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Parliamentary
and Health Service
Ombudsman

Dying without dignity

Investigations by the Parliamentary
and Health Service Ombudsman into
complaints about end of life care

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Contents

Introduction	2
Not recognising that people are dying, and not responding to their needs	6
Poor symptom control	9
Poor communication	12
Inadequate out-of-hours service	16
Poor care planning	18
Delays in diagnosis and referrals for treatment	21
Conclusion	24
Glossary	25
Acknowledgements	26

Introduction

Every year, approximately half a million people die in England. For three quarters of people, death is not sudden but is expected, and many of them may benefit from end of life or palliative care. There is potential to improve the experience of care in the last year and months of life for approximately 335,000 people.¹

As the independent organisation responsible for investigating complaints about the NHS, we see tragic cases where people's suffering could have been avoided or lessened with the right care and treatment as they approached the end of their lives. The anguish that this causes them and their loved ones is unimaginable.

End of life care is, sadly, a recurring and consistent theme in our casework. It has also been a key issue for the NHS for some time. We are committed to making sure that complaints make a difference. By highlighting the key themes we see in our casework, we can inform the debate about how, as a society, we can drive up standards to improve the quality of end of life care offered across the country.

This short report features 12 cases that illustrate the issues we regularly see in our casework on end of life care. The examples represent a diverse collection of powerful stories, drawn from a range of different health care settings. They are from all parts of the country and represent different areas of concern.

Key themes are:

- **Not recognising that people are dying, and not responding to their needs**

– if the needs of those who are close to death are not recognised, their care cannot be planned or co-ordinated, which means more crises and distress for the person and their family and carers.

- **Poor symptom control**

– people have watched their loved ones dying in pain or in an agitated state because their symptoms have been ineffectively or poorly managed.

- **Poor communication**

– poor communication is an important element in our complaints on end of life care. It is clear that healthcare professionals do not always have the open and honest conversations with family members and carers that are necessary for them to understand the severity of the situation, and the subsequent choices they will have to make.

- **Inadequate out-of-hours services**

– people who are dying and their carers suffer because of the difficulties in getting palliative care outside normal working hours.

¹ NHS England (Nov 2014) Actions for End of Life Care: 2014-16. Available at: <http://www.england.nhs.uk/wp-content/uploads/2014/11/actions-eolc.pdf>.

- **Poor care planning**

– a failure to plan adequately often leads to the lack of co-ordinated care, for example, GPs and hospitals can fail to liaise.

- **Delays in diagnosis and referrals for treatment**

– this can mean that people are denied the chance to plan for the end of their life and for their final wishes to be met.

The themes in this report chime with the findings and recommendations of other reports and inquiries.² National audits (Royal College of Physicians and Marie Curie Palliative Care Institute, 2014) found that, for example, discussions with patients about their wishes for end of life care are recorded in less than half of cases, and only one fifth of hospitals provide ‘face-to-face’ palliative care services seven days a week. In March, the Health Select Committee published its report into *End of Life Care*.³ The Committee advocates that a named clinician supports the co-ordination of care. It also calls for further training in order to support difficult conversations. The Committee considers that all clinicians and providers should be aware of the Five Priorities of Care that were outlined by

the Leadership Alliance for the Care of Dying People in its report *One Chance to Get it Right* in June 2014:

1. The possibility that a person may die within the next few days or hours is recognised and communicated clearly, decisions are made and actions taken in accordance with the person’s needs and wishes, and these are regularly reviewed and decisions revised accordingly.
2. Sensitive communication takes place between staff and the dying person, and those identified as important to them.
3. The dying person, and those identified as important to them, are involved in decisions about treatment and care to the extent that the dying person wants.
4. The needs of families and others identified as important to the dying person are actively explored, respected and met as far as possible.
5. An individual plan of care, which includes food and drink, symptom control and psychological, social and spiritual support, is agreed, co-ordinated and delivered with compassion.

² The Leadership Alliance for the Care of Dying People (June 2014) *One Chance to Get it Right*. Improving people’s experience of care in the last few days and hours of life. Available at: <https://www.gov.uk>.

The Choice in End of Life Care Programme Board (Feb 2015) *What’s important to me*. A review of choice in end of life care. Available at: <https://www.gov.uk>.

Every moment counts: A narrative for person centred co-ordinated care for people near the end of life. Available at: <http://www.nationalvoices.org.uk>.

³ Health Committee (March 2015) *End of Life Care: Fifth report of session 2014-15*. Available at: <http://www.publications.parliament.uk/pa/cm201415/cmselect/cmhealth/805/805.pdf>.

The Leadership Alliance for the Care of Dying People was a coalition of 21 national organisations that was set up to provide a focus for improving the care of people who are dying and their families. *One Chance to Get it Right* set out a new approach to caring for dying people that health and care organisations and staff in England should adopt in future, irrespective of the healthcare setting. The cases in this report clearly show that these priorities need to be implemented.

Following on from the work of the Leadership Alliance, NHS England published *Actions for End of Life Care: 2014-16*. This set out NHS England's commitment to end of life care and was one component of a wider ambition for statutory and voluntary partners in health and social care to work together to develop a vision for end of life care beyond 2015. This work is ongoing and is being carried out by the Ambitions for End of Life Care Partnership.⁴

