

# The way we die now

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Personal stories of terminal illness in the UK

November 2015



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Care and support  
through terminal illness

# We believe everyone should have the right to palliative care when they need it



Everyone's experience at the end of their life is different. The stories of how people die are as individual and complex as their lives.

At Marie Curie, in our role offering care and support to people living with a terminal illness, and their families, we hear many thousands of stories every year. But there are some themes that recur, time and time again.

They include the importance of clear communication, the need for emotional support as well as clinical support, and the damage that can be caused by unnecessary stays in hospital.

Very often, though, we simply hear that the care and support people wanted was not always there when they needed it.

People may be told that things are too complex or not possible. They may not be told anything at all. Or support may be offered to them too late to really help them.

This report presents just a handful of the stories we hear, day in, day out, from people affected by terminal illness.

They show that, when someone has a terminal illness, they and their family find themselves in a situation entirely new to them, dealing with unfamiliar organisations, concepts and people.

People with a terminal illness, and their families, often don't have a clear sense of what care and support might be available and what they are entitled to.

These issues should concern us all. More than half of the people over 50 in the UK have been affected by the terminal illness of a friend or relative in the last ten years.

And more than half are not confident they will get the care they need towards the end of their lives.

We know it is possible for people to feel safe, supported and cared for right up until the end.

We want that for everyone.

We believe everyone should have the right to palliative care when they need it.

A handwritten signature in black ink that reads "JECollins". The signature is written in a cursive style with a long horizontal line extending to the right.

Dr. Jane Collins,  
Chief Executive, Marie Curie

# Personal stories of terminal illness

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*The stories in this report paint a picture of inconsistent care for people with a terminal illness in the UK.*



We at Marie Curie would like to thank everyone whose story is told in this report for sharing their experiences – their good memories and their painful ones alike.

## Rose's story

*Rose was diagnosed with gastro-oesophageal cancer just over a year before she died in December 2013 at the age of 54.*

*Her husband Philip explains:*



**Rose (above) needed more care during the day**

We did think something was seriously wrong. Rose had been losing a lot of weight; she had real trouble swallowing and so eating was very difficult.

My daughter-in-law took her to the hospital for the endoscopy as I had to work. After the procedure, they took her into a side room and told her it was cancer.

It was devastating and a real shock.

She had chemotherapy, but it was palliative treatment. I knew that and I think she knew but we never actually talked about it.

I always tried to be positive. I was looking to the future. I think if I had been negative, then she wouldn't have lived as long as she did in a way.

Within two to three months, she was going downhill quite fast. She had a stent fitted onto her oesophagus and that gave her more pain. She had oral morphine and that was delivered by the district nurse once a week.

The doctors were just out of their depth. Our GP wasn't a specialist and just didn't know what to do with us. Looking back, I wish I had asked for more help but I didn't know what to ask for really.

I wish we had got more care during the day when I was at work - a carer coming in or a nurse. But we had always been independent and I didn't know what to ask for. She didn't need help with bathing and things like that. I used to fill a little capsule for her morphine for the day before I went to work and leave it by her.

Looking back on it, it must have been awful for her, being on her own all day. I find it hard to think about that.

“Our GP wasn’t a specialist and just didn’t know what to do with us. Looking back, I wish I had asked for more help but I didn’t know what to ask for really.”

About nine days before she died, I stopped working. It was at that point that a carer did come in. But by then it was too little, too late.

At the end, she just lay down as she had gotten too weak. It was a Thursday evening and she died peacefully with us all there.

It was a relief really as she couldn’t carry on any more. She was too weak. I’m glad we were all there with her and that she wasn’t alone at the end.

I’m still depressed. I did try to get bereavement counselling but the GP didn’t get back to me.

It’s very hard but I am trying. I have to just cope.

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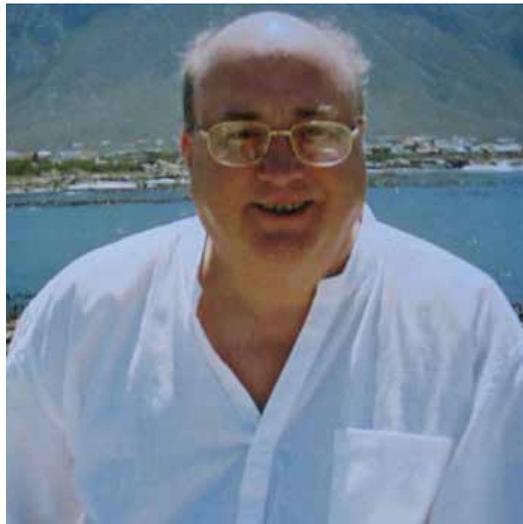
## What does Rose’s story tell us?

