

When End of Life Care Goes Wrong



Exposing the scandal in 'end of life care' in Britain today

The purpose of this Report

In 2014, following public outcry over the staggering number of untimely and distressing deaths caused by the now infamous Liverpool Care Pathway (LCP), the protocol was scrapped. In 2015, the UK regulatory body National Institute for Health and Care Excellence (NICE) replaced the LCP's one-size-fits-all, blanket approach with a set of individualised recommendations, based on the best available research evidence. However, in many hospitals, hospices, care homes, and for patients receiving home-based end of life care, those recommendations are being ignored, with the result that vulnerable patients are still being subjected to premature and unnecessary death.

In response to a growing number of complaints received by Voice for Justice UK (VfJUK) from bereaved relatives, The Lords and Commons Family and Child Protection Group (LCFCPG) commissioned an investigation into end of life care in Britain today. The findings were horrifying. From over 600 complaints (the tip of an iceberg), 17 case studies, that fulfilled the rigorous medical and legal requirements felt to be necessary, were selected for inclusion into our Report, *When End of Life Care Goes Wrong*.

Lynda Rose, Anglican priest, former barrister, and convenor of the LCFCPG, said *"Our Report shows all too clearly that misdiagnoses and mis-assessments as to quality of life and proximity to dying are disturbingly common. Excessive and inappropriate use of Midazolam and Morphine, rendering a patient comatose, coupled with the withdrawal of food and hydration, have combined to impose a death sentence on the elderly and vulnerable from which there is no right of appeal. Life matters, and every last moment of life matters for those bound together by love. We shall all one day have to cross that final bar – so for all our sakes, we need to end the abuse now and ensure that the vulnerable – whose voices are so often ignored – are respected and that they receive the best possible care society can offer."*

Shocking findings

The 17 medically assessed case studies are provided in their own words by families left stunned at the inhumane treatment suffered by their relations. In many cases, the person who died had a seemingly trivial condition. One patient, for example, was

admitted for treatment for constipation. Another, otherwise healthy, came into hospital for knee replacement surgery, and yet another for elective eye surgery. Others were known to be approaching the end of life and entered hospice care, only to receive undignified and callous treatment that paid no regard to their, or their families', wishes or concerns.

Denise Charlesworth-Smith, lay member of the LCP review panel, former reviewer for Care Quality Commission and founder of the 'LCP support group', who furnished the majority of the complaints from bereaved families, said: *"Things looked good when they scrapped the LCP, but by 2018 I was getting an increased number of very distressed families reaching out to me, saying that the More Care Less Pathway review was being ignored. I knew I had to do something, so that year I set up a new Facebook support group. Since that time over 800 families have joined. Without doubt, there are many, many more – too wounded to share their story, or completely oblivious that they are not alone. I've said it before and I'll say it again, this HAS to stop."*

Sam H. Ahmedzai, emeritus professor of palliative medicine and chair of the 2015 NICE guideline committee, said: *"When I was asked to review the 17 case studies I was shocked to read the extent of how badly patients and their families had been treated at the hands of those who should have known better, including hospice specialists. I examined all the families' submissions and reviewed source documentation from hospitals, hospices and care homes wherever these were available. In some cases, coroners and the Ombudsman had already highlighted negligent practices contributing to suffering and untimely death.*

"When I compared the case studies with relevant NICE and General Medical Council (GMC) guidelines, I was dismayed how flagrantly these had been ignored. Perhaps the most chilling case study concerned a young lady of 21 years with physical and learning disabilities, who entered a large teaching hospital for a planned minor operation and who died three weeks later, having been essentially starved to death, according to the coroner's inquest."

Legal failings and implications

James Bogle, barrister of the Middle Temple, co-author of Law and Medical Ethics, says: *"I was asked, as a lawyer with experience in end of life and other medical cases, to review the 17 case studies legally. I was disturbed to find a recurrence of the very problems that had been highlighted by the Neuberger committee. The case studies include some particularly harrowing situations which should not have arisen. They include seemingly egregious examples of neglect, negligence and breaches of human rights. Moreover, the burden for seeking accountability seems often to have lain upon the shoulders of the bereaved themselves. Such a situation is clearly contrary to what our care quality standards and the law are meant to encompass and engender."*