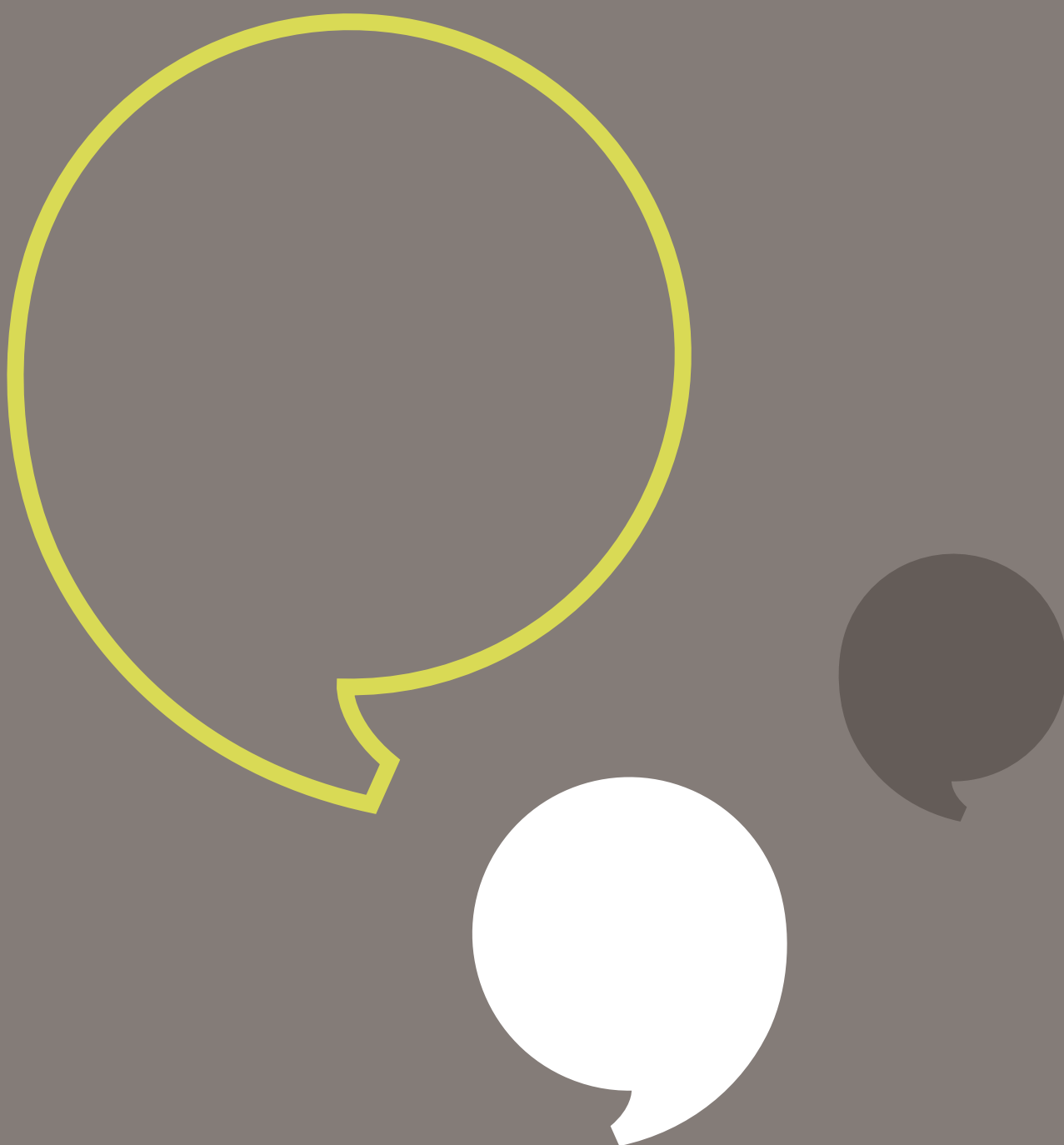
The Partnership aims to transform experiences of end of life care by: focusing on what would improve person-centred care; encouraging local communities to engage with the need for high quality care at the end of life; highlighting what would enable better co-ordination of care, in the last days of life as well as earlier in the course of the illness; and supporting networks of facilitators and champions.

Ultimately, if the NHS is to learn from when things go wrong, the findings in this report should inform any new aims for better end of life care in the NHS in future. Our casework supports the work of the Ambitions for End of Life Care Partnership. We expect the members of the Partnership to make sure the findings in this report lead the way, so that standards and quality of end of life care are improved, and unacceptable variations in care are reduced.

● The experiences of people who are dying and their loved ones of the care provided by the NHS is a recurring theme in complaints. ●

⁴ The Partnership has been formed from members of the Association of Directors of Adult Social Services; Association of Ambulance Chief Executives; Association for Palliative Medicine; the Care Quality Commission; College of Health Care Chaplains; General Medical Council; Health Education England; Hospice UK; Macmillan; Marie Curie; National Bereavement Alliance; National Care Forum; National Council for Palliative Care; National Nurse Consultants Group; National Voices; NHS England; Patients Association; Public Health England; Royal College of GPs; Royal College of Nursing; Royal College of Physicians; Social Care Institute for Excellence; Sue Ryder Care; and Together for Short Lives.

From our casebook



Not recognising that people are dying, and not responding to their needs

In many of the cases that we reviewed, clinicians failed to recognise that the person was dying. In other cases, clinicians did not identify the person's needs. While we appreciate that this is not always easy, there are certain key signs that clinicians should be able to see when someone is coming to the end of their life.

When clinicians do not recognise these signs, it means there is a failure to properly plan and manage care needs, and this is more likely to lead to crises that could be avoided. Inevitably this causes unnecessary distress to the person and their loved ones. It also delays understanding the real situation, and the dying person's wishes. In turn, this does not allow those close to the person to be involved with their death.



Man suffered for four months before receiving the care he needed at the end of his life

What happened

Mr N was a 60-year-old man. He had high blood pressure, poor circulation, and poor mobility. He also suffered from kidney failure that had been treated with dialysis for nine years. Mr N's care was managed by different hospital specialists and his GP Practice.

When Mr N began to have regular episodes of vomiting, it was clear that his health was getting progressively worse. His wife, Mrs N, became increasingly worried, as she was finding it more and more difficult to give her husband the care he needed.

Mrs N contacted a local hospice and asked them for support at this difficult time. But when the hospice spoke to Mr N's GP Practice about referring him, the Practice said he was not yet ready for end of life care because he was still being considered for heart surgery.

Mr N continued to deteriorate. He suffered pain for four months before the Practice referred him to district nurses to give him support at home. Just five days after that, Mr N's Practice registered him on the Gold Standard Framework (which sets out a GP's responsibilities in providing care for patients who are dying) to plan his care because it recognised he was approaching the end of his life. Sadly, Mr N died three days later.

