonbeneficial emergency surgery in elderly patients with serious illness. *Ann Surg* 2014; **260**(6): 949–957

Appendix 3

'THINKING AHEAD': GOLD STANDARDS FRAMEWORK ADVANCE CARE PLANNING PRO-FORMA

This discussion pro forma is printed here with the kind permission of the Gold Standard Framework Centre.

'Thinking Ahead' – GSF Advance Care Planning Discussion



We wish to be able to provide the best care possible for all patients and their families, but to do this we need to know more about what is important to them and what are their needs and preferences for the future.

The aim of any discussion about thinking ahead, often called an Advance Care Planning Discussion, is to develop a better understanding and recording of peoples' priorities, needs and preferences and those of their families and carers. This should support planning and provision of care, and enable better planning ahead to best meet these needs. This philosophy of 'hoping for the best but preparing for the worst' enables a more proactive approach, and ensures that it is more likely that the right thing happens at the right time.

This example of an Advance Statement should be used as a guide, to record what the patient DOES WISH to happen, to inform planning of care. In line with the Mental Capacity Act (2005), this is different from a legally binding refusal of specific treatments, or what a patient DOES NOT wish to happen, which is called an Advance Decision (to refuse treatment) (ADRT).

Ideally an Advance Care Plan should be discussed to inform future care at an early stage. Due to the sensitivity of some of these issues, some may not wish to answer them all, or may quite rightly wish to review and reconsider their decisions later. This is a 'dynamic' planning document to be adapted and reviewed as needed and is in addition to Advanced Directives, Do Not Resuscitate plan, or other legal document.

Name:	Date completed:
Address:	GP Details
DOB:	Hosp / NHS no:
	Hospital contact:

Family members involved in Advance Care Planning discussions:

Name: Contact tel:

Name of healthcare professional involved in Advance Care Planning discussions:

Role: Contact tel:

Patient signature	Date
Next of kin / carer signature (if present)	Date
Healthcare professional signature	Date
Review date:	

Appendix 4

FRAMEWORK FOR M&M MEETING DISCUSSION

An example entry is illustrated in italics

Aspects of 'a good death'	What care did the patient receive in line with the aspect of care?
Recognised early and communicated clearly	<i>Patient had indicators that he was approaching end of life because of his poorly controlled COPD, which weren't recognised prior to invasive surgery</i>
Decisions over care made in accordance with patient's wishes	
Sensitive communication between staff and the dying person	
Well-coordinated care	
Needs of supporters met, as far as possible	
An individual plan of care is offered, and where appropriate, made	
An individual plan of care is delivered including: <ul style="list-style-type: none"> • food and drink • symptom control • psychological support • social support • spiritual support 	
Bereaved provided with appropriate support	

<p>Did this meet the expected standard? Red = No Amber = Yes, but room for improvement Green = Yes, delivered exceptionally (Please circle)</p>	<p>What actions need to be taken to improve?</p>	<p>Who is responsible to affect change?</p>
<p>Red Amber Green</p> <p>Red</p>	<ul style="list-style-type: none"> • Teaching for surgeons on indicators that patients are approaching end of life • Indicators listed to jog memory on emergency clerking proforma • Discussion with anaesthetic colleagues 	<p>Jane Roberts</p> <p>Michael Ashley</p> <p>Sarah Duncan</p>
<p>Red Amber Green</p>		



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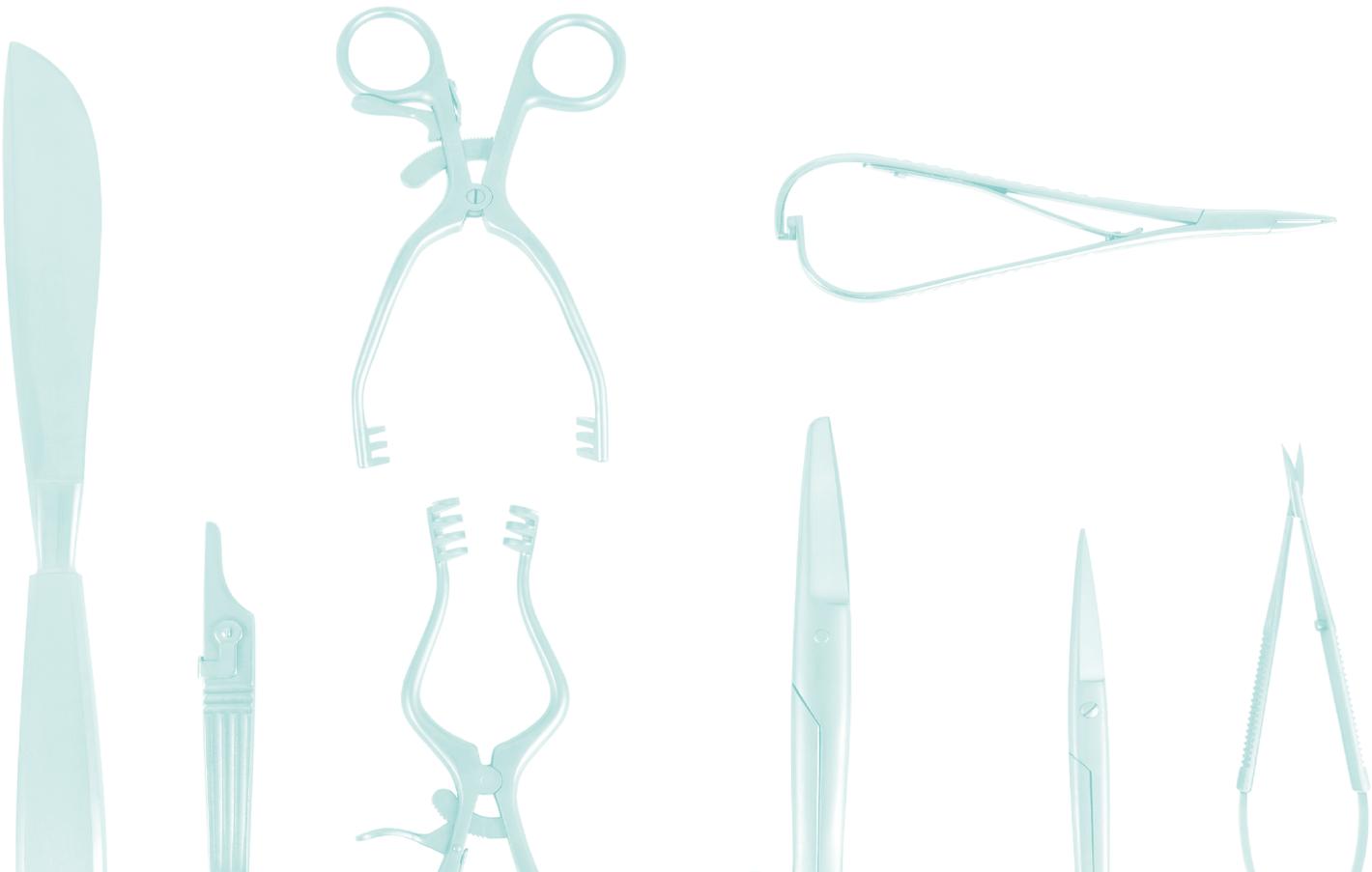
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35-43 Lincoln's Inn Fields
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