At the heart of Rose’s story is the need for specialist palliative care support to be available for those providing medical care, who may not be experts in this field, as well as for the person who has a terminal illness and their loved ones.

People shouldn’t feel, like Philip does, that there was more that could have been done if only he had known what. We need to recognise the impact on carers of looking after a loved one with a terminal illness, and make sure they don’t feel alone and that they can get the support they need when they need it.

## Bernard's story

*Bernard was diagnosed with end stage liver disease about six months before he died, at the age of 58. His wife Jayne describes their experience:*



**Bernard (above) was told he had two years to live**

Bernard woke up one morning with jaundice; after an emergency GP appointment, he was sent to hospital for tests and was diagnosed with end stage liver disease. He was told he would only have two years to live.

He was given his terminal diagnosis while he was staying in hospital, within the earshot of other patients. There was so little privacy for him to get such news, and he had to break the news to me during that evening's visiting time.

It wasn't a good experience, from the beginning to the end. Bernard was out of hospital for a few weeks after his diagnosis and we saw his GP each week.

But what became apparent to us was the lack of communication between the hospital and the community services. Sometimes they didn't seem to know what was going on, or what they should be doing for us.

I had to give up a job I loved to be my husband's main carer, while I took up another job that was closer to home. Being a carer also meant a loss of financial stability. My whole life situation changed.

In the last few weeks before my husband died, one of his toes had to be amputated because of his diabetes. After being discharged for just one week, he was back in hospital again because he had developed septicaemia.

After spending a week in intensive care, he was moved to a general ward with 20 other patients. I spent some nights sleeping on a chair next to him so I could be with him.

We were not offered any palliative care support. The only day that we had any dealings with the palliative care team was on the day before he died. A palliative care nurse came by,

“At the hospital, there was no personal space for us to spend our time together. In his final weeks, he was bed-bound and in a lot of pain because of all the bed sores he had.”

to let us know that my husband only had hours to live, and to ask us if he needed a priest.

I wish there was more communication, and earlier in time, to help us prepare for the end and to discuss his last wishes.

At the hospital, there was no personal space for us to spend our time together. In his final weeks, he was bed-bound and in a lot of pain because of all the bedsores he had. He was mostly

confused, as he was heavily sedated. It was hard seeing him coming out of sedation and then waiting in agony for painkillers.

In his last few days, I asked the hospital staff if he could come home and they told me it wasn't an option they could consider as it took too much organising. We weren't given the option of care in a hospice either.

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## What does Bernard's story tell us?

We know healthcare professionals don't refer people with some terminal illnesses for palliative care as consistently or quickly as they do for those with other conditions. We know that people with illnesses like Bernard's can benefit considerably from the early intervention of palliative care.

Bernard's last weeks and months would no doubt have been better for both him and Jayne had the healthcare professionals looking after him been better at communicating. Often this is because they have not had training or not been offered ongoing support to help them care for people who have a terminal illness. These conversations between healthcare professionals and their patients are often not easy ones, but they are ones which can be made easier with the right help in place.

## Joan's story

*Joan was diagnosed with vascular dementia in August 2014 and died that December. Her granddaughter Sara had to move from her home to care for Joan:*



Joan (seated) with (from left) her granddaughter Sara, her daughter and great-granddaughter

I knew my nan didn't want to be in a home. I am the only child of an only child so there was just me. My mum is elderly herself. She has Parkinson's disease and she just couldn't cope. I left my husband and my kids to move to care for Nan.

When I first moved in, I contacted social services but was told Nan wasn't entitled to any care. So we decided to pay for private care. The carers were nice, but they were not experts in dementia care. They just thought she was this sweet old woman

and then couldn't understand why she suddenly swore at them or got really upset and angry.

So from August until she went into hospital in November, I was on my own. It felt like I was battling for everything and going round in circles dealing with social services. For example, I was given a crisis number as I was having a problem managing my nan's aggressive behaviour. So I called it but they gave me a different number that sent me somewhere else. It was very stressful.

There was also a lack of any physical help. When Nan had a fall, the carer refused to lift her due to health and safety regulations. So I called 999 but was told it wasn't a priority. So I called my mum over and together we managed to lift her up, but we both hurt our backs doing it.

It was only when Nan was admitted to hospital with a kidney infection that a social worker told me she was actually entitled to some financial support. She also told us I qualified for an increased carer's allowance. But I should have got it a lot sooner and it would have been really helpful.