Mrs N explained *'I needed someone to say "right, let's get together in the same room, and here's the plan, we'll all work together so that we can help Mr N", but no one thought it was necessary to do that. They were all interested in their own "bit" and not the person in the middle of it'.*

What we found

Our investigation found that Mr N's GP Practice did not assess his care needs or discuss his priorities for care when it became clear he was so unwell that he was likely to die within the year.

It failed to communicate with other specialists to co-ordinate and plan Mr N's care until three days before he died, even though this was central to its role. We also found that Mr N's Practice could have registered him on the Gold Standard Framework earlier, even though he was still being considered for surgery.

Not enough was done to improve the lives of Mr N or his wife in the four months leading up to his death. Mrs N did not feel supported by the organisations that were meant to help her and her husband in their time of need. This would have made Mrs N's distress even worse and marred the last few months of her husband's life.

● It failed to communicate with other specialists to co-ordinate and plan Mr N's care until three days before he died. ●

Palliative care failure meant man spent the last few hours of his life in pain

What happened

Mr C was 74 when he went to hospital after four days of abdominal pain and vomiting. He was admitted to a surgical ward for investigation, and staff inserted a drip to give him medication and fluids. Mr C spent five days in hospital before he died. During those five days, he suffered ongoing abdominal pain, nausea and vomiting, build-up of fluid on his lungs, breathlessness, chest pain and excessive sweating.

The day after Mr C was admitted, a CT scan showed that he had cancer in his abdomen which had spread to his liver. Clinicians discussed the results with him two days later and further tests were planned. The next day, a different doctor saw Mr C, and this doctor explained that surgery was not an option because the cancer had spread, and that palliative care would be the best course of action.

On the same morning, Mr C saw the palliative care nurse, who recognised that he was approaching the end of his life. She could see he was in a lot of distress, so to relieve his symptoms of breathlessness and bring him some comfort in his final hours, she recommended a chest drain. She also said that pain relief and other medication should be administered subcutaneously (injected under the skin to avoid unnecessary pain), which also would have made Mr C feel more comfortable.

Later that day, Mr C's drip came out and three junior doctors tried to reinsert it 14 times. Staff contacted the on-call anaesthetist to help, but they did not arrive until the next day. Over the course of that afternoon and evening, Mr C

continued to suffer pain. When the anaesthetist arrived, they noted that Mr C was clearly nearing the end of his life. It took them 40 minutes to reinsert the drip, but shortly afterwards, Mr C died. The junior doctors and on-call anaesthetist failed to realise that the reason they struggled to insert the drip was because Mr C's veins were shutting down as he was close to death.

What we found

It was clear from the medical records that the hospital knew Mr C was approaching the end of his life. Despite this, staff did not recognise that a drip was no longer an appropriate treatment option for someone as close to death as Mr C. Because of this, they failed to provide treatment to ease Mr C's discomfort in his final hours.

Mr C was subjected to 14 unnecessary attempts to reinsert the drip, which would have caused him further pain and discomfort in his final hours. The junior doctors and anaesthetist should have acted on the advice of the palliative care nurse and provided him with the necessary medication subcutaneously to make him more comfortable.

Because Mr C was close to death, he was unable to swallow properly, yet the hospital tried to administer pain relief orally. In addition, his pain was not properly monitored and staff recorded that the medication he was given was not working effectively.

Mr C suffered unnecessarily at the end of his life. Mr C's family witnessed this, which caused them additional anguish on top of their inevitable distress at his diagnosis.

Poor symptom control

These cases show how pain, agitation and other distressing symptoms were not adequately controlled as people neared the end of their lives. This caused additional unnecessary suffering for the person who was dying, and also for their loved ones, who were by their bedside in their final days and hours. In many cases, this distress could have been avoided.

● Ms K was receiving
no pain relief to make her
feel more comfortable
in the last stages of her life. ●

Young man dying from cancer suffered for over 11 hours because hospital failed to give effective pain relief

What happened

Mr T was a 29-year-old man who had been diagnosed with widespread cancer. He had stopped responding to treatment and was admitted to hospital with persistent vomiting. It was clear that his health was deteriorating and his family, as well as those involved in his care, agreed that he was dying. As nothing more could be done to treat his cancer, Mr T was transferred to the palliative care unit (the unit) for ongoing support. One of the core goals was to make sure he was pain-free in the last days of his life.

Before being transferred to the unit, Mr T had been receiving continuous pain relief through a syringe driver. At around 1pm on the day that he was transferred, Mr T had been suffering increased pain, restlessness and agitation, so the sister on the unit requested a review of Mr T's pain relief from the on-call doctor. By 8.30pm, the on-call doctor still had not come, so the sister contacted her again. The on-call doctor advised her to call the palliative care advice line about increasing the dose.

After talking to the advice line, the sister spoke to the on-call doctor again to ask that she write up the new prescription for Mr T. However, there had been a change of shift and the new on-call doctor said that she could not come to the unit for an hour. By 11pm, an on-call doctor had still not arrived. Unable to watch her son suffer any longer, Mr T's mother – who had been at his bedside all day – contacted A&E and spoke to an on-call doctor. A surgical doctor then attended at 11.40pm, and prescribed increased pain relief for Mr T, which was set up at 12.30am the following day. Mr T died two days later.

Witnessing her son in the last days of his life was extremely upsetting for Mr T's mother. But knowing he was in pain during this time, and feeling those responsible for caring for him were not relieving his discomfort, added to her sadness and distress. She recalled how her son had pleaded with her: *'Mum please get me out of here. I'm better looked after on ward seven when the doctor comes straight away'*.

What we found

One of the main goals of Mr T's care was to keep him pain-free because he was so close to death. We found that Mr T experienced unnecessary pain and distress for more than 11 hours because the on-call doctors did not respond to the sister's request to review his pain medication, and this issue was never escalated to senior staff.

In addition to this, we found that the delays in Mr T's pain relief meant his mother endured a significant level of additional distress because she had to watch her son in unnecessary pain during the last hours of his life.

Mr T's mother told us that she wanted changes to be made so that the *'same thing that happened [to her son] does not happen to anyone else'*.

