Victory for Vicki — and a cheque for £94,000

Woman with dementia wins two-year care funding battle with NHS

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Vicki Keiller, pictured in 1944, has won £94,000 thanks to the efforts of her family, including husband Don, pictured in 1940KEILLER FAMILY

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The NHS has paid nearly £94,000 to a woman with dementia after a two-year battle over the cost of her care, which Money first highlighted last December.

Vicki Keiller, 90, who lives in Midfield Lodge, a nursing home near Cambridge, received the payment after her son, Don, 60, fought to prove she was entitled to receive state support covering all her care costs, regardless of her wealth or income, under the little-known continuing healthcare (CHC) scheme. Typically the state steps in only when you have assets, including property, worth £23,250 or less.

THE SUNDAY TIMES

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At 95, I'm fighting the NHS to fund wife's care

The health service has had to stump up millions in back payments after wrongly refusing to cover bills. A war veteran tells **Ali Hussain** his story

Smiles all

How Money revealed the Keillers’ struggle last DecemberTHE SUNDAY TIMES

The Keillers’ story exposes the mind-boggling complexity of the assessment process that must be endured to receive a penny under CHC. The funding is not automatic if you are diagnosed with a particular condition such as Alzheimer’s: some get it, others don’t. Even some healthcare professionals seem not to understand the system.

NHS England is conducting a review of the procedures followed by Cambridgeshire and Peterborough clinical commissioning group (CCG), the health authority that assessed Vicki, after her son proved it had repeatedly misrepresented the evidence of an independent review panel approving her right to funding.

It has also invited Don — whose record-keeping and persistence were key — to make recommendations so the review’s lessons can be shared.

The university lecturer said: “It has been a long, arduous, frustrating struggle. I know there are many others who are being unlawfully denied CHC funding, feel impotent in the face of intransigence from the health service and are in despair. Hopefully my victory will inspire them.”

Care crisis

Don Keiller has been helped by his father, also called Don, 96, a Second World War veteran.

Since Money first reported their battle, two senior members of the CCG who were directly involved with Vicki's case and were severely criticised by the Keillers have resigned. Neither Dr Neil Modha, who was chief clinical officer, nor Sue Jestice, the head of complex case management, responded to Money's attempts to contact them.

The CCG has also paid Don Jr £1,000 in "recognition of the difficulties you have faced in getting the CHC funding for which your mother was eligible".

The CCG said: "We have met with [Don] Keiller over recent months and we have had useful discussions around his concerns. Dr Modha also met with [him] recently and it would not be appropriate for the CCG or Dr Modha to comment on what was a private meeting.

"Dr Modha left the CCG on 31 July, 2016 and Sue Jestice left on 31 May, 2016. The CCG does not make comments on former employees."

The need for reform

Baroness Gale, head of the all-party parliamentary group on Parkinson's, said: "Many people don't even know that NHS continuing care exists, while those who do get the help may be subject to a postcode lottery of service.

"Don's experience highlights the need for reform. The Continuing Healthcare Alliance, chaired by Parkinson's UK, will publish new evidence next month, with key recommendations on improving the current system. I look forward to seeing the full report and will urge the government to act to ensure vulnerable people receive the support they need, when they need it."

George McNamara, head of policy at the Alzheimer's Society, said: "It is shameful so many people with dementia are losing out, and often only the persistent and those who can navigate an unfriendly system can benefit."

How the family won

Don Keiller's dossier of evidence shows a catalogue of mistakes, misrepresentations and possible conflicts of interest in his mother's assessment.

He first asked whether Vicki was eligible for funding in February 2013 after she was hospitalised with a pelvic fracture. He was told she was not.

He later discovered a "CHC checklist" — an assessment to determine whether an individual should be assessed for CHC funding — had been conducted on her without his knowledge. This found Vicki to be "an articulate lady" and "socially appropriate".