Call for remedial actions

Robert S. Harris, the Report's editor and leader of the Working Group on End of Life Care for the LCFCPG, says: *"Having examined the many clinical failures, and what sometimes appears to be blatant abuse, the LCFCPG working group felt strongly that it was unacceptable many care providers are still using the discredited guidance and practices of the LCP, and that such practices should now be subjected to Parliamentary scrutiny and brought to an end. We are calling as a group for urgent remedial action."*

Actions being called for include:

1. **A national inventory of local end of life care plans, policies and procedures currently being used in all healthcare settings**
2. **A national rapid response service to advise and support people who have a loved one currently experiencing poor quality end of life care**
3. **A fast track advice helpline for recently bereaved families**
4. **A national register of cases where end of life care has fallen below standards or breached guidelines**
5. **The urgent adoption of a uniform national system to capture patients' preferences for end of life care**
6. **Further high quality research into social, medical and nursing aspects of end of life care**

Carla Lockhart MP, Chair of LCFCPG, says: *"This LCFCPG report When end of life care goes wrong exposes the horror of the 'callous and inhumane treatment' meted out to some patients as they approach the end of life. These include interventions such as the withdrawal of oral hydration – even when the patient is sometimes begging for a drink – or the administration of strong sedatives, prescribed with the sole intention of rendering the patient unconscious, while hastening death.*

We believe this is unacceptable in British society and we urge the NHS, healthcare professional organisations and relevant charities to challenge these practices. We look to Parliamentarians to enact the 'Call for remedial actions' as soon as possible."

**Presentations from the launch
in Parliament hosted by
Danny Kruger MP and Carla Lockhart MP
7-3-23**

Revd Lynda Rose

(Convenor, Lords and Commons Family and Child Protection Group [LCFCPG])

Thank you for joining us this evening for the launch of our Report, *When End of Life Care Goes Wrong*. It feels to have taken a long time, putting it together, and I'm going to ask Robert to say a bit more about that whole process in a minute, but first I just want to say why we have felt this Report to be so important – and so necessary at this time.

You'll remember, I'm sure, the scandal that erupted around 10 years ago, following the staggering number of premature and inappropriate deaths that had resulted from the Liverpool Care Pathway, the LCP as it was known. In effect, use of the Pathway had become a tick-box exercise for busy doctors, a one-size fits all approach,

applied unthinkingly, with the inevitable result that it became not care, delivered with compassion, but managed death. It sounds extreme, but is perhaps accurate, to say that doctors and nurses who followed the Pathway had become agents of death. It was entirely right, back then, that it was scrapped, and our thanks go to the Neuberger Inquiry, which worked so hard to expose the abuse.

The problem is, however, that though the Pathway was scrapped, the practices still remain – albeit with a different name. Today we no longer have a ‘Pathway’, but rather end of life care plans, that in theory are individually tailored to meet the needs of the patient, agreed in consultation between them and their family and the doctors. So, *in theory*, end of life care today is collaborative, with medical staff and patients working together to agree best treatment.

Now please don’t get me wrong. When end of life care in the NHS works correctly, it’s very good. The NICE guidelines for providing such care – drawn up by the committee chaired by Prof Ahmedzai, one of the main contributors to our Report – are excellent. But the reality is that all too often these guidelines are being completely ignored, and patients are still being subjected to that same tick-box exercise – a kind of multiple choice test that determines whether or not the ‘candidate’ should be allowed to live, with a pass or fail mark, and no chance of a resit or right of appeal.

It may be, of course, that busy clinicians are simply unaware of the NICE guidelines – there is, after all, a lot of ignorance around – or it may be that medical staff are prioritising the allocation of resources, but our Report shows that misdiagnoses and mis-assessments as to quality of life are all too common, and that treatment based on that evaluation is deliberately designed to hasten death. The shocking truth is that people, of all ages, who cannot speak out for themselves, are being prematurely and thoughtlessly written off.

Time after time, our Report shows that excessive and inappropriate use of Midazolam and Morphine, prescribed unnecessarily and with the inevitable result that the patient became comatose, coupled with the withdrawal of food and hydration, have combined to impose a death sentence, which, in the current climate, it is extremely hard to challenge.

Such treatment is not just callous and inhumane, but is a betrayal of the trust we all put in doctors, and in those charged with safeguarding the wellbeing of society. Our Report details 17 medically analysed and validated case studies, which have literally been drawn from hundreds of similar complaints. But this is just the tip of a very large iceberg. We have no idea of the exact number of people in society who have been and are affected, but I guarantee that if you start to speak about this among friends, someone will immediately say, ‘That happened to me My father, my mother... my partner ... or even, perhaps most heart-breaking of all, my child.’