Woman received two lots of sedative and no pain relief because of problems with equipment

What happened

Ms K was a 55-year-old woman who was terminally ill with cancer. At the point she was admitted to the hospital, Ms K was suffering from pain and was becoming increasingly distressed and agitated. Three weeks after her admission, a palliative care consultant prescribed a sedative and pain relief to be given by two subcutaneous syringe drivers (these administer a steady dose of medication under the skin).

Two days after the medication was started, a nurse recorded that one of the syringe drivers was faulty, and a replacement was found to have a low battery. The nurse did not record whether the low battery in the new syringe driver was a problem or whether any action had been taken to resolve this. The records show that due to the faulty syringe driver, Ms K had much less medication than prescribed. In addition to this, staff discovered that both syringe drivers contained the sedative, which meant Ms K was receiving no pain relief to make her feel more comfortable in the last stages of her life. Staff noted the error in Ms K's records later the same day, and both syringe drivers were stopped. After a review by the palliative care team, the syringe drivers were restarted.

There was no indication that Ms K was assessed in light of the error or that the hospital looked into the effect having extra sedative and no pain relief would have had on her. Ms K died a week later.

Ms K's brother told us that before the problems with the syringe driver, his sister was communicating, but following the incident she was so drowsy that she was unable to speak to him. Her brother said this meant they didn't get the chance to say goodbye to each other. He was also concerned that his sister suffered unnecessary pain as a result of the error.

What we found

We found that the records for Ms K were so poor that we could not say how or when the syringe driver error occurred, or for how long Ms K received a double dose of sedative. A nurse should have verified the contents of the syringe driver before starting Ms K's medication, and this should have been properly documented on the records. Neither of the syringe drivers delivered the prescribed medication at the correct rate, and no reason for this was given in the records.


Once hospital staff spotted the error, they did not take the appropriate actions to make sure that no harm had come to Ms K, and there was no information to suggest that the incident was properly investigated. The Trust's poor record keeping and failure to thoroughly investigate the incident at the time meant we were not able to reassure Ms K's brother that his sister did not suffer or experience unnecessary harm and pain at the end of her life as a result of the mistake.

Poor communication

Almost all the cases we looked at highlighted failings in communication: between clinician and patient, clinicians and families, clinicians and their team, clinicians and other teams, and between hospitals and care providers in the community.

Poor communication with the person who is dying, and those close to them, means there are uncertainties, unrealistic expectations, indecision about preferences, and missed opportunities for better care and involvement of loved ones, which leads to them being unable to grieve. Failings in communication within and between clinical teams, and poor co-ordination of care, contribute to inadequate palliative and general care.

Doctors can be in no doubt about what is expected of them in terms of communication. The General Medical Council guidance makes it very clear that patients must be given the information they want or need in a way they understand, that doctors must show consideration to those close to the patient, and that doctors must work collaboratively with colleagues.



● It was inappropriate for the Practice manager to break the news that his mother was dying. ●

GP Practice failed to tell older woman she was dying from cancer

What happened

Mrs W was an 89-year-old deaf woman who had been diagnosed with incurable bladder cancer. She visited her GP because she had been coughing up blood, and was sent for a chest X-ray. At a follow-up appointment with her GP, Mrs W was told that the X-ray had found the cancer had spread to her lungs. That same day, Mrs W's GP called the hospital and was told that Mrs W only had a short time to live. It was agreed that the GP would break the news to Mrs W and arrange for her to receive palliative care.

The following day Mrs W's GP Practice referred her to the Macmillan nursing team and wrote to her explaining that her GP would like to see her. Mrs W did not respond to that request and the Practice did not follow this up. Almost two weeks later, Mrs W's son, Mr W, visited her GP Practice and at this point, the Practice manager told Mr W that his mother was dying. Mr W was extremely upset that his mother had not been made aware of the seriousness of her condition sooner. The following month, Mrs W's GP Practice referred her to the district nursing team for support. She died a month later. Her son said that *'the GP Practice had marginalised her as a profoundly deaf person'*.

What we found

As Mrs W was deaf, rather than call her, the GP Practice wrote to her explaining that her GP would like to see her to discuss her prognosis. This was understandable. However, given how important it was to let Mrs W know that she was dying, we concluded that her GP Practice should have followed up on its letter when Mrs W did not respond. We agreed with her son that it was inappropriate for the Practice manager to break the news that his mother was dying, and we could appreciate how distressing it must have been for him to have found out in this way that his mother was dying.

Although the GP Practice had taken relevant steps to involve the Macmillan and district nursing teams in Mrs W's care, its delay in telling her she was dying meant that a plan for Mrs W's palliative care was not made as soon as it could have been. We felt that the Macmillan nursing team would have been able to provide more effective care and support for Mrs W, if she had known that she did not have long to live.

Woman's family left without explanation of her genetic disorder months after she died

What happened

Mrs E was 69 years old and had been suffering with severe mental health problems for many years. She was admitted to hospital as an emergency patient because she was no longer able to swallow. Her husband, Mr E, who was her main carer, explained that this was preventing her from taking the medication she needed to manage her mental health condition. After several weeks in hospital, a junior doctor told Mr E that a blood test result showed that she had Huntingdon's disease, a hereditary disorder of the nervous system characterised by the development, in middle life, of jerking movements and progressive dementia.

There is no specific treatment for Huntingdon's disease. The children of someone who has the condition have a 50% chance of developing it themselves.

The doctor gave Mr E some printed information about Huntingdon's disease but was not able to answer his specific questions about what the diagnosis meant for Mrs E and her children and grandchildren. Mr E said that the news of his wife's illness came as a complete shock. Feeling very concerned, he contacted the specialist to discuss the diagnosis, and the likely progression of his wife's disease, and to find out how it might affect his family. The specialist was away. When he returned, staff made an outpatient appointment for three months' time without contacting Mr E to find out what he wanted. Mrs E died before the date of the appointment.

Mr E complained about the delay in providing an appointment and was told that the specialist was not responsible for his wife's care. The specialist offered to arrange for a second opinion but that did not happen. In the end, three months after the death of his wife, Mr E had to ask his GP for a referral to another specialist to answer his concerns. Mr E said that the hospital did not treat him and his family as people with concerns and feelings:

'This "not knowing" caused us considerable distress... knowing that my children and grandchildren may have inherited the disease. This was totally unnecessary.'