Keiller disagreed. He also knew he should have been informed and been present for the checklist, as he has lasting power of attorney over his mother's affairs. At his request, a second checklist was carried out in July 2013. It found Vicki should receive a full CHC assessment. This in turn found her eligible for NHS funding.

However, Jestice said that a decision to award the CHC would not be appropriate while Vicki had a cast on her leg. She said Vicki's case would be reviewed after the cast was removed "to establish how this impacts on her mobility".

The CCG agreed to fund Vicki's nursing home costs until her next assessment, which occurred in January 2014 — but this found her not to be eligible.

The Keillers asked for an independent NHS review panel to examine the decision, claiming the assessment was not fair or transparent. Concerns raised by Vicki's nurse at Midfield were not recorded in the second assessment. The review panel agreed, saying: "It was unclear why the comments had not been included."

The panel decided Vicki was entitled to funding despite the findings of the second assessment and said: "It is expected that in all but the most exceptional of circumstances the CCG will accept the panel recommendations."

However, Jestice wrote to the family saying: "The CCG does not agree with the panel recommendation." No details of any "exceptional" circumstances were provided.

The Keillers claim that there was a potential conflict of interest at the time because Jestice was listed as the "programme manager" who had to meet a "savings target" of £1.8m from CHC funding, detailed in the clinical commissioning group's operational plan for 2014-16.

After several more twists — including repeated mistakes by Modha over the dates of Vicki's eligibility for funding — Maureen Donnelly, chairwoman of the CCG governing body, took over the case this year. In a letter to the family she acknowledged "the exceptional circumstances surrounding this case, including the unacceptable delays incurred".

Victory for the Keillers

Finally, the CCG said in July it would pay £93,414 to cover Vicki's nursing home fees from January 2014 to June this year. The money was paid into her account last month. The CCG is now paying the monthly cost of Vicki's care, which is £2,823, and will continue doing so until her next annual assessment.

Learning lessons

Keiller has been invited to share his experience with NHS officials to improve the CHC assessment process. He has also had a three-hour meeting with Sylvia Knight, deputy director of nursing for NHS England Midlands and East, to determine the terms of reference for the review of the CCG.

In a joint statement NHS England Midlands and East medical director Dr Alistair Lipp and director of nursing Vivienne Stimpson, said: “The involvement of Dr Neil Modha in [Don] Keiller’s case is being assessed through NHS England’s routine process for investigating concerns about GPs. These are confidential proceedings.”

The expert’s guide to obtaining funding, by Don Keiller Jr

Never give up: Vicki Keiller’s son Don and her husband, who is also called DonDON KEILLER

Get lasting power of attorney

If your relative is suffering from Alzheimer’s or another form of dementia, it is vital to get lasting power of attorney (LPA). This allows you to make decisions in their best interest, access their medical records and speak for them. It is then much easier to apply for continuing healthcare (CHC) on their behalf.

Ask whether your relative is entitled to funding

If a relative requires nursing or medical care at their home or in a care home, they may be entitled to CHC funding. You will probably need to ask for an assessment.

Make sure the correct procedures are followed

Your relative cannot be ruled ineligible for CHC without a "checklist" assessment. If you have LPA, the local clinical commissioning group (CCG), which holds the purse strings, has to inform you when and where this will happen, and you have the right to be there.

Before the assessment, download the checklist (tinyurl.com/forms-CHC) and fill it in based on your own view of your relative's needs. You can then compare the list with that of the assessors, who have to give you a copy. If you don't agree with their assessment, tell them why.

If you are convinced the assessors have got it wrong, complain to your local patient advice and liaison service (tinyurl.com/pals-complaint).

Get a continuing healthcare assessment

If your relative "passes" the checklist, there will be a further assessment by the CCG to determine whether they have a "primary healthcare need".

This is done using a decision support tool (DST). Again, complete the assessment form yourself (it can also be found at tinyurl.com/forms-CHC) based on your view of your relative's needs.

With LPA you have the right to attend the assessment and argue your relative's case. Take notes or have a friend do it on your behalf.