“There were times when she was being looked after in the community that it felt like she was a social embarrassment and I struggled to get her the care she needed.”

Nan came out of hospital with a discharge care package. She stayed in a residential home for a week, as her boiler wasn't working. But once the boiler was fixed, we brought her home. That was what she would have wanted if she'd been able to express it.

She deteriorated quite quickly and the GP advised that she needed end of life care. He made the referrals to the district nurse and I asked him to make a referral for a Marie Curie Nurse too. It all happened in 12 hours which was

really good. A hospital bed was brought around and they got the dose of pain relief right and made sure she wasn't in any pain.

I have no complaints about my nan's care when she was terminally ill. At the end, she was treated like an individual. But there were times when she was being looked after in the community that it felt like she was a social embarrassment and I struggled to get her the care she needed.

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## What does Joan's story tell us?

Although often not recognised as such, dementia is a terminal illness. Early support from palliative care specialists can bring great benefits to patients, not just in areas like pain relief but also emotional and practical support.

Joan could have heard much sooner about her entitlements if she had been referred to a palliative care social worker or even just signposted to an information service like the Marie Curie Support Line.

## Chris' story

*Chris was diagnosed with a brain tumour in 2008, and died 18 months later. He had two young sons who were just seven months and five years old when they lost their dad. Chris' wife Helen explains:*



Chris (above) with his wife Helen

Before he was diagnosed I started noticing changes in Chris' personality; he was suffering from frequent headaches, having difficulty concentrating, and had become moody and distant. He was being treated by his GP for stress and depression.

He had his first serious fit in March 2008 and was admitted to hospital as an emergency case. Two weeks later he was transferred to another hospital and eventually diagnosed.

Chris had brain surgery, which removed most of the tumour, but the biopsy results showed he would need additional radiotherapy, the side-effects of which were profound.

He was unable to return to work and struggled with things that he used to enjoy, like reading and playing guitar, which was emotionally very hard for him. He would struggle with making decisions and thinking things through and had to surrender his driving licence.

In addition, Chris' balance and co-ordination were affected and he was prone to seizures which would make him fearful and distort what he saw around him. He suffered terrible headaches and nausea and, on occasions when we had to call out district nurses to administer injected pain relief, we waited several hours for them to arrive.

He began chemotherapy in February 2009 and had further brain surgery in June. However, in August, Chris was diagnosed as terminal and referred to the palliative care team.

We did have some good support during Chris' illness, but services are very fragmented and I had to research what we were entitled to. We had support from Macmillan to negotiate the benefits system, and our GP surgery referred us to a district nurse.

The local hospice referred us for overnight nursing care which was initially one night a week, then two

“I don’t think people realise how minimal the available support can be for the terminally ill. Everyone should have a choice. Ours was taken away.”

as Chris became more unwell. Social services organised a carer who came to help us every morning for an hour.

Unfortunately, no friends or family were able to help us, so I would be looking after our five-year-old son, our baby and my dying husband, with no help for five or six nights a week. It was daunting.

We had planned our baby’s naming day for the end of August 2009. The night before, he took a turn for the worse. I was persuaded to agree to a hospice admission, for two days, to review his medications. He was there ten days and never came home.

I was at the end of my tether and they could probably see that, but I would have preferred to have had support looking after my husband at home, or at least a discussion about what was possible. In the absence of that, the hospice was presented to us as the only option.

I don’t think people realise how minimal the available support can be for the terminally ill. Everyone should have a choice. Ours was taken away.

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## What does Chris’ story tell us?

For many people, the most important consideration about their care at the end of their life is whether or not they have the right support in place if they choose to live and die at home.

We know this isn’t always possible but for many it can happen.

For these choices to be widely available we need:

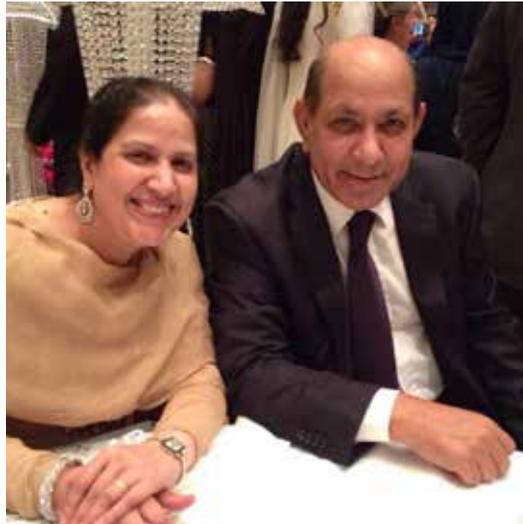
- investment in community services
- better co-ordination between acute and primary care
- a real commitment to changing how resources are prioritised.

