

Righting the wrongs: the appeals process

Appealing a decision about NHS CHC can be time consuming, complex and distressing. Often people can wait months and even years. During that time, it is likely that individuals are paying for care unnecessarily and also engaging solicitors to support them through the process. In England, there are three stages people can go through:

Local appeal

This is the first stage of the appeals process. There are very few guidelines in the National Framework about this. As a result, CCGs conduct these meetings in very different ways. Some CCGs offer informal meetings to get people's points of view, others conduct a panel stage if there is a significant complaint, while some do a half hour telephone call. The appeals process should be dealt

with within three months, but the alliance knows it can sometimes take more than a year just to complete the local stage. It's hugely variable.

Independent review panel (IRP)

The IRP is governed by NHS England and we have heard mainly positive feedback on the way these are conducted. There are usually three decision makers including an independent lay chair (often an academic or legal person who has gone through training on this), a health professional and a social care professional (who can't be from the same CCG who made the decision). The professionals should all work together to make a decision, and often seek the advice of a clinician and specialist in the condition of the person applying.

Parliamentary and Health Service Ombudsman (PHSO)

People can contact the PHSO if they have exhausted all other appeal routes.

Current challenges

- The person applying, or their family and friends, often need information and advice around the appeals process. Yet **55%** of professionals who completed our survey said they did not feel confident giving people information on how to appeal decisions.
- IRPs cannot overturn the original eligibility decision – all they can do is advise the CCG that they should change their mind. CCGs can technically ignore this instruction, though the National Framework says they have to have a good reason to continue to say no.
- Worryingly, some people admitted they resolved their appeals by accepting less than the full amount to which they were entitled.
- The alliance knows from speaking to people that many decide not to appeal their decision on NHS CHC eligibility. This is not because they feel the decision was correct, but because they are too distressed and exhausted to go through the complex appeals process.

What needs to happen?

- NHS England must ensure that CCGs adhere to the appeals timescales as laid down in the Department of Health guidance¹⁰.
- When appeals are upheld, care costs incurred must be repaid in full.
- Training should be improved to ensure that professionals know how to direct someone towards the NHS CHC appeal process, and can explain the system comprehensively.
- NHS England must monitor the outcomes of the local appeal process. If they are consistently proven to be unduly lengthy, or not impartial, individuals should be able to bypass this stage and proceed straight to the IRP.

¹⁰ [National framework for NHS continuing healthcare and NHS funded nursing care](#) (Nov 2012) paragraph 95



“ I'd always been fit and healthy, running every other day, doing martial arts, and being a member of the Territorial Army. I'd never had a broken bone! Having been self-employed for over 30 years, I only ever had a handful of days off sick. My life changed when I went on holiday and fell down a flight of stairs. I ended up with a severe spinal cord injury (SCI). I now rely on a wheelchair and need 24 hour support for even basic tasks like going to the toilet, washing and eating.

Following an assessment, my MDT recommended that I receive NHS CHC. We thought this decision would be approved by my CCG. I couldn't believe it when they came back and said no.

The CCG didn't accept the scores I'd been given and thought my case had been over stated. But they didn't provide any reasoning for their comments, and had never met me. We challenged the outcome, and the CCG came back saying they were deferring their decision. Without a definite yes or no I couldn't officially appeal. This situation went on for months. I believe it was a delaying tactic.

It was such a distressing time. Two years earlier there was nothing wrong with me. Now I was fighting a complicated system I knew little about, in a situation I didn't want to be in, far from home. I can see why people give up. It's an uphill

struggle, you go round in circles and no one takes responsibility. After much chasing, the CCG confirmed I wouldn't be given NHS CHC. I took my case to local appeal but the CCG chose who would sit on the panel, and unsurprisingly they came up with the same decision.

I then said I wanted to take it to an IRP. The CCG told me I had to apply for this through them, so I did. Nothing happened for three months. After chasing my CCG they admitted they had got the information wrong and I actually had to go directly to NHS England. So my appeal hadn't moved forward at all and I only found out because I kept calling and eventually someone told me. Once in touch with the IRP organisers, they thought I had a good case. They decided to uphold my appeal and requested my CCG grant NHS CHC. Even after this, the CCG didn't provide help straight away. If the CCG refuses to adhere to the IRP's ruling only the courts can enforce the decision. It doesn't seem like they are accountable to anyone.

Without NHS CHC in place I couldn't go back to my house. From the time of my accident, I had been kept in a specialist spinal unit and then moved to a residential care home. I had expected to be home after a few months, but I didn't go home for more than three years. My whole experience of this process was simply appalling.