This is not just unacceptable, it has become a scandal. And indeed, in some cases, such treatment may be illegal. How we treat and care for the vulnerable goes to the heart of our humanity, and there are none more vulnerable and deserving of our compassion and care than those at the end of life. There are many challenges facing society at the moment, and NHS resources are clearly overstrained, but this cavalier treatment of those who cannot defend themselves must end.

My thanks go to all who have worked so hard to give ‘life’ to this Report, especially to our medical and legal experts, respectively Prof Sam Ahmedzai and James Bogle. But special thanks are also due to Denise Charlesworth-Smith, who was a part of the Neuberger Inquiry and who, since then, has worked tirelessly to support families – often in shock and always angry – who have been left bereaved. It perhaps goes

without saying that she has been the main source for our case studies. My thanks too to Robert Harris, our editor, and to Alice Jones, our highly skilled copy editor, who's kept us all up to scratch. And lastly, but by no means least, thanks to Carla Lockhart, chair of the LCFCPG, and to Danny Kruger – may they be successful now in calling in Parliament for better regulation and change.

Robert S. Harris

(Leader of the LCFCPG Working Party on End of Life issues)

Good evening and welcome everyone. I'd like to begin by thanking Carla Lockhart our Group Chairman, and also Danny Kruger, for hosting this launch event today.

I am Robert Harris. I am the Lords and Commons Family and Child Protection Group Working Party Leader on End of Life Care Issues. We have been working for quite a while producing this report and there have been many introductions to make this work possible, especially in terms of how our case studies were gathered.

One of the earliest steps in this project was my making contact with Nikki Kenward, a well-known, disability rights campaigner. She introduced me to the neurologist, Professor Patrick Pullicino. He was one of those who had voiced strong public concerns about Liverpool Care Pathway practices, and who was one of the very first medical figures to go public in this way. He is here this evening.

As this was going on, my colleague, Lynda Rose, who as CEO of Voice for Justice UK, had already put out a call to the organisation's subscribers for personal stories involving end of life care. Without Voice for Justice UK, the publisher of this report, we would not have been able to produce this work for the Lords and Commons Family and Child Protection Group.

A few other introductions from families also came from Professor Pullicino, who also helpfully introduced us to Denise Charlesworth-Smith. Denise is unable join us this evening. Her own father died under the LCP, and she soon became a national campaigner for better end of life care.

Sir Norman Lamb, the Health Care Minister under the coalition Government, invited Denise to serve as a lay member on Baroness Neuberger's Review Panel, an offer she accepted. The Neuberger Review Panel would later come up with 44 recommendations, as a way of replacing the old LCP system, and to ensure even higher standards for end of life care. As for those whose stories feature in this Report, Denise also introduced us to some people from her online support group, which currently numbers 800 people.

Denise then introduced us to our medical expert, Professor Sam Ahmedzai, a distinguished palliative medicine specialist (who chaired the NICE committee that developed the guidelines on end of life care in 2015). Of the approximately thirty individuals who originally submitted stories from all the sources I have mentioned, half were accepted for inclusion into the report, because the others generally failed to comply with our strict criteria. Most of the families who wrote accounts of their loved ones' last days in this report, also submitted large volumes of medical documentation in support of their claims. This enabled Professor Ahmedzai to verify what they were saying from various kinds of medical records, coroner reports and so forth.

One of the members of the Lords and Commons Family and Child Protection Group, Louise Kirk, very helpfully introduced us to our legal expert, a barrister of some

thirty years, James Bogle, whose experience includes a number of high profile medically-related public law cases. He had represented Archie Battersbee in the very last days of his life, the 12-year old brain-damaged boy, whose tragic story stole the national headlines last year.

We are very grateful to both Professor Ahmedzai and James Bogle whose authoritative commentary on the featured case studies makes this report compelling reading, but also a wake-up call, because any of us sitting here in this room, or any of our nearest and dearest, could one day find ourselves in a vulnerable position in a hospital or other care setting, so it would be a mistake to think: "this is a problem for others, not me". We would all expect to be treated with dignity and respect and to be given the best available treatment, especially when it's in accordance with our wishes to live.

Finally, I want to thank the 16 families whose stories feature in this report. Without them, none of this would have been possible.

Professor Emeritus Sam H Ahmedzai FRCP FFPMRCA

Thank you, Mr Chairman and Lynda, for that introduction, and good afternoon my Lords, Ladies and gentlemen.