## Mohammad's story

*Mohammad was diagnosed with a serious lung disease in 2012.*

*He was 56 when he died just over two years later.*

*His daughter-in-law Aisha says:*



Mohammad (above) with his wife Sajida

Dad was diagnosed with idiopathic pulmonary fibrosis, a serious lung disease, in 2012.

He was diabetic as well, but before his diagnosis this was managed easily with one daily tablet; after his diagnosis he had to go on to insulin.

Soon after the diagnosis, he started to decline rapidly – he couldn't get out of bed or walk or even feed himself.

He was put on steroids and put on a lot of weight, and had a heart failure early on – the disease was putting a lot of pressure on his body.

He had two major strokes and one mini-stroke, losing feeling on the left side of his body. During one of his

hospital stays, he contracted swine flu – his body became very weak and prone to catching things.

There weren't many treatment options for Dad; the only thing that would have made a difference would have been a dual lung transplant.

The final decision from the doctors was that he wouldn't benefit from it – they didn't even know if he would make it through the surgery.

This was devastating for all of us. As a family we were looking at other options, what would happen if we went private and so on and so forth.

They told us the only thing that they could do was to make him as comfortable as possible, but it was a nightmare getting the home adjustments in place.

For example, Dad hadn't had a real bath for months because he couldn't get up the stairs, but by the time the adaptations at home were due to start, he had already died.

We didn't have any help advocating for the things we needed. The council paid for us to have a bit of help, and we had some help from paid carers, but a lot of Dad's care was left up to us.

“As a family, we wanted to do our best to be there for Dad but the stress started to take its toll, and he was understandably feeling low emotionally.”

As a family, we wanted to do our best to be there for Dad but the stress started to take its toll, and he was understandably feeling low emotionally.

The paid carers came in the morning, when Mum was still working. They would administer his medication, check his oxygen levels, and try to keep him comfortable even though he was in excruciating pain 24/7.

But Dad really needed constant attention; he got forgetful and confused, and would do things like try to take his oxygen out.

Mum eventually had to give up her job and became Dad’s sole carer. She was exhausted. We were very happy when our GP put us in touch with Marie Curie Nurses, who were there for Dad’s last four months.

The night that he passed away, one of the night nurses was there, voluntarily, and I don’t know what we would have done without her. When he passed we just didn’t know what to do.

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## What does Mohammad’s story tell us?

Many more people will be dying with complex needs in the future and Mohammad’s story gives an insight into just how important it is to ensure that all aspects of someone’s care are addressed.

More complex needs will also mean a much more important role for co-ordinating care effectively between different specialities, hospitals and primary care, the NHS and charities such as Marie Curie.

Specialist palliative care can help support decisions about treatments and provide that all-important emotional support.

## Jenny's story

*Jenny was diagnosed with terminal cancer in February 2009. She died in 2014 at a Marie Curie Hospice. Her sister Sally says:*



Jenny (above) wanted to help people as part of her legacy

In February 2009, Jenny went to the GP with a lump on her tongue and a few weeks later went for scans. She found out straight away that she had terminal cancer.

She asked me for my help – I was working in NHS management at the time, so she knew I could help her navigate the system.

She had radiotherapy, chemotherapy, palliative chemotherapy and two rounds of research treatment that she volunteered to do. Jenny wanted to help people as part of her legacy.

Jenny had to have most of her teeth removed prior to treatment, as she was likely to be prone to ulcers and infections. Jenny was unable to tolerate having false teeth in – she said it was barbaric.

I advocated for her to have some tooth implants put in, and they made a huge difference to her last 18 months.

After her first round of treatment she was very thin and weak. She wasn't coping at home, and was struggling with her feeding tube. Her friend contacted a nurse to arrange for her to be taken to the hospice where she had been a day patient. On arrival at the hospice, Jenny was distressed and confused. An ambulance took Jenny to the nearest hospital (not the hospital where she had undergone treatment).

I got a call much later in the evening. When I got there, it was horrendous – she had been in A&E for hours and had not had the care she should have done. She was on a trolley in extreme distress in soiled clothes. At this stage immediately after her treatment, Jenny was unable to speak, and she was unable to communicate with staff clearly.

She was being treated appallingly. I was furious. Jenny checked herself out early the following day, as soon as she felt able, as it was such an awful experience. I knew this couldn't happen again.

On Jenny's second A&E admission I was prepared. She had diabetes and it was causing her to act strangely. She had a friend at home with her, who was very worried.

