

Continuing to care? Information sheet for supporters

When you have serious health needs, getting the professional care you, or someone close to you, needs shouldn't be a battle. But all too often it is. NHS continuing healthcare – also known as NHS continuing care or NHS CHC – is free healthcare provided outside of hospital that is arranged and funded by the NHS. It can be received in any setting, including a care home, hospice, or the home of the patient or their relative. When delivered effectively, it can enable people to go on living as full a life as possible. It can also have the benefit of reducing anxiety and minimising pressure on family and friends.

The Continuing Healthcare Alliance believes that NHS CHC is failing people across England. The current system attempts to artificially divide the care and support that sick and disabled people need into 'health' care and 'social' care. However the dividing line between a healthcare need and a social care need is fundamentally blurred. Many people who should be found eligible are being denied this much-needed support due to flawed processes. Alongside this, those granted NHS CHC funding are often given inadequate care packages that don't meet their needs.

Key problems

Our report presents evidence from across England on how the system works. We heard from people who had applied for NHS CHC, as well as professionals who work in the system. We also asked every Clinical Commissioning Group (CCG) in England to tell us how they manage NHS CHC in their area. CCGs are local organisations across England. They are responsible for areas such as mental health services, urgent and emergency care and community care. They assess local needs, decide what the priorities and strategies should be, and then buy services on behalf of the population from providers such as hospitals and clinics. CCGs include members from local GP practices, clinicians and nurses. Often the decision on whether someone is eligible for NHS continuing healthcare is made by people who work for the CCG and the money will come out of their budget, which is originally provided by NHS England.

The results of our research confirm that the system is letting people down:

- **40%** of professionals who completed our survey told us that their experience of decision making in a multidisciplinary team (MDT) can be very mixed. In some assessments opinions are weighted equally, while in others they are not.
- **66%** of survey respondents felt the professionals in the assessment did not possess any in depth knowledge – or knew very little – about the condition the person being assessed was living with.
- **80%** of professionals surveyed said the Decision Support Tool (DST) was not fit for purpose, or there was room for improvement in some areas.
- Those with well-managed needs are often assessed as being ineligible despite having needs that qualify. Denial or withdrawal of care could result in making their needs worse.
- **42%** of survey respondents who had applied for NHS CHC told us they waited more than 28 days (the deadline set by the National Framework) to receive their final decision regarding eligibility.
- **35%** of survey respondents told us they had been told by the multidisciplinary team that eligibility would be recommended, only to have that decision rejected by the review panel.
- Some CCGs are introducing policies that force people into care homes if the cost of their care is more than a residential care package, irrespective of whether this approach meets their assessed needs.
- When less funding is received patients can be transferred to another care company, resulting in the loss of professional carers that the person and their family know and trust.
- **44%** of people surveyed had gone through at least one reassessment after being awarded NHS CHC.

Susan's experience

“ I met my husband, Bob, while at university. After getting his PhD in applied sciences, he became an engineer and went to work for the Ministry of Defence. He worked through the Gulf War, commissioning special equipment for desert conditions. He got the Queen's Commendation. In his early sixties, Bob was diagnosed with an aggressive form of Parkinson's. Within six years he went from being independent to needing a wheelchair, hallucinating, having short-term memory loss, being awake all night and having bowel collapses. I was caring for Bob alone until our Parkinson's nurse suggested we apply for NHS CHC. I had never heard of it so didn't know where to start. She helped me fill in the forms, but I didn't hear anything. When I phoned, the Clinical Commissioning Group (CCG) always said they were waiting for more information, but didn't say what. I was shoved from pillar to post. It didn't feel like anyone knew what was going on.

Bob had to move into a nursing home, and passed away aged 70. The day after his death the CHC assessor knocked on my door to conduct his assessment. I explained the situation and she said she'd conduct a retrospective assessment. Seven months later, I received a 64 page document. It came with a covering letter asking me to read through the information and provide comment. I didn't really understand what I was reading, but having to focus on details of Bob's condition was painful and I got very weepy. When I finally got to the end, on the final page it said their decision had already been made, and they were rejecting our application. I couldn't believe it! Surely they should have told me that up front before I started? The whole process was dreadful. I'm an educated and capable person but I was exhausted and really angry. They seemed to forget they were dealing with real people.

Key recommendations

For NHS CHC to improve, the Department of Health, NHS England, Clinical Commissioning Groups and local authorities should initiate the following changes:

- Ensure multidisciplinary teams are composed of professionals who are experienced when making decisions around NHS CHC, with knowledge of the person, their condition(s), needs and aspirations.
- Design a mandatory programme of training for professionals who organise and assess people for NHS CHC to ensure they understand the eligibility criteria and how to use the current decision tools.
- Rewrite the checklist and Decision Support Tool so they more effectively measure individuals' healthcare needs against the lawful limit of care that the local authority can provide.
- Introduce an option for professionals to select if they agree that someone should not be reassessed for eligibility of NHS CHC. For people marked down as permanently eligible, reviews should only look at changing needs, for example, where someone may need increased support.
- Prevent people with long-term, serious health conditions being forced into residential care, or living at home with unsafe levels of care, by ensuring packages of care are needs-driven and not purely financially motivated.
- Publish data on how many people apply for NHS CHC – whether they are successful or not – as well as the number of people who proceed past the checklist stage to the full assessment.

Help us make change happen

With your support, we can improve the NHS continuing healthcare system. Help us spread the word by going to our website, where you can easily share our report with your local MP and Clinical Commissioning Group.

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