

'Unfair' care decision leaves family footing huge bill for dementia patient

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recommendation of eligibility". However, the CCG said it would be "not be appropriate" to make a decision while Vicki had a plaster cast on her leg because of the fracture.

Sue Jestice, head of complex case management at the CCG, said her case would be reviewed after the cast was removed "to establish how this impacts on her mobility".

The group agreed to fund the cost of the nursing home until the next assessment. Before it took place, a separate assessment ruled that Vicki was entitled to NHS-funded nursing care. This provides £112 a week, but the family still have to cover the £3,375 monthly fees for the home. If they had CHC funding, all their bills would be paid.

The second continuing healthcare assessment was in January last year. The assessors included a senior geriatric nurse who had looked after Vicki since the previous September, and a care manager from Cambridge social services.

Vicki's mobility issues were downgraded from "severe" to "high", though her cognition rating was still "severe". With only one box ticked "severe", she no longer met the criteria for a recommendation for CHC funding.

The Keillers asked for an independent review panel to examine the decision. The panel decided that 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 circumstance were provided.

After pressure from the family, the CCG has agreed to a new assessment. Vicki's husband said: "If I thought I was not entitled to this funding, that's fair enough, but her condition is so bad in many ways that we should get it. We are being treated very unfairly."

WHY ARE THE KEILLERS DEMANDING A RETHINK?

The family believe the CCG assessments were not fair or transparent. Concerns raised by Vicki's nurse were not recorded in the second assessment, for example.

Keiller asked the nurse to write a signed note expressing her concerns about his wife's case. It reads: "My opinion, as a nurse that has been caring for Vicki since she arrived at Midfield from hospital, is her situation regarding her mobility remains severe and not high."

The review panel raised concerns about the omission of

The local authority refers to him as a social worker. He is selected by the local authority to support the continuing healthcare nurses in the [application] process."

The Keillers claim there is a potential conflict of interest because Jestice is listed as the "programme manager" who has to meet a "savings target" of £1.8m from continuing healthcare funding. This is detailed in the CCG's operational plan for 2014-16.

Don Jr said: "My advice to those unfortunate enough to have to apply for continuing healthcare funding is to keep

make his assessment.

The council said: "[The care manager] contributed to a multidisciplinary discussion in his capacity as a care manager employed by us. He is an experienced professional with extensive knowledge of continuing healthcare, and was one of several professionals on the multidisciplinary team who made the recommendation collectively. The ultimate decision regarding eligibility for continuing healthcare was made by the CCG."

Julie Wood, head of NHS Clinical Commissioners, an umbrella organisation, said: "CCGs have the responsibility to assess claims for continuing healthcare and need to do this against a backdrop of balancing delivery of national and local priorities within their overall resource allocation."

WHAT THE CRITICS SAY

Luke Clements, a Cardiff Law School professor who specialises in care issues, said: "Families are having to go through a highly stressful and arbitrary process, and often having to employ not inexpensive lawyers, to get funding in situations where 99% of ordinary people would have expected the NHS to be responsible."

"The problem is that in some NHS areas a culture of ineligibility has developed that is in clear conflict with the law and the NHS guidelines."

George McNamara, head of policy at the Alzheimer's Society, said: "Figures showing retrospective payments made by numerous CCGs testify to the alarming volume of inadequate assessments for funding that have taken place."

Another charity chief, Steve Ford of Parkinson's UK, said: "Although it is pleasing to hear that some of the decisions have been rightly overturned, this is not an avenue that everyone can follow."

"Tragically, some people are dying before they can get access to the care they need or are forced into dire financial situations to pay for care they are entitled to."

Additional reporting:
Mary O'Connor



Vicki, now 89, and Don, 95, met during the Second World War

the nurse's opinions from the assessment, particularly regarding Vicki's mobility issues. "It was unclear why the comments had not been included," the panel said.

The family also asked the CCG for information about the care manager's qualifications and his fitness to assess Vicki, as they claimed that he had dominated the second assessment.

The CCG refused to give details, despite receiving a freedom of information request, until the Information Commissioner's Office forced it to respond. As a result, Keiller discovered that the care manager was not a qualified social worker.

In an email response, Jestice said: "I have been made aware that [the care manager] is not a qualified social worker. He is a very experienced manager.

records of every piece of documentation from day one. Challenge decisions that you honestly believe to be wrong and never give up."

WHAT THE AUTHORITIES SAY

Cambridgeshire and Peterborough CCG said it could not comment on individual cases.

In a statement, it said: "The recommendation that someone is eligible for NHS continuing healthcare is made following assessments by professionals involved in the patient's care. The group works within the national framework, supported by local policies and procedures. All budgetary decisions are made with full CCG oversight and scrutiny."

Cambridgeshire county council confirmed that the care manager was not a qualified social worker and he had spent just 90 minutes with Vicki to