“She was being treated absolutely appallingly [in hospital] and I was furious. She checked herself out early as it was such an awful experience.”

I asked her friend if she could hold on until I got there, so my husband and I could collect her and take her to the hospital where she was being treated ourselves. The ambulance staff had informed me that they could not take her to this hospital as it was not the closest hospital to her home.

I contacted the hospital where Jenny had had her treatment and told them that I was bringing Jenny to A&E and arranged for her to be seen by her consultant’s team and to be taken up to the ward where she had been a patient for her treatment.

This was the best possible outcome, but it wouldn’t have happened if I hadn’t physically brought her there and co-ordinated the admission myself.

We managed to avoid a further A&E admission six weeks before Jenny died, while she was staying with us at Christmas.

With the intervention of myself and my husband, the ambulance staff did not take Jenny to an A&E near to my home, and instead arranged for the local hospice to do ‘outreach’ care in my house. It was only because we were insistent that this potential admission was avoided that Jenny had the best care possible in the circumstances and in accordance with her wishes.

Though my sister’s doctors were very good, and she had good support from her local hospice, I know that without me helping her, things could have been very different. You have to be very assertive to get things done.

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## What does Jenny’s story tell us?

Jenny’s story shows us just how important planning in advance is. It also shows how fragile those plans can be if the care system is not properly co-ordinated or geared up to the particular needs of people with a terminal illness. A big part of addressing this is about people talking, not just to the doctors and nurses looking after them, but to their family and loved ones so they can be part of ensuring they get the best possible care.

# What do these stories tell us?

These stories paint a picture of inconsistent care for people with a terminal illness in the UK.

We believe everyone living with a terminal illness deserves the care and support they need; when they need it; and where they need it. Everyone should be able to live as well as they can until they die. Our last years, months, weeks and days are an incredibly precious time.

What these stories tell us is that this is possible. However, they also tell us that, for many, this is not their experience.

Marie Curie wants to change the conversation around terminal illness, to create an environment in which people feel increasingly comfortable to talk about their choices and start to put in place what's needed to support them.

We have developed a simple checklist that health and social care professionals and governments can use to test whether they are doing all they can to support people being able to live as well as they can until they die:

## For governments:

- Do you have policies, strategies and resources in place which will ensure:
  - consistent access to quality care and support regardless of who you are, where you are and what your condition is?
  - all aspects of your policies and strategies take into account the impact they might have on people living with a terminal illness, and the growing numbers of people who will be dying with increasingly complex needs?
  - all the agencies over which you have influence and control work together in the interests of the individual and work to support that person's choices?

## Healthcare professionals

- Do you have strategies and plans in place which will deliver quality care and support to everyone living with a terminal illness?
- Are you working closely with other partners and providers in a way which focusses on a person's choices?
- Are you ensuring that as many of your staff as possible are aware of the benefits palliative care can bring, when this care is appropriate and how they can access this care on behalf of their patients?
- Are you working with your staff and patients to explain what palliative care is and to dispel any stigma attached to it?

## Social care professionals

- Are you working in partnership with other organisations developing and delivering services that focus on the choices of people living with a terminal illness?
- Are you ensuring that all the services you provide or commission are designed in a way that supports the needs of people at the end of their lives?

It is easy to put all the onus of responsibility for improving care and support for people living with a terminal illness on government and health and social care professionals. The voluntary sector, including Marie Curie, also has responsibilities.

## Voluntary sector

- Are we ensuring that the services we provide meet people's needs and are an effective and efficient way of using the funds our supporters give us?
- Are we always looking at new ways to support more people living with a terminal illness and their families?

## How you can help

There are things we can all do to help, such as ensuring we know what the wishes of those close to us are, should they be diagnosed with a terminal illness.

Getting to know what palliative care is and how it can help will mean that you can ask the right questions, and insist on the right support either for yourself or a loved one. You can find lots of the information you'll need on the Marie Curie website.

To help more widely, you can contact those who make decisions about care and support for people living with a terminal illness to encourage them to make it a priority. We can help you do this and in turn you can help us in our campaign to ensure everyone has a right to palliative care when they need it.

You can also volunteer to help Marie Curie or one of many other charities, such as your local hospice, to raise funds or work in a shop or in a host of other ways that will make a difference.

**Find out more about how you can help:**  
[mariecurie.org.uk/change](https://mariecurie.org.uk/change)

We're here for people living with any terminal illness, and their families. We offer expert care, guidance and support to help them get the most from the time they have left.

[mariecurie.org.uk](https://mariecurie.org.uk)

 [MarieCurieUK](https://www.facebook.com/MarieCurieUK)

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