

Who cares and how much? The provision of care

Once someone has navigated this complex process and been awarded NHS CHC, the CCG is required to commission a package of care. A growing area of concern for the Continuing Healthcare Alliance is the lack of suitable care packages put in place once eligibility for NHS CHC has been granted.

Positive progress

- NHS England has stated that personalisation and choice are priorities for them¹¹. This focus ties into NHS CHC because care packages should be focused on the individual and their needs and aspirations, not just the cost of care.

¹¹NHS England (Oct 2014) 'Empowering patients' [Five Year Forward View](#); p12.

What needs to happen?

- Where an individual has been found eligible for NHS CHC, the CCG should demonstrate that:
 - they have conducted a comprehensive assessment of the individual's health and social care needs and offered a package of care sufficient to meet all of these
 - they have taken all possible steps to ensure that the individual's preferences have been met by the package of care they are offering
 - the package of care offered compliments the current national agenda of personalised healthcare provision¹²
 - the package of care is needs driven and not purely based on financial considerations

¹²NHS England (Oct 2014) 'Empowering patients' [Five Year Forward View](#); p12.



Marie's experience

“Dad was a carpenter, and had always been very active. When he reached his eighties, completely out of the blue his health went downhill fast. He stopped being able to stand up and we got a diagnosis of MND that was a huge shock. Within a week of us knowing anything was wrong we were having to make some really big decisions. It was traumatic. Someone at the hospital told us about NHS CHC and helped dad get a fast track assessment. Dad was found eligible and the CCG said they would fund his care. He wanted to go back home so we tried to investigate what needed to be done to make this possible.

The next day I got a call from someone telling me that they had just visited my dad, without any of the family present, and he now wanted to go into a nursing home. I just didn't think this sounded right as he'd never said anything like that to me. When I saw dad that evening he started talking about not wanting to be a burden, which again he'd never said before. We spoke to the people from the CCG who were supposed to arrange his NHS CHC package and they said that if he stayed in his own home they would only be able to pay for four care visits a day. We asked what he was supposed to do overnight and they agreed he wouldn't be safe. It was confusing because they knew he couldn't cope with only four visits a day, but their job was to provide the care he needed. I feel like dad was forced into a nursing home because the CCG wouldn't pay for the care he needed in his own home. We should have been told what the options were to help him live independently. He was given no choice.

Current challenges

- In some geographical locations, funding for these care packages can take a long time to come through.
- The National Framework promotes individual choice and control, but only requires CCGs to provide packages of care that they consider to be appropriate. This creates a problem between assessed needs and reasonable needs. People can be told they are eligible, and then allocated less care than they have been paying for independently. For example, someone may have been paying for 24 hour care themselves, and then the CCG grants NHS CHC but deems two hours a day satisfactory. Members of the alliance believe that CCGs have a duty to meet all of the individuals' assessed care and support needs.
- When less funding is received patients can be forced to transfer to a different care provider, resulting in the loss of professional carers who the person and their family know and trust.
- For some people, residential care and nursing homes provide a really positive option for their ongoing care. However this choice should be made by the individual and their family. Despite this, some CCGs have introduced policies that force people into residential care if the cost of their care at home is more expensive. Of those who responded to our FOI request, **19** CCGs admitted to already having a policy in place that caps the cost of a care at home package. The lowest cap in 2015-2016 was just **£614.97** per week, meaning anyone whose care at home package cost more than that would be forced to live in a care home whether they wanted to or not. To maintain positive health and wellbeing, CCGs should prioritise keeping someone at home if that is their preference. The alliance believes that forcing people into residential care could become a huge problem.
- Many long-term conditions require a high level of specialist care that some care homes are unable to provide. People can then be asked to leave residential care because their needs cannot be met.
- Personal Health Budgets (PHBs) were introduced to give people choice and control over the care they need. However **53%** of survey respondents said they were not offered a PHB, with a further **22%** saying they weren't sure if they were offered one or not. When assigned incorrectly, PHBs can mean even more pressure is placed on the person applying for support and those close to them.
- Almost **20%** of survey respondents who were awarded CHC said the cost of their care was not met by their NHS funding, resulting in them having to pay top-up fees. Without these top-up fees, more people would end up in increasingly dangerous situations. As an NHS service, CHC should not allow top-ups.