What we found

We said that the Trust had not treated Mrs E and her family in a patient-focused way, and that the problems they experienced could have been sorted out many months earlier with a quick telephone call to establish what Mr E wanted to talk about. We also found that there were significant communication failings in this case between different parts of the Trust, as well as the Trust and Mrs E's family.

Mr J discovered he had cancer after reading his hospital discharge note

What happened

Mr J, 67, had been experiencing chest pain and was referred for an X-ray. The radiologist noted that one side of his diaphragm was elevated but put this down to a high-placed liver. As the radiologist felt the X-ray did not raise any concerns, no further investigations were carried out. Over the next year, Mr J had two more X-rays because of chest pain and breathlessness. Then, almost 12 months after the first X-ray, he had a scan that indicated he had lung cancer. Despite further tests and specialist appointments, Mr J was not told about this before he was discharged from hospital.

Details of Mr J's diagnosis were included on the discharge note to his GP and he was given a copy, which was when he learnt of his likely cancer. His daughter wrote *'it was I who read the discharge note first and I was devastated. I had to decipher the medical terms... before daring to tell the rest of the family including my father this awful news'*. Further tests confirmed lung cancer, and that it had spread to Mr J's bones and brain. Mr J was treated with radiotherapy, but his health continued to deteriorate.

Two months later, Mr J was admitted to hospital because he was struggling to breathe. Once he was on a ward, his pain relief was stopped because it was thought he was becoming too dependent on it. He was started on pain relief again the next day, but by that point Mr J was severely agitated and in pain. He died in the early hours of the following morning.

What we found


The way that Mr J and his family learnt of his diagnosis was appalling, and failed every principle of established good practice in breaking bad news. There was an avoidable delay in making a diagnosis: an earlier diagnosis would have meant opportunities for better palliative care. Mr J's pain relief was inappropriately stopped and staff did not help to address his family's concerns about his pain relief and agitated confusion.

In addition, we found that the clinicians treating Mr J recognised that he was at the end of his life but did not explain this to his family in a way they could understand. All of these failures meant that Mr J and his family's experience of his care in the last few days of his life was significantly more distressing than it should have been.

● The way that Mr J and his family learnt of his diagnosis was appalling. ●

Inadequate out-of-hours service

We also considered several cases where people who were dying had extremely poor experiences in getting support outside normal working hours. This can be because emergency medical services are often under pressure out of hours, and many specialist palliative care services are not able to provide round-the-clock availability.



● This team would only have been available from 9am, because its staff did not work overnight. ●

Family watched loved one suffer because the palliative care team were not available to help control woman's distressing symptoms in last hours of her life

What happened

Ms B was a 56-year-old woman with epilepsy who suffered a cardiac arrest at home. She was resuscitated and was admitted to the intensive care unit in hospital. Two days later, the clinical team decided that there was little more that could be done to actively treat Ms B because she had suffered severe brain damage when her heart stopped. Staff discussed this with Ms B's son and her sister, Mrs A, and Ms B was treated using the Liverpool Care Pathway.

At around midnight the following day, Ms B's care was transferred to a general ward. The information that the intensive care unit gave the general ward before the transfer is not documented. Also, the medication Ms B was given on the intensive care unit was not written up for use on the general ward, which meant Ms B did not get pain relief and sedation on the general ward until 3.30am. At this time, a nurse noted that Ms B was suffering from a fever and was having a seizure, and that the medication had little effect in controlling her symptoms of stiffness, twitching and gurgling.

Five hours later, the ward sister asked the consultant to review Ms B because she had continued to be unsettled, despite being given additional pain relief and sedation overnight. The consultant prescribed additional sedation, which Ms B did not receive for nearly another two hours. Ms B's symptoms remained the same, so the ward sister called the palliative care team for help. This team would only have been available from 9am, because its staff did not work overnight. At 11.45am, the palliative care team prescribed additional pain relief and sedation for Ms B, but she died shortly after.

Ms B's sister and son remained at her bedside throughout this time and described how distressing it was to witness her rapid breathing and her chest bubbling while they waited for the palliative care team to relieve her symptoms.

