

Why are we waiting? The delays experienced by people applying

In the past there was no substantive guidance on timelines for the NHS CHC process which meant that many people were kept waiting weeks or months for a result.

Positive progress

- The National Framework gives clear guidelines to all CCGs and local authorities on the timelines that should be followed. It makes clear that the time between the checklist being received and the decision being made shouldn't exceed 28 days.
- The National Framework introduced a fast track pathway tool so that someone who is in very poor health, and near the end of their life, can have their eligibility determined as quickly as possible.

Sue's experience

“ My dad was a district surveyor for the City of London and cared for my mum who had colitis and suffered a stroke. Sadly he's not in a good way himself now so I've been trying to get him NHS CHC. He has dementia, rectal cancer, stage 4 kidney disease, a poor heart, and is totally incontinent.

The process of applying for NHS CHC has been really distressing. We've experienced huge delays, it's been appalling! We didn't receive a written decision on dad's application for 21 months.

We asked for the checklist to be done in April 2014, but they didn't come for three months. Following the checklist, they agreed dad should have a full assessment, and we assumed this would happen quickly.

Dad finally had the assessment in March 2015 – 11 months after the checklist had been completed. When it was over, the nurse assessor told us that she was going to recommend dad be turned down.

We knew we wanted to appeal the decision, however we couldn't begin this process until we had the official outcome in writing. We didn't get the negative confirmation until January 2016. That is 10 months after the assessment, just to receive the letter confirming it was a no.

I rang the local CHC team every month, only to be told each time that they had a backlog. The delays were dreadful, and we weren't told what was happening at any stage.

This whole process has really affected our family emotionally. The system is so time consuming. It takes ages to read all the information and analyse it.





Current challenges

- We know from people applying, and professionals, that the 28 day timeline is rarely achieved. **42%** of survey respondents who had applied for NHS CHC told us they waited more than 28 days to receive the final decision regarding eligibility. On top of this they were not kept well informed of the new timescales.
- Almost **20%** of professionals who responded to our survey told us that the decision timeline never, or almost never, adhered to the 28 day timeframe. Alongside this people are sometimes unaware that the countdown should start from the checklist referral, rather than when the MDT conducts the first full assessment.
- From more than 100 responses, only 14 CCGs told us they kept within the 28 day timeframe. In 2015/16 one CCG reported it didn't conduct someone's assessment for **255** days after receiving the checklist. It is unacceptable that anyone should wait this long, particularly since their health and wellbeing will often be deteriorating.
- Many individuals made reference to being told about a backlog as a reason for the delay in their decision. This backlog can often be as long as **18** months.
- The alliance has seen examples of people in hospital getting a more timely assessment, at the expense of people in care homes or with an existing care package.
- The alliance has been contacted by many people who have told us that their fast track assessments were not processed quickly, and sometimes these delays have resulted in people passing away before being assessed. This stands in stark contrast to the Government's policy focus around people having a choice about the care they receive towards the end of their life, and its commitment to support people to die at home.
- Applications for fast track assessments are sometimes being rejected⁸. There are reports that the 'rapidly deteriorating' criteria in the fast track assessment tool⁹ is being interpreted to mean anything from 12 weeks to two weeks, and anyone thought to live longer than that is being rejected for this assessment. To be eligible for fast track, it is not necessary to predict the time left until the patient dies.
- The alliance knows that there is sometimes a general confusion about the use of fast track, with the assumption that it is only available for people with cancer. This is not the case.

⁸ People have shared this experience with many of the organisations represented within the alliance. It is also mentioned in Macmillan's report, [Can we live with how we're dying?](#)

⁹ [Fast track pathway tool for NHS continuing healthcare](#)

Natalie's experience

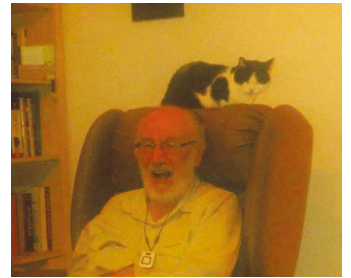
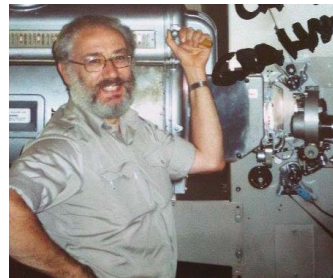
“ Dad had MND and it was progressing fast. He couldn't talk at all or convey expression through his face. He couldn't move, so had to be hoisted. He was fed through a tube into his stomach, couldn't go to the toilet and his breathing was compromised. I moved dad in with me, and was caring for him while trying to work full time. It was a lot of pressure.

Our district nurse was really supportive, and requested a fast track NHS CHC assessment for us. She made the request just before New Year.

At this time our palliative care consultant said she didn't think dad had long to live. Despite this, the

assessment didn't happen quickly, and took place in mid-February. I experienced so much worry and anxiety during this time, as I waited to find out whether he would be eligible. Though logically, I didn't know how much more could have been wrong with him in order to make him qualify.

When the assessor finally came, it was clear to me she didn't know anything specific about MND. She said they should only be doing fast track assessments for someone who is end of stage and then followed that by saying, 'which he clearly is not'. Dad died two days later.



What needs to happen?

- CCGs must stick to the time frames for providing an assessment and the result. If they are unable to do this they should proactively contact the applicant or their representatives to explain the delay and provide a revised timeline.
- NHS England must strengthen sanctions against professionals, CCGs or local authorities who refuse fast track applications.
- To reduce delays in the future, greater investment is needed to allow CCGs and local authorities to recruit more professionals to co-ordinate and undertake NHS CHC and assessments.