As you have heard, I am a retired Emeritus Professor of Palliative Medicine with 30 years' experience of working in both hospice and hospital settings, as well as in academia. Indeed, I was involved in setting up the specialty of palliative medicine in the 1980s and, through my research, publications and work with bodies such as NICE and the Royal College of Physicians, I feel I have contributed to the research evidence-base and guidelines that we work to in this country.

I am thus immensely proud of the UK's standing in the world as a model for providing high quality end of life care. But our purpose today is not to rest on our laurels, but to see where, sadly, we are failing our patients.

Our story starts with the public and professional anger about the Liverpool Care Pathway or LCP. This was essentially a philosophy and protocol for managing a dying person in the last days of life, which started in hospices in the 1990s and by the early part of this century, was being rolled out across the NHS in hospitals and community. But there had been no research to test what was, essentially, a new health technology. The LCP was predicated on aiming for a 'good death', in the style of what hospices could offer. Hospices have a high proportion of trained, specialist staff, who have one job – to care for dying people.

But now, it was being applied in NHS environments with very few staff dedicated to end of life care, and others who were conflicted by also trying to save lives. Without the research, and without sufficient training and monitoring, the LCP came to be a one-stop, blanket approach giving everybody the same treatment.

Under the LCP, hydration and nutrition were routinely withdrawn or withheld, because they were thought to be inconsistent with the notion of a 'good death'. Drugs were prescribed in a blanket fashion so that some patients, especially when there was a lack of senior staff, received multiple drugs without a clear reason. These included painkillers such as morphine and sedatives such as midazolam or major tranquillisers.

As you've just heard, the LCP was reviewed in 2013 by Baroness Neuberger's independent panel and the decision was made to abolish it from the NHS by the middle of 2014.

Some of the areas where the LCP had been found wanting were:

- Poor advice on how to recognise if a person was actually dying – or how to recognise and to rapidly change course, if there was possibility of recovery
- The blanket and immediate withdrawal of hydration – even when the person was begging for a drink
- Unilateral or secretive decisions about ‘Do not attempt cardiopulmonary resuscitation’ orders – which were sometimes either inappropriate or, very often, imposed without consultation
- Failure to take account of lack of mental capacity and the need to initiate procedures in conformity with the Mental Capacity Act 2005.

The Department of Health’s response to the demise of the LCP was to commission the National Institute for Health and Care Excellence (NICE) to produce new national guidance - based on the best available research evidence – which could apply throughout the NHS. I was appointed by NICE to chair the guideline committee and we published the guidance called NG31 at the end of 2015. I also later helped NICE produce Quality Standards based on this guideline to help the NHS to monitor its usage and impact.

You’ve heard from Lynda Rose why, and how, this report was set up – because there was increasing evidence that in some places, the same LCP practices were continuing, but under different names. You’ve also heard about the extraordinary work of Denise Charlesworth-Smith, who set up an online support group after her father died under the LCP. This group now holds over 700 families. Most of the case studies we are reporting today have come from Denise’s group.

A word about the provenance and scientific status of our ‘sample’. Let’s be clear – this is not research – not even formally ‘qualitative’ research. We suggest that our 17 cases coming from 16 informants may represent a much larger number who currently have no platform to share their stories.

Bodies such as the Royal Colleges and the National Audit of Care at the End of Life (NACEL) perform important benchmarking exercises. These may cover many thousands of cases over a set period of time, and yield percentages for this, or that, outcome. But what we are sharing today are the individual human stories that probably occur all year round, and which underpin those statistics.

My specific remit in the project was to analyse and verify the medical content of the chosen case studies. I did this by reading the statements, asking for and reviewing clarifications and corrections; asking for and reviewing source documents from medical and nursing notes; also reviewing correspondence between families and trusts or hospice management, Ombudsman and coroners.

I then wrote an analysis of each case, pulling out the key medical events. I tried to find explanations for the medics’ choices on specific drugs and their doses; on hydration, nutrition, resuscitation and other life-saving or palliating decisions. In each case I compared the practice at the bedside against the 2015 NICE guideline – which applies to all healthcare professionals - or against the guidance for doctors published earlier by the General Medical Council (GMC) in 2010.

The stories and my conclusions were then scrutinised by my learned colleague James Bogle, who will shortly give you his legal insights.