What we found

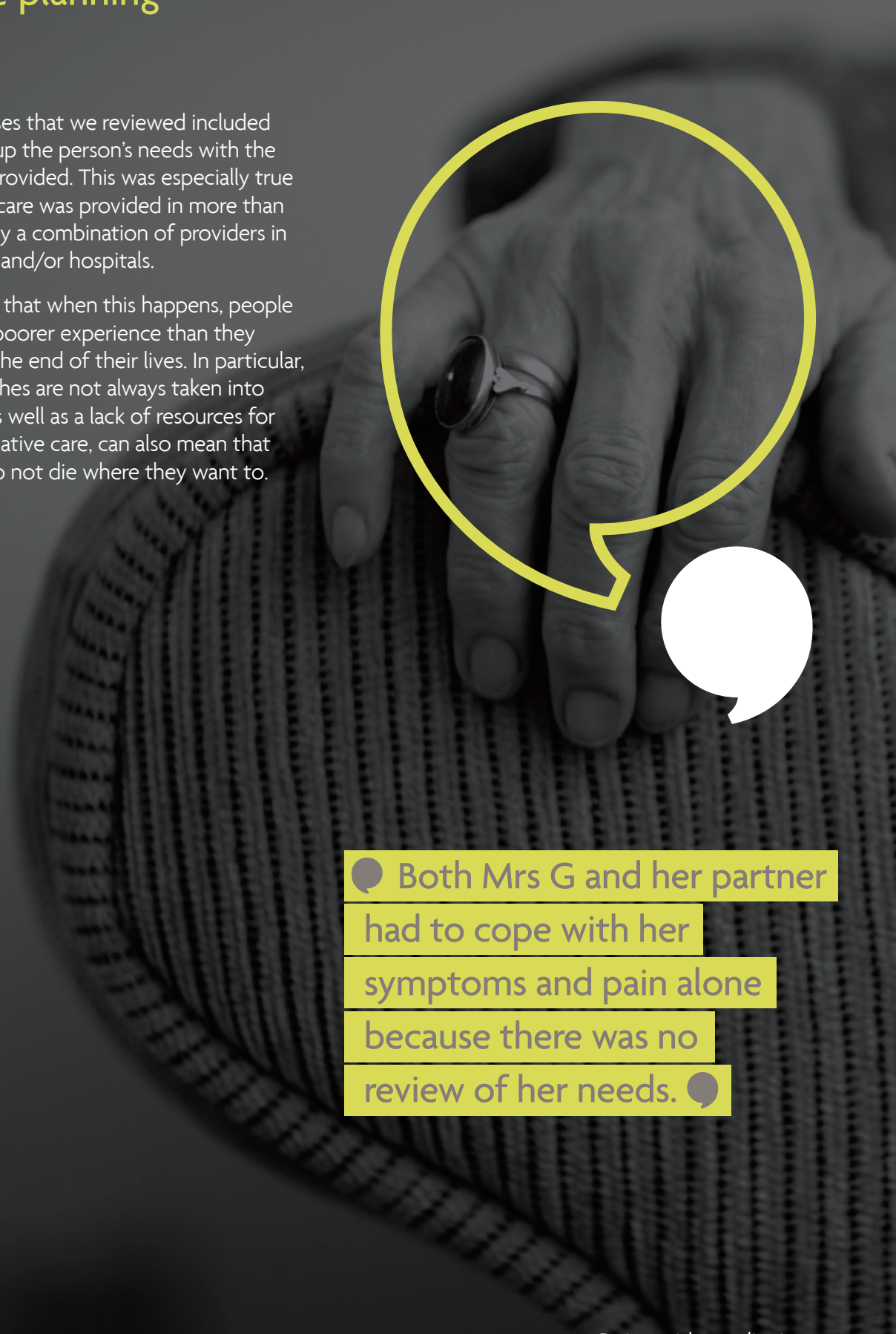
The Trust's decision to withdraw active treatment and place Ms B on an end-of-life care pathway was appropriate, and had been properly discussed with Ms B's family. However, we said that Ms B needed to be treated in an environment with intensive nursing and appropriate medical staff who were available to prescribe and administer medication that was needed once the decision to withdraw active treatment was made. But this did not happen until the palliative care team was called, and there were unnecessary delays in giving Ms B pain relief and sedation on the general ward.

We said that because national guidance discourages the transfer of patients between the hours of 10pm and 7am, this situation could have been avoided had Ms B not been transferred to the general ward overnight, when the palliative care team was not available. It could also have been avoided if the transferring intensive care team and the receiving ward team had carried out an appropriate handover. We agreed that Ms B's son and her sister have been caused significant unnecessary distress at witnessing their loved one suffer because her symptoms were poorly controlled.

Poor care planning

Many of the cases that we reviewed included a failure to link up the person's needs with the services being provided. This was especially true of cases where care was provided in more than one setting or by a combination of providers in the community and/or hospitals.

Our cases show that when this happens, people tend to have a poorer experience than they should have at the end of their lives. In particular, the person's wishes are not always taken into account. This, as well as a lack of resources for community palliative care, can also mean that people often do not die where they want to.



Both Mrs G and her partner had to cope with her symptoms and pain alone because there was no review of her needs.

Terminally ill woman denied her wish to die at home

What happened

Mrs G was an 82-year-old lady with advanced lung cancer that had spread. She lived alone and had limited sight because of diabetes. By the summer, she was no longer fully able to move around without help and her partner (who complained to us) said that Mrs G had been told that there was no more that could be done to treat her cancer. Mrs G told her partner that she wished to die at home surrounded by her loved ones.

Mrs G's GP and a Macmillan nurse saw her regularly until the summer, when she saw an out-of-hours doctor because of abdominal pain, vomiting and shortness of breath. She did not want to go to hospital, so the out-of-hours doctor asked her GP to review her. Her partner also requested a GP visit but this did not happen because she was admitted to hospital later that day.

Mrs G was discharged the next day. The discharge summary noted that Mrs G *'was desperately keen to go home... She was deemed safe to return home with support from community palliative care'*. The discharge note to the Practice asked the GP to confirm that he would call on her as planned two weeks later. This did not match the appointment scheduled by the Practice, which said the visit was due to take place three weeks later. Mrs G was not seen or reviewed by Practice staff after her return home.

Mrs G's illness progressed, and 12 days after her discharge from hospital she called paramedics because of chest pain. A note of her contact with the paramedics asked for the GP to review

her. Mrs G had an appointment at the oncology clinic on the same day, where clinicians noted that her condition had quickly deteriorated and she admitted that she was not coping at home. She was taken to hospital to wait for a hospice place to become available. Mrs G died a few days later, shortly after moving to the hospice.

What we found

Mrs G's GP did not take the appropriate steps to help her plan for the inevitable progression of her illness or to discuss her wishes and needs before she died. The Practice then missed an opportunity to react when it became clear in the summer that her condition was deteriorating, and she was accessing out-of-hours care. At this point the Practice could have reviewed her to make sure that she had the support that she needed at home.

After she returned home, Mrs G struggled to cope with the pain and other symptoms of her terminal cancer, as well as her pre-existing medical conditions. Both Mrs G and her partner had to cope with her symptoms and pain alone because there was no review of her needs. They experienced the distress of her worsening health with little support. We concluded that Mrs G would have been able to die at home as she had wished, if her GP Practice had made proper plans to support her through the end of her life.

Mental health trust failed to manage terminally ill man's care needs while he was detained in hospital

What happened

Mr M was a 77-year-old man with Alzheimer's disease. He had been diagnosed with bowel cancer that had spread to his lungs. He had also been diagnosed with a brain tumour and had been told by his oncologist that he only had three months left to live.

The following month, Mr M moved into a hospice for a period of respite care. During his stay, he became very agitated, confused and distressed, and tried to leave on a number of occasions. Hospice staff carried out a mental health assessment, and Mr M was detained under the *Mental Health Act 1983*. As a result of this, he was transferred to a mental health hospital.

