Is West Hampshire CCG fit for purpose for delivering NHS Continuing Healthcare?

Following the failings of the NHS Continuing Healthcare review for my wife in November 2017, a new review was arranged for January 2018. At this time, we were still unaware that the first review had no legal basis and, as such, did not obtain informed consent from us.

Throughout most of this review, we felt that we were being listened to and that the process seemed much more appropriate. The case coordinator, Jo Craven, had prepared properly, read all the supporting documents and listened carefully to us. Our one concern was that we were being asked to grade ourselves against the Decision Support Tool scoring system – a process that is used in Multi-Disciplinary Team meetings that assess eligibility. We had not experienced this in any previous review. West Hampshire CCG has repeatedly refused to answer whether this was standard practice.

All seemed fine. My wife scored one priority and two severes, along with various other scores between low to high across the twelve domain areas. It is expected that eligibility will be confirmed if there is one priority <u>or</u> two severes. Eligibility can still be determined if there are a range of other scores. Consideration is given to nature, intensity, complexity and unpredictability. This was not doubted in our case at the review.

Whilst one priority was scored (with us understanding that one priority is all that is needed), we stated that we would only agree no need in 'Breathing' if it were appropriately scored in 'Altered State of Consciousness', as happened in the original DST of 2009. It transpires that this is wrong. The life-threatening issue of my wife's epilepsy should be represented in both domains.

To our utter shock and dismay, we were informed that our case would have to go to a Multi-Disciplinary Team meeting to reassess eligibility. We were told it was due to a minor change in an irrelevant domain which had gone from moderate to low (whilst another had increased). Jo Craven said it was "simply the guidelines." Any change has to go the MDT. THIS WAS A LIE. There are no guidelines stating this and Pauline Dorn, the new Head of Continuing Healthcare at West Hampshire CCG, stated at a meeting with us approximately three weeks later that the wrong outcome was determined at the review (we will cover this in the future as, despite the admission, the CCG ignored the failing and then in our view covered it up). Jo Craven agreed that it was a waste of NHS time and money, stating "it doesn't make sense, does it?"

Following further discussion, it was agreed that Jo Craven would ask a senior manager if the case really had to go to MDT as there was one priority and two severe domains agreed. She phoned back 75 minutes later to inform that the senior manager had said it must go to MDT due to the minor change in one domain.

We challenged this in writing. The decision contradicted the National Framework, the CCG's Joint Operational Policy and a direct statement from the CCG's response to our previous complaint, which was signed off by the Chief Officer, Heather Hauschild:

"The decision support tool review meeting should be facilitated when there is an indication, when aligned with the initial decision support tool, that there may be a change in outcome of NHS Continuing Healthcare eligibility."

Following the letter from us, without our knowledge or consent, the senior manager (Meriel Chamberlain) accessed my wife's records and conducted her own 'review'. Despite the conclusive medical evidence (as previously documented), Meriel Chamberlain determined that my wife was not a priority in Altered State of Consciousness, resulting in it being at best 'High'. Jo Craven also changed the agreed decision of cognition, lowering it from severe. As such, the review document now stated that my wife only had one severe and no priorities. Please note, we have never met Meriel Chamberlain and

she has never had, to our knowledge, any previous involvement in our case. This re-review of our case was unlawful as consent was not given and is not in line with the National Framework for NHS Continuing Healthcare.

Pauline Dorn accepted that the changes made after the meeting should not have happened. Despite this, the CCG continued to state the outcome of the review was the need for an MDT. They also repeatedly claimed that they were following due process, in accordance with the National Framework. This is completely untrue.

To our dismay, Social Services, the Parliamentary and Health Service Ombudsman and the NMC found no fault in the CCG's actions. We will highlight the failures of these organisations in future correspondence. We have no doubt that the actions we have faced represent organisational abuse, cover up and unlawful behaviour.

We emphasise the importance of remembering that we have evidence of every statement we have made, including recordings and internal emails. We will share these on request.

In our next update, we will highlight West Hampshire CCG's response to our complaint against the process of the second review. Some of the responses are staggering, especially as they have finally admitted that there is no evidence of documents that they have referred to. We are also preparing an open letter to Matt Hancock and William Vineall (Director at Department of Health and Social Care), inviting them to investigate our case in order to highlight the failings in the accountability processes in the NHS.