One thing we had to settle at the beginning was which definition of ‘end of life care’ to use. We chose the same as the NICE 2015 guideline, namely ‘care of dying adults in the last days of life’. Note that this is not the same as stated for ‘end of life care’

on the NHS website, which refers to care in the last year or so of life. The NHS clearly has to be interested in delivery and coordination of services to people over months and years before they die.

Baroness Finlay's hard work on the Health and Care Act, passed last year, will no doubt have a great impact on the delivery of palliative care services in the NHS. Our focus, as I said, is on clinical care at the bedside for people who are currently considered – rightly or wrongly – as dying within days. This group can include people who are coming to the end of a progressive condition such as metastatic cancer, advanced heart, lung or kidney disease – what we used to call 'terminal stages' of chronic illness.

But – as we are reminded by the GMC and also NICE – 'end of life' includes people who were previously healthy (for their age) and who've had a catastrophic illness such as stroke or heart attack, from which they avoided immediate death - but were now thought to be dying. Clearly in this category, the people and their families will have had less time to become aware of the situation and to make important decisions.

Importantly, most patients in this category would not normally come under the purview of palliative care – no matter how much extra resources may be put in to extend these important services.

Let me present an analysis of the deaths we reviewed. Table 1 (see below) gives a detailed breakdown of the cases, whose year of death spanned from 2012 to 2021. Table 2 (see below) summarises the key points. There was almost an equal number of males and females; their ages ranged from 21 to 94 years. Twelve of the deaths occurred in hospital; two in an in-patient hospice; two at home under hospice-at-home care; and one in a care home. Fourteen deaths took place in England and three in Wales.

It was important for me to consider the timing of the deaths in relation to the use of the LCP and, after its abolition, other national guidance. Thus, the first two deaths occurred during the time the LCP was actively in use. The third fell in the period after the Neuberger panel's review in 2013 but before the LCP abolition in 2014. The next two deaths were in the period between the LCP's abolition and the publication of NICE guideline NG31 in 2015. The last twelve deaths occurred once the NICE guidance was in use. I also had to remember that the GMC's guidance on end of life care decision-making for doctors had already existed from 2010.

For each case, I determined as well as I could from the materials available to me, what the main medical conditions were that brought the patients into the final place of care. These are summarised in Table 3. Note that the underlying conditions listed here will not necessarily be the same as the recorded cause of death. Cancer was the single most common disease affecting 5 individuals. There were two patients each who had as their main illness, heart failure and dementia. All the other conditions determining an admission which became end of life care occurred in single cases; or in the case of community-acquired pneumonia, two cases.

It is important to recognise that cancer, heart failure, dementia, kidney failure and chronic lung disease (which together accounted for twelve of the deaths) could fall into the category of predictable end of life at the end of a chronic condition; thus, they may have benefited from palliative care services. The other five may have occurred in frail elderly people (although one was actually 21 years of age), but the admission during which they died fell under the category of acute crisis; palliative care services would not normally be involved in their care.

I found that for each of the scenarios for which the LCP had been criticised, and which were now subject to guidelines from NICE for healthcare professionals, or the

GMC for doctors – there were flagrant examples of the same old LCP practices. Far from being placed on individualised care plans, patients received one-size-fits-all care. Patients' and families' pleas for changing this medical approach fell on deaf ears. In the report, I summarised after each case study where I found the clinical decision-making and the actions, inactions and prescribing to be in breach of NICE or GMC guidance, or both.

Of course, I understand that NICE or GMC guidelines are not 'law' and clinicians can opt to ignore them. But if they do, and a patient suffers and dies as a result, they need to be held accountable.

Thus, 5 case studies show examples where patients were started on end of life treatment, but without a proper assessment of being near to 'dying' by suitably experienced staff. In my views, not all of these should have been considered as 'end of life'. In other cases, patients may have been potentially dying at first assessment, but then stabilised or had the capacity to improve, and yet continued to be managed as if they were still approaching death.

The most distressing stories were those where a person thought to be dying was denied hydration - either naturally, by taking drinks, or medically assisted, through a drip or tube. This occurred in no less than 10 of our 17 cases – even when patients and their relatives were pleading for a drink. The NICE guideline NG31 makes it clear that families should be allowed to help patients to drink if they are capable of swallowing. And it recommends clinicians consider a trial of assisted hydration in those who cannot.