On the day of Mr M's transfer to the mental health hospital, he was seen by a doctor who was unable to complete a full assessment and examination of him because there were six other patients waiting to be admitted at the time. Staff set up basic care plans to manage Mr M's care, and nurses were asked to record daily observations of his condition.

The following day, the nurses noted that Mr M had a high temperature so they asked a doctor to see him, but the doctor did not attend. A doctor carried out a ward round two days later, but Mr M was still not examined. It was only when Mr M's family raised concerns about his worsening condition two days later that a doctor was called. The doctor examined Mr M, and he was taken to A&E, where staff diagnosed him with pneumonia. Mr M returned to the hospice after six days of treatment, but died the following day.

Mr M's daughter said that she knew her father would die, but she felt that she and her family were '*robbed of quality time with him*' because his pneumonia was not diagnosed and treated sooner.

What we found


The mental health trust failed to take appropriate action to plan and deliver Mr M's complex end of life and palliative care needs. This included a failure to discuss those needs with him and his family, and a failure to communicate with the hospice and other specialised staff to arrange Mr M's end of life care plan and organise his care.

The nurses and doctors failed to carry out appropriate examinations or tests, particularly when it came to responding to Mr M's worsening health. Staff only took action on the day he was taken to A&E because of the concerns his family raised. We said that Mr M's family were caused unnecessary distress by having to witness these basic failings in his care.

Delays in diagnosis and referrals for treatment

Delivery and organisational problems also mean that people experience delays in diagnosis and treatment.

Our casework shows that this often results in delays in referrals to palliative care, failure to implement important aspects of an agreed care plan, and poor needs assessment, leading to inadequate personal care and poor nutrition. The result can be a lack of dignity at the end of a person's life.



● It was at least another five hours until Mrs D received the pain relief she needed and she died hours later. ●

Delayed diagnosis meant man and his family did not get vital support at the end of his life

What happened

Mr P was 67 years old when he started to suffer from chest pain. His GP sent him for an X-ray, which showed fluid in the chest cavity. Mr P had a procedure to drain this, and a CT scan. Mr P saw a consultant a week after his CT scan who told him that no cancer cells had been found in the fluid drained from his lung and the scan had not detected a mass on his lungs. It was agreed that he would be reviewed in two months. Six weeks after this consultation, Mr P was admitted to hospital with breathlessness and pain in his right side. Clinicians drained more fluid from his chest and he was sent home a few weeks later with plans for further investigations.

Over two months after the consultation, staff discussed Mr P's case at a multidisciplinary team meeting, and raised the possibility of cancer. At the next multidisciplinary team meeting two weeks later, clinicians agreed to carry out a computer-guided biopsy, and this was scheduled for the following month. Between this meeting and the biopsy, Mr P was admitted to hospital again with chest pain. His GP prescribed him morphine.

When staff discussed Mr P's biopsy test results a few weeks after the procedure, they agreed that he had cancer, but further tests were needed to confirm what type of cancer this was. Shortly after, doctors gave Mr P his provisional diagnosis and an appointment was made for him to discuss palliative care. But when he attended the appointment, the consultant was not there. Mr P continued to deteriorate. He struggled to cope with daily tasks so his family bought a shower chair for him and arranged for him to borrow a wheelchair. Just over a month after receiving his cancer diagnosis, Mr P died at home.

Mr P's family were concerned about the delays in diagnosing his cancer, and felt that his pain was not well managed. They explained that he had been in terrible pain, had lost a lot of weight and it was clear that he was very ill for six months before he was given a diagnosis.

His daughter said Mr P's family felt he had been let down by the NHS in his hour of need. She said that because of the uncertainty, lack of communication and support, he and his family had suffered additional stress.

What we found

As no cancer diagnosis had been made by the time of the initial consultation, the consultant should have considered what else could be causing Mr P's symptoms. If clinicians had explored other options at that time, it is likely that they would have diagnosed Mr P's cancer much sooner. We said that the delay in arranging the biopsy further delayed his diagnosis. There was then a delay of four weeks in confirming his provisional diagnosis, during which time more could have been done to support Mr P and his family.

If Mr P's diagnosis had been made earlier, it would have meant that palliative care, pain relief and appropriate advice and support could have been put in place much sooner. Not only would this have reduced the impact of the illness on Mr P and his family, but it would have given them time to come to terms with the fact that their loved one was in the last stages of his life.

Woman left without cancer treatment until it was too late

What happened

Mrs D was a 63-year-old woman who had been referred to hospital by her GP because she was bleeding from her vagina. It had been more than ten years since her periods had stopped. A registrar reviewed her after a scan showed that she had an abnormality around her right ovary and fallopian tube. Following discussions with a consultant, the registrar scheduled a procedure to examine Mrs D's womb using a camera, and to perform keyhole surgery to remove her right ovary and fallopian tube.

A second registrar carried out the examination ten days later, but the keyhole surgery did not take place and the reasons for this were not documented. The second registrar told Mrs D her vagina and cervix were wasting away, and gave her cream to treat this. A follow-up appointment was planned for four weeks' time, but Mrs D was not seen again until two months later.

At the next appointment, Mrs D saw a third registrar. Even though she was experiencing ongoing heavy bleeding, the plan was for her to be reviewed in the gynaecology clinic again in two months' time, and for blood samples to be taken the following month to test for cancer. But Mrs D's GP had grown very concerned about her condition, particularly after she reported that she had *'felt something coming out of her vagina'*. She referred Mrs D to the hospital again and asked that she be reviewed by a consultant.

In response to the GP's letter, a consultant saw Mrs D the next month. The consultant arranged a further scan and a blood test for cancer. Mrs D was then referred to a third consultant, who found a solid mass of dead tissue in Mrs D's vagina and pelvis. He suspected she might have cancer, and arranged for a biopsy to be taken for

testing. Ten days later, cancer of the cervix was confirmed.

The third consultant arranged an appointment for Mrs D to see a gynaecological oncologist, but four days before the appointment was due, Mrs D's condition suddenly worsened. She was admitted to hospital with intense pain and vomiting.

