

Never accept ‘no’ for an answer on care funding

A man’s three-year battle over his mother’s nursing home bill finally paid off — thanks to Money

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Zoe Harris spent just four months at Pinhay home in Lyme Regis — which served as a location in *The French Lieutenant’s Woman*, with Meryl Steep. But it took far longer than that to settle who should pay for Zoe’s care

ZOE HARRIS wanted to leave some of her £109,000 estate to two charities she had been supporting for years. One works with the care home she had lived in for seven years and the other airlifts vital medical supplies to remote parts of the world.

The retired GP died in June 2011 at the age of 96, leaving clear instructions in her will to make the donations. The rest of the money was to be divided between her five children, her sister and her goddaughter.

But almost five years after her death, her son Robert, 72, a retired solicitor, who was an executor of his mother’s will, has been unable to donate a single penny or distribute the rest of the money.

This is because of a litany of mistakes and a lack of communication by the NHS on a decision about who was responsible for the £12,400 it cost to care for Zoe during the final four months of her life.

The health service has admitted that the delay was “unacceptable” and has apologised and paid up.

The NHS clinical commissioning group (CCG) in Dorset, which was responsible for the decision, failed to act for years. It was only after Money got involved this month that the family were given a decision — and awarded almost £7,500 in costs and interest.

The story highlights the complexity of the continuing healthcare (CHC) system. The scheme entitles people who have severe and multiple healthcare needs — for example, they need help feeding themselves — to be funded fully by the state regardless of the value of their estate. However, the system relies on a complex assessment process involving multiple healthcare professionals who seem, on occasion, to be unaware of how the rules work.

But families who challenge a decision can be rewarded. A 95-year-old Second World War veteran, whose struggle to get CHC funding for his wife was reported by Money last month, has been told he will be given about £15,800 by Cambridgeshire and Peterborough CCG. His family had been denied payment on several occasions.

Cambridgeshire and Peterborough CCG said negotiations with the family were ongoing and declined to comment further.

Baroness Gale, head of the all-party parliamentary group on Parkinson's, which published a report on CHC funding in 2013 called *Failing to Care*, said: “It's disappointing to hear that a family already dealing with the grief of a bereavement are having to battle to get the funding they are owed — this is simply unacceptable.”

A freedom of information request by Money shows that millions of pounds have been paid by CCGs after an initial rejection. The largest single payment was for £763,000, awarded by Liverpool CCG. There are 62,328 people in England receiving CHC funding, 5,778 in Wales and 385 in Scotland, but these figures are likely to grow as more people live beyond 100.

Zoe's story

Zoe Harris's husband, Paul, died in 1994. A decade later, she decided to move from her home in Dorset to the Abbeyfield residential home in Devon, a 90-

minute drive away. Zoe was still extremely active at this point and spent many happy years at the home. But her health deteriorated and she was diagnosed with cancer in early 2011. She eventually needed constant monitoring and support for everyday activities.

After a stint in hospital, she moved to Pinhay nursing home in Lyme Regis in February 2011. It is a converted mansion that featured in the 1981 film *The French Lieutenant's Woman*, starring Meryl Streep. Zoe paid £750 a week to the home using her savings and income from her pension. By the time of her death in June, she had paid just over £12,400.

Her son, Robert, later found out about CHC funding from his brother-in-law, who suggested Zoe's condition was severe enough for the NHS to cover the cost.

This prompted Robert to lodge a claim on behalf of Zoe's estate for retrospective CHC funding from Dorset CCG. The claim was made on October 22, 2012 — but this marked only the start of the saga.

Because Zoe had instructed her son to pay 4% of her estate to the two charities — the Abbeyfield Society and the Mission Aviation Fellowship — Robert could not settle the estate until a decision had been made. "As my mother's will gave two charitable legacies as a percentage of her net estate, I have had no alternative but to pursue the claim," he said.

Delay after delay

It took Dorset CCG until December 12, 2012, to acknowledge receipt of the claim. Robert telephoned in January 2013 for an update and was told the case had been referred to an "assessor" and someone would get back to him with further details. But they did not, leaving him to phone repeatedly. "We were constantly promised that something was going to happen, but it never did," he said.

On December 27, 2015 — more than three years after he had lodged the claim — Robert complained in writing to the CCG. On January 6, he wrote to *Money* to share his frustration.

Nine days after we contacted the CCG, Robert was told his mother's estate was entitled to just over £6,500 to cover the cost of care, plus £900 in interest.

"It's miraculous that the CCG was able to act so quickly after being contacted by *The Sunday Times*," he said. "I am delighted with the outcome, but it really should not have taken a newspaper to get them to act."

What does the NHS say?

Paul Rennie, head of continuing healthcare at Dorset CCG, said: “We would like to offer our apologies to Mr Harris and his family for the time taken in the handling of this claim and we acknowledge that the delay has been unacceptable.”

The CCG decided to pay only half the original claim as it deemed Zoe qualified for funding only for the final two months of her life, when her healthcare needs were most acute.

This is despite the team of professionals who assessed her saying she was eligible for continuing healthcare funding for the entire period.

Given how long this process has taken, however, the family have understandably decided not to appeal.

Your story

Are you struggling to obtain NHS funding for care? Email money@sundaytimes.co.uk

Are you eligible?

What is continuing healthcare?

This is the name of a care package arranged and funded entirely by the NHS. The funding covers all care and residential costs if you have to move into a home — regardless of any savings or assets you have. If you do not qualify for the funding, you are expected to pay for your care or accommodation, or both, until your assets, including property, are worth £23,250 or less.

Who is eligible?

Eligibility is not automatic if you have a condition, illness or diagnosis such as Alzheimer’s or Parkinson’s. People with the same diagnosis can have very different needs — one might receive funding and another not.

How are needs assessed?

Health and social care professionals use a checklist that marks patients on their behaviour, cognition and ability to communicate, among other categories. The levels range from “N” for no needs to “P” for priority — the most severe. Under

the NHS guidelines, an individual will be recommended for funding if one category is classed as priority or at least two are severe.

Can I appeal against a decision?

You can take your case to an independent review panel, which can recommend that the CCG pays — although the panel cannot force it to do so. If you are found to be ineligible, you can approach the Parliamentary and Health Service Ombudsman.