Accepting a 'Do not attempt cardiopulmonary resuscitation' decision should not automatically lead to a host of other supportive and comfort measures also being withheld. But we saw cases of exactly this happening, especially withdrawal of fluids and previous medications. Disagreements about decisions regarding resuscitation cropped up in 8 cases. There were at least 2 cases in which, as a clinician, I felt that the possibility of having resuscitation could have saved their lives.

Many cases involved people in whom mental capacity was impaired – either older people chronically ill because of dementia, or acutely, because of an illness or possibly sedative medication. In 7 of our cases, doctors failed to take mental capacity into account when making decisions about starting or withholding treatments. They also failed to consult with relatives who held lasting power of attorney. This is in clear breach of the Mental Capacity Act 2005 and, I believe, of their human rights.

In all 17 cases, there were failures with respect to communication with the patients and their families, leading to a denial of the shared decision-making which is required by NICE and GMC guidance. Furthermore, in many instances, staff had misinformed and misled the patients; and treated them in degrading or dehumanising ways.

After deaths, just a few relatives who had the mental and financial resources, had sought answers. Many told us they would have wanted to, but were emotionally worn down by staff's attitudes and misinformation. One courageous and persistent family obtained an inquest after 4 years. The coroner found at her inquest that their daughter, a 21 year old lady with Patau syndrome (a congenital disease with physical and learning disabilities), who had come into hospital for a routine minor eye surgery, had died after 3 weeks experiencing a catalogue of neglect, including starvation, that contributed to her death.

In some instances, families were denied a coroner's inquest because of misinformation or even careless handling by the police. Even when a coroner's or

Ombudsman’s judgement was obtained, it is evident to me that not a single member of staff has been censured or suspended.

I will now hand over to my learned colleague James Bogle, who will expand on the legal aspects of the case studies.

Table 1. Demographic characteristics and geographical distribution

Case Study	Year of death	Gender	Age	Place of Death	Country	City / County	Relationship of informant
1	2012	Male	82	Hospital	England	Sutton-in-Ashfield, Nottinghamshire	Father
2	2012	Male	68	Hospital	England	Liverpool	Father
3	2014	Male	78	Hospital	England	Chester	Husband
4	2015	Female	86	Hospital	England	Canterbury	Mother
5	2015	Female	82	Hospital	England	Stoke on Trent	Mother
6	2016	Female	88	Hospice at Home	England	Harrow, Middlesex	Mother
7	2016	Female	21	Hospital	England	Sheffield	Daughter
8	2017	Female	86	Hospital	England	Hull	Mother
9	2017	Male	52	Hospice	Wales	Cardiff	Husband
10a	2017	Male	88	Hospital	Wales	Cardiff	Mother
10b	2021	Female	92	Hospital	Wales	Cardiff	Father
11	2018	Male	61	Hospice	England	Milton Keynes	Husband
12	2018	Female	94	Hospital	England	Wigan	Mother
13	2020	Male	89	Care Home	England	Carlisle	Father
14	2020	Male	47	Hospital	England	Manchester	Father
15	2021	Female	73	Hospice at Home	England	Ivybridge, Devon	Mother
16	2021	Male	84	Hospital	England	Northallerton, North Yorkshire	Father

Table 2. Summary characteristics of cases

Gender: 9 males; 8 females

Age range: 21 – 94 years

Place of death: Hospital 12; Hospice 2; Hospice at home 2; Care home 1

Geographical location: England 14; Wales 3

Dates of death: 2012 - 2021

Timing of deaths in relation to LCP and GMC guidance:

- 2 during LCP
- 1 after Neuberger panel but before LCP abolition
- 2 between LCP abolition and new NICE guidance
- 12 after NICE guidance

NB: GMC guidance or doctors applied from 2010

Table 3. Medical condition of decedents

Medical condition	Case study	Frequency
Cancer	6; 9; 11; 12; 15	5
Heart failure	3; 16	2
Pneumonia	4, 5	2
Dementia	10; 13	2
Kidney failure	14	1
Diabetes	4	1
Chronic lung disease	3	1
Fall/fracture	5	1
Infection	2	1
Frailty	10	1
Knee surgery	8	1
Patau syndrome; learning disability; eye surgery	7	1
Constipation	2	1
Undetermined	1	1

James Bogle, Barrister

May I also thank our hosts for hosting this event and for their support. May I also thank my colleagues, Rev Lynda Rose, Robert Harris, Denise Charlesworth-Smith and Prof Sam Ahmedzai for their considerable work and effort in helping put this report together. I am indebted to all of them for their support.