While she was in the hospital, Mrs D received pain relief through a syringe driver. On the day before Mrs D died it was agreed that her pain relief needed to be increased because she was anxious and in pain. At 2.15pm that day, a palliative care nurse noted that pain relief had still not arrived. It was at least another five hours until Mrs D received the pain relief she needed and she died hours later, ten days after being admitted.

Mrs D's sister said that had her sister known sooner, *'she would have acted very differently in the last months of her life'*.

What we found

The hospital had let relatively junior doctors care for and treat Mrs D without making sure her care was discussed with a skilled and experienced supervising consultant. The doctors involved failed to recognise the type of bleeding Mrs D was experiencing and missed opportunities to perform relevant investigations, including a biopsy, at an earlier stage. There were also delays in follow up and review. Even though Mrs D would still have died, if her condition had been identified and treated sooner, she could potentially have been given more time. Over the final days of her life, Mrs D suffered unnecessary discomfort and agitation because of failure to assess her pain and the effectiveness of her pain relief.

Conclusion

As the Parliamentary and Health Service Ombudsman is at the apex of the complaints system, by definition we only see those cases that it has not been possible to resolve locally. However, our casework adds insight into what goes wrong in the most complex cases and what learning there might be for the NHS to prevent similar situations occurring again.

Our casework shows there is a need for the NHS to get better at:

- recognising that people are dying – the cases in this report show that if clinicians better recognise the risk of approaching death, important conversations can take place to establish the patient's preferences, needs can be assessed and planned for, and crisis interventions can be avoided;
- making sure that symptoms are properly controlled – the greatest fear expressed by people about dying is being in pain.⁵ Yet with good care it is unusual for pain not to be controlled acceptably. This report illustrates that some clinicians need to be more confident with established good practice, such as the skilled use of morphine and other opiate drugs;
- communicating with people, their families and each other – the cases in this report show health care professionals need to be supported to be better at having open discussions about care towards the end of life. There is a need to communicate in a way that is both sensitive but also makes clear the prognosis and what options there are for

care based on the outcomes individuals may want for themselves. This report shows that patients, but also their families, should have opportunities to discuss their concerns and fears;

- providing out of hours services – our casework shows the harrowing results when patients cannot get the services they need. For the benefit of their comfort, dignity and wellbeing, all in need should have access to specialist palliative care services whenever they need it; and
- making sure that service delivery and organisation help people have a good death – the importance of linking up people with services and ensuring that the service they do receive is timely and appropriate is clear from the cases in this report.

How we die is part of the core business of the NHS, and a matter of concern to all. Getting better in these ways would improve the experience of dying immeasurably.

The learning from our casework provides further evidence in support of several of the findings of the House of Commons Health Select Committee report, in particular the need for more access to palliative care services; improved resources for support in the community; and better leadership. This is why we are now calling upon the Ambitions for End of Life Partnership to use the learning identified in this report to underpin any new ambitions for end of life care, and upon the whole of the NHS to find the collective will to make those ambitions a reality.

⁵ As reported by 83% of those surveyed by ComRes for 'Dying Matters' in 2011.

Glossary

Alzheimer's disease – A progressive condition, and one that is the most common cause of dementia. It results in brain cells dying, leading to the loss of mental ability.

Anaesthetist – A doctor who specialises in pain management and pain relief.

Biopsy – A medical procedure that involves removing a sample of tissue so that it can be examined under a microscope in a laboratory, usually in order to diagnose a condition.

Cardiac arrest – An emergency condition that happens when a person's heart stops beating, or when their heart beat is no longer effective enough to pump sufficient blood around their body.

CT scan – X-rays configured by computer to give three-dimensional images far more powerful than those produced by conventional techniques.

Cervix – The part of the female reproductive system that connects the vagina to the womb.

Dialysis – A treatment in which waste products, excess salt and excess water are artificially filtered from the bloodstream because a person's kidneys are not healthy enough to perform this function.

Drip – A thin tube used to deliver fluids or medication directly into a patient's vein.

Fallopian tube – One of the two parts of the female reproductive system that connect the ovaries (see below) to the womb.

Gold Standard Framework – A national training and co-ordinating centre supporting clinical staff and organisations to use processes and to work in ways to ensure best possible care for those nearing the end of their lives.

Gynaecologist – A doctor who specialises in the diagnosis and treatment of conditions affecting women, particularly those involving the female reproductive system.

The Liverpool Care Pathway (for the dying patient) – Was developed through the 1990s with the intention of extending the principles of hospice care to other community and hospital settings. Its holistic approach included measures for comfort; stopping treatment that was no longer appropriate; prescribing medicines to help anticipated difficulties; psychological and spiritual care; and support for the family.

Macmillan nurses – Experienced nurses who specialise in palliative care and who work mainly in people's homes and in NHS hospitals. They support patients with cancer, assess complex needs, and support other involved professionals. Marie Curie nurses fulfil a similar role, but provide more 'hands on' care and longer periods of direct care, often including overnight.

The Mental Health Act 1983 – Legislation that was introduced in the UK that sets out how to manage and treat people who have, or are suspected of having, mental health problems.

Morphine – An opiate-based drug that is used to relieve severe pain.

Multidisciplinary team – Professionals from different specialist health and social care backgrounds working together to meet a patient's individual needs.

Oncologist – A doctor who specialises in the diagnosis and treatment of cancer.

Ovary – One of two parts of the female reproductive system that is responsible for releasing eggs.

Palliative care – Care that is delivered to relieve the symptoms and distress of serious illness, rather than provide a cure.

Pneumonia – Inflammation of the lung(s), usually caused by an infection.

Radiologist – A doctor who specialises in the interpretation of medical images, and how they are used for treatment.

Radiotherapy – A treatment that uses high-energy beams of radiation to kill or slow the growth of cells, usually in cases of cancer.

Subcutaneous treatment – The delivery of treatment, usually fluids or medication, through an injection under the surface of the skin.

Syringe driver – A medical device that allows the continuous delivery of liquid medication over a period of time through an injection under the skin.

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