

## In the dark: the provision of information and advice

People enter the health and social care system when they are at their most vulnerable. With NHS CHC marking the boundary between healthcare and social care, all too often people slip into that void where no one gives them the advice they need. Whether applying for themselves while living with a serious health condition(s), or applying for someone close to them, without good support and information the experience can be a distressing one. Since its introduction, the application and assessment process for NHS CHC has been incredibly complex. Many people told us they had to become overnight 'experts' in a daunting and complicated system.

### Positive progress

- NHS England acknowledged there was a need for independent information. To tackle this they funded an information and advice service through a social enterprise specialising in supporting people going through the NHS CHC process, called Beacon. The NHS pays for people to have 90 minutes of free advice.
- In April 2015 the Care Act came into force. It places an obligation on local authorities to provide information and advocacy to individuals. However, it is not clear how much this is happening in practice<sup>4</sup>.

<sup>4</sup> There is some concerning evidence about Local Authority short term and inadequate funding arrangements for independent advocacy under the Care Act – <http://www.seap.org.uk/getfile/6102>

### Current challenges

- **60%** of people in our survey said they did not know about the existence of NHS CHC until very late on in their journey through the health and social care system. When they did find out, it was usually by chance, or being told to apply by a friend.
- Signposting to NHS CHC should come from health and social care professionals but worryingly in our survey only **3%** of respondents told us they found out about NHS CHC from their GP. **5%** were told by their clinician, **15%** were informed by a hospital doctor or nurse, and **11%** found out through their social worker.
- The system is still complicated, confusing and intimidating for those who need NHS CHC. More than half (**54%**) of survey respondents said they were not provided with enough information or advocacy. And it's not just people applying who believe the process is difficult to navigate; **39%** of professional survey respondents said they found the NHS CHC assessment process complicated, and more than three quarters (**78%**) believed the system is difficult or very difficult for patients and their families to navigate.
- **65%** of survey respondents told us they did not feel well informed throughout the process, with **39%** of people saying they did not know what criteria the assessment would measure.

### What needs to happen?

- NHS England, CCGs and local authorities need to ensure that there is a clear process for health and social care professionals to proactively signpost individuals to NHS CHC, as well as promoting experienced, independent advocacy and support at every stage.
- NHS England must provide information about the system publicly – including the checklist, Decision Support Tool criteria and details on fast track assessments – through their communication channels and partners.

## Jane's experience

“ In October 2015 my mum was diagnosed with motor neurone disease (MND). She was only 72. As a family we were in complete shock. Our dad, who had colon cancer, became mum's main carer. Mum deteriorated very quickly. In January dad died, leaving mum grieving for her husband of over 50 years, and with no full time care. We organised a mix of paid for care alongside friends and family.

She collapsed in February and had a feeding tube fitted directly to her stomach, as she could no longer swallow solid food. We knew it was unsafe to send her home, so she went to a hospice while we waited for a room in a care home. While in the hospice, mum asked the doctor how long she had to live. She was told, 'no more than six months', and the MND medical consultant agreed.

We had a brilliant occupational therapist (OT) who told us about NHS CHC. We'd never heard of it as it's not advertised anywhere obvious. At that time she felt mum wouldn't be eligible for it, but said it might be a good idea to apply for an assessment anyway to get mum into the system. Mum couldn't walk, could hardly move her arms or use her hands, struggled to swallow, and was functionally incontinent. So I found it surprising she didn't think mum would qualify.

My sister contacted the CCG to start the process. We were advised that mum would be assessed a couple of weeks later. No one told us that this wasn't the full assessment, but only a checklist to see if mum would go on to the next stage. I don't know why this was necessary when two independent doctors agreed mum had less than six months to live due to a hugely debilitating



terminal illness. The assessor told us that if mum qualified for a full assessment we'd have to wait at least six weeks.

After doing a bit of research ourselves, we became aware of fast tracking. The CCG told us that this was up to the care home, or mum's GP. We contacted the GP, but he felt it wasn't for him to do. My sister did further research online and sent the GP a link to the documents for fast tracking, with information on what he needed to do. The GP continued to say it wasn't his role. I contacted the MND medical consultant to ask if he could help with this. He replied saying it was a task for the GP or the nursing home. The whole system needs to be reviewed and simplified. It needs to be clear who is responsible for each stage of the process. There should be simple information for patients and carers and CCGs need to have teams in place who provide help.

Mum died in May still waiting for her full assessment. To say I feel let down is a complete understatement. On one hand the NHS implies that they help people with medical conditions that require significant healthcare, and yet the process is so protracted that I'm not sure who actually gets this support. There needs to be more transparency and greater clarity on what should be funded. My mum deserved much better than this.