I am James Bogle. I am a barrister in private practice and, amongst other areas of practice, I have been involved in medical cases, including some high profile public law case, over my 30 years of practice, including, for example, the *Dianne Pretty* case, the more recent *RS* case and, as you heard, the *Archie Battersbee* case, among others.

I was asked to write a legal overview to the case studies that we selected for the report and was happy to do so, since I have been concerned about the state of end of life care in our health service for some time, not least as a result of numerous cases that came across my desk. In so doing, I have expressed my own views as to the legal position.

I can, in particular and from my own experience, repeat the concern that, the “box-ticking” and “one size fits all” tendency, that seemed to become a feature of end of life care during the currency of the ill-fated Liverpool Care Pathway, did not disappear with the demise of the LCP.

Clearly, then, further work is needed to ensure that end of life care is brought back up to the very high standards that we have come to expect from our health service in other areas of health care. To that end, may I draw your attention particularly to our chapter that we have headed “call to remedial action”.

The case studies set out in this report make harrowing reading.

What is of particular concern is the extent to which a succession of mistakes and clinical errors, frequently coupled with a lack of proper communication with the patient and his or her family, occurs. Moreover, these are but representative cases, reported with the permission of the families concerned, reflective of what we believe are many other such cases occurring in our health service which, in turn, represents a significant level of failure across many parts of the health service as a whole. What is of considerable concern is the extent to which this state of affairs did not, as was anticipated, end with the demise of the LCP but appears to have continued, and without proper investigation or regulation. Certain features emerge as being representative and, often enough, as not uncommon.

It is not uncommon for patients, thought to be terminal, to be placed on a syringe driver in that way, for the dosage to be increased, ostensibly to “make the patient comfortable” (sometimes even when the patient is not actually suffering any pain), and, when the patient dies, a doubt remains as to whether the patient died from his or her condition or from incremental doses of the potentially lethal combination of midazolam and morphine.

Midazolam and morphine can be very useful in end of life care, if used appropriately, but it is precisely because they can be used well that makes it all the easier to conceal when they are being used badly or terminally.

There have even been cases of misdiagnosis where a patient had been declared to have a terminal condition (often cancer), was placed on the pathway and died but, after post-mortem, and to the quite unimaginable distress of the families, was found not to have had the diagnosed terminal disease at all.

In my overview, I cite the example of Mr Jones, a case from some time ago but nonetheless instructive, who was not taken off the pathway and was not treated for chest infection and so died of it, needlessly and pointlessly. Thereafter, it was found that, in fact, he did not have cancer at all and could readily have survived for many more years of life. It is important to remember that it remains a criminal homicide to bring about a patient's death deliberately, recklessly or negligently.

It was expected that, following the Neuberger Report, *More Care Less Pathway*, closer scrutiny of end-of-life care, and associated protocols and pathways, would follow. However, we have found that such scrutiny still leaves much to be desired.

Case Study 2 ended up in the Supreme Court in the landmark case of *Aintree University Hospitals NHS Foundation Trust v James* [2013] UKSC 67. In that case, Baroness Hale laid down some very useful and helpful guidance and made it clear that the starting point is a strong presumption in favour of life and a profound respect for the sanctity of human life (reprising Lord Bingham in the famous case of *Airedale NHS Trust v Bland* – the Hillsborough disaster victim case). However, by the time the case reached the Supreme Court the damage was done and the patient's chances of survival had shrunk dramatically. Put shortly, the patient, of no great age, came into hospital with constipation but left the hospital dead. There has been very little explanation as to how this was allowed to occur and why it was not avoided or, after the event, properly investigated.

But did things improve after the demise of the LCP?

We have found that in a significant number of cases it did not, even after the publication of the otherwise excellent NICE guideline, NG31, produced by a committee chaired by Prof Ahmedzai. If NG31 had been properly followed, most of these cases would not have arisen. But it is clear that NG31 has often not been properly followed.

Case Study 3 was particularly disturbing, with a concatenation of apparent mistakes and errors and both it, and Case Study 4, exemplified, once again, the familiar pattern of poor communication with the family and, in the latter case, a denial of hydration to the patient which contributed to the patients' death, particularly as hydration was denied for 2 whole days.

Dehydration is an extremely painful and distressing way to die and is not always relieved by analgesic pain relief. No person, including patients, may be subject to degrading and inhuman treatment, such as deliberate dehydration, since such is contrary to their human rights under Article 3 of the European Convention on Human Rights, and the Human Rights Act 1998.