Work together

Make friends with the nurse in charge of your relative's care. Ask them to come to the CHC assessment. Their input can be vital. If necessary, ask the nurse to describe your relative's medical conditions to the assessment panel.

Get a copy of the assessment

You should receive a copy of the assessors' DST form. Compare it with your own. If you disagree with it, tell your CCG contact why.

If you genuinely believe the conclusions do not fit your relative's medical condition, lodge an appeal with the local resolution dispute panel(tinyurl.com/dispute-panel).

Prepare your case

Before the meeting, send the appeal panel a summary. Bring someone with you to take notes. You are entitled to see the reasons for the appeal's success or failure. Ask for complete details rather than a summary.

Ask for a review

You can appeal to the NHS England* independent review panel (tinyurl.com/review-panel). Note any flaws in the CHC assessment and send all information to the panel in advance. You will be asked to present a case, so rehearse your arguments and facts.

Don’t worry about the good and bad days

If your relative is assessed on a “good” day, this can actually be helpful, as one of the assessment criteria is “unpredictability”. Remember too that “well-managed needs are still needs”, according to the NHS. It is only because of the skilled medical treatment that your relative’s condition might have “improved or stabilised”. Again this shows that medical intervention is required.

No one on the review panel will meet your relative, so take photos of them to personalise your case. If this appeal fails, ask for a transcript and the rationale for the decision.

Complain to the ombudsman

Your last “official” option is to make a complaint to the Parliamentary and Health Service Ombudsman (ombudsman.org.uk).

Talk to your MP and the press. Anecdotally, the ombudsman is more likely to find in your favour if your MP is involved and the case has been publicised.

** Funding rules are different in Scotland (tinyurl.com/funding-scotland) and Wales (tinyurl.com/funding-wales).*

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EnglishRose 2 hours ago

It is very unfair and very patch funding. My father spent £130k on at home dementia care in his last year of life and died 2 weeks just after his life savings were exhausted. He had worked for the NHS as a doctor since its inception until he reached maximum NHS age. Even someone like that who has given their life to the NHS does not get care.

Being a generation younger I have decided Big State is never to be relied up on and will just fleece us at every turn. Be responsible for your parents and children and you cannot go wrong in life. Rely on the state and you will come a cropper. I will work until I die. I expect nothing from the state, or not much at all. I might get a small state pension when I turn 70 I suppose.

Also the rules are very complex. The state announced with great fanfare that people would be provided with some elements of care home costs - not the hotel and food element but the physical care over a certain sum I think it was which was based on the average time in those homes until death - about 3 - 4 years. However, you still have to pay the hotel sum which is high although not as high as the at home £130k my father paid for care at home. I don't begrudge my father using every last penny for care at home as the security, power, familiarity and all the rest which goes with living at and dying at home is absolutely priceless. I would have funded every penny myself.

However, I do feel that compact between the middle class and the state has been lost. I used as a single mother to get child benefit. that was stripped away. When universal benefits go you think what on earth is the point in my working full time 6 days a week just to fund all these others who work full time or are retired or don't choose to work at all. When instead you do actually get something out of the system like say child benefit or a new universal payment to everyone over 18 which be then you feel the system is worth making an effort to support.
I am about to pay well over £100k in extra tax just to take pension money to help the children with property deposits - again I feel stripped of cash by the state at every tunr. 45% is a massive tax hit just to help a child deal with high house prices/

mama mia 4 hours ago
Remembering the constant struggles, I had with funding my father's care at home when he was in his 90s, I take my hat off to the Dons. The stress fighting for someone's rightful assistance is enormous. I used to spend whole days on the telephone being passed back and forward with no-one willing to make a decision. Actually looking after my father was nothing by comparison. It is so very complicated that one becomes certain that the convolutions are in place to stop people being able to access help at a time when they are at their most vulnerable, and that is wrong. The whole

system needs to be clarified, simplified and be made to work for everyone who needs it.