

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

This is the third instalment of our national campaign regarding NHS Continuing Healthcare. This time we will focus on the fundamental principle of **informed consent**. This is enshrined in the Data Protection Act and the NHS Constitution. It is also a key principle in the NHS Continuing Healthcare National Framework. In trying to navigate their way round our complaints, West Hampshire CCG has claimed to us, and others, that they had a legal basis for the review process that they put us through. This is not true and we will evidence this in our next instalment.

Medical records are classified as personal, sensitive data. As such, they have greater protections for their use and disclosure. Informed consent requires the individual to have full understanding of why and how data will be used and by whom.

We have spent most of our complaint with West Hampshire CCG stating that we did not give informed consent for the reviews they put us through. Their most recent response (6 June 2019) states:

"On 13 April 2017 Mrs Austen Jones signed a consent form that specifically includes consent for reviews to take place. In addition both you and Mrs Austen Jones were at the review meetings and did not raise any objections at the time."

This statement ignores many factors and is factually wrong:

- The April 2017 consent form, which was signed, was from a previous review. It does include a reference to future reviews but this is only valid if the individual has all the information they need to take part in future reviews.
- WE DID CHALLENGE THE REASONING FOR THE REVIEW PROCESS. We questioned it prior to the November 2017 review meeting and then at the meeting. We were then told by Roy Dube, the case co-ordinator, that reviews take place every 3-6 months. Roy Dube's statement is completely untrue as the CCG's own policy for NHS Continuing Healthcare states that reviews are annual unless there are exceptional circumstances (the CCG has tried to alternative reasons but we will evidence in our next instalment that their claims are completely false). As such, we were misled. Thus, consent was not informed. The CCG has never answered the question as to why we were told this.
- We have been challenging the CCG ever since and continue to do so.
- The January 2018 review took place and all seemed to be going properly, only to be told that "guidelines" meant our case had to go to a Multi-Disciplinary Team (MDT) meeting. We challenged this but no evidence of these "guidelines" has ever been produced. As such, we were misled about the process which means the implied consent is invalid. Pauline Dorn, the Head of Continuing Healthcare at West Hampshire CCG, later accepted that guidelines meant that an MDT was not required as on-going eligibility had been identified in the review meeting. The CCG has not rectified the mistake and has gone on to claim that the consent was valid.
- After the January Review, Meriel Chamberlain (a senior manager) did a private review with the case coordinator without our knowledge or consent. This changed the outcome of review, making my wife's condition appear less severe. Pauline Dorn informed us that this review should not have taken place. Despite this, the CCG continued to use this outcome to try to force the MDT.
- As a result of the actions of Meriel Chamberlain and the process of the January 2018 review, we submitted a formal complaint. Pauline Dorn did her own private, unconsented review of our case. This determined the outcome of the complaint even though the complaint was about process. No investigation had been carried out at this point.

In our view, it is scandalous that West Hampshire CCG has never obtained informed consent and yet continues to try to claim it did. This is made even worse when we were misled at both reviews (the CCG has yet to provide evidence that we were not) and then we were not even aware of reviews being conducted behind our backs that impacted the actions of West Hampshire CCG.

We have raised these concerns with Social Services, the Information Commissioners Office, the Parliamentary and Health Service Ombudsman and the Nursing and Midwifery Council. In our view, none of them have carried out their roles properly and we will provide evidence of this in the coming weeks and months. Unfortunately, the scandal we have faced has not been limited to one organisation. It appears that the lessons of the Gosport War Memorial Hospital scandal have yet to be learnt.

Our question is simple: if they are doing this to us when we have consistently challenged them for twenty months, how many other people are having decisions made without them giving properly informed consent?

As ever, more detailed information is available on our website, chcinhamshire.com. If you wish to discuss any of the matters we have raised, please email us. We will happily provide our telephone number on request, along with all evidence to back up our statements.