Once again, in Case Study 6, there appears to have been a breach of duty in denying the patient the comfort and dignity of having assisted fluids, yet offering assisted hydration in different ways has been standard practice in hospitals, and indeed in hospices, for decades.

Case Study 7 was particularly disturbing, as the patient was a 21-year-old lady with severe learning disabilities who went into hospital for a "routine" eye operation, but died three and a half weeks later without her nutritional needs having been met, such that a coroner found that malnutrition contributed significantly to her death. It was all the more harrowing given that her parents were regularly asking daily for assessments and for clinical assistance with her nutrition. There was an apparent

failure to call a “Best Interests” meeting, in breach of s.4(7) of the Mental Capacity Act 2005, as is usually required for persons lacking mental capacity.

Case Studies 8 and 9 appear to be further examples of failure to provide proper nutrition and hydration and a failure to follow NG31.

In Case Studies 10, 11 and 13, nutrition and hydration again appear to have been withheld or withdrawn contrary to proper procedure and NG31. Insistence upon a DNACPR order was also seen in at least one case. This is particularly troubling where such an order is interpreted as condoning withdrawal of other forms of life-sustaining, and even comfort, treatments. The leading authority on DNACPR is probably *Tracey*¹, followed in *Winspear*² as regards the mentally incapacitated, where the courts held that, ordinarily, there must be consultation with the patient before placing such an order.

The reluctance of families to lodge a complaint or raise concerns, particularly when the patient is still alive, is by no means untypical, because families are often traumatised by the experience of their loved one’s end of life care.

That is a particularly disturbing feature of many of these cases and, when coupled with the complexity and often ineffectiveness of complaints procedures in achieving any real redress, this means that serious cases can often escape proper and effective scrutiny so that the problems risk being repeated with impunity, time and again.

Case Studies 12, 14, 15 and 16, appear to have been further cases of lack of proper communication with families, failures to follow guidance properly, or even at all, and a reversion to the “box-ticking”, “one size fits all”, blanket approach that was often associated with the old LCP.

In some cases of mentally incapacitated patients, there appear to have been failures to follow the Deprivation of Liberty Safeguards (DOLS) – soon to be replaced by the Liberty Protection Safeguards (LPS) under the Mental Capacity (Amendment) Act 2019. Patients should never be deprived of liberty unless all proper legal safeguards have been followed. Moreover, relatives with a lasting power of attorney (LPA) must be consulted in all decisions affecting the patient that are covered by the LPA. Failure to do so is unlawful.

I return to our calls for remedial action. I commend them to the consideration of parliamentarians, health-care professionals and generally, particularly our call for a national inventory of end of life care plans, policies and procedures currently being used in all healthcare settings and a national rapid response service to advise and support people who have a loved one currently experiencing poor quality end of life care.

Of the various non-litigious methods of attempting to obtain relief or redress of grievance, many, all too often, are simply not working. Going down the route of litigation is expensive and can also be unsatisfactory, since it is necessarily adversarial, when, much of the time, a non-adversarial approach might be better and might lead to a less defensive approach being taken by health care trusts and staff.

The aim of this report is to highlight the problem, to present it in some detail to public policy makers and generally, and to offer practical suggestions as to how the situation might be rectified.

¹ *R (on the application of Tracey) v Cambridge University Hospital NHS Foundation Trust*, Queen's Bench Division (Administrative Court) [2012] EWHC 3670 (Admin), 19 Dec 2012.

² *Winspear v City Hospitals Sunderland NHS Foundation Trust*, Queen's Bench Division [2015] EWHC 3250 (QB), 13 Nov 2015.

The wider aim is that these tragic situations be avoided in the future and the intense suffering that they necessarily entail, for the patient and bereaved families and relatives who have had to endure them, be obviated and avoided. I accordingly commend the report to your attention.

Thank you.

Call for Remedial Actions

- 1. A national inventory of local end of life care plans, policies and procedures currently being used in all healthcare settings**
- 2. A national rapid response service to advise and support people who have a loved one currently experiencing poor quality end of life care**
- 3. A fast track advice helpline for recently bereaved families**
- 4. A national register of cases where end of life care has fallen below standards or breaches guidelines**
- 5. The urgent adoption of a uniform national system to capture patients' preferences for end of life care**
- 6. Further high-quality research into social, medical and nursing aspects of end of life care**