

Our Ref: 4588

21 December 2017

Private & Confidential
Mr and Mrs Austen-Jones

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Dear Mr and Mrs Austen-Jones

Re: Clinical Review

Thank you for your letters dated 10 November 2017 and 12 November 2017 addressed to the Continuing Healthcare team and also received from Leo Docherty MP regarding the review held on 8 November 2017.

To enable me to investigate the issues you have raised, your complaint was shared with the Continuing Healthcare team and I am now able to respond.

I apologise that the review was not carried out to the expected standard. The review process, as outline in the National Framework for NHS Continuing Healthcare, should take place annually, as a minimum. This should be done in consultation with the person being reviewed and any other relevant people who know the person who are present at the review. The focus of the review should not just be on whether the individual remains eligible for NHS Continuing Healthcare but on whether needs are being met and whether the package of care remains appropriate. The outcome of the case review will determine whether the individual's needs have changed, and that will then determine whether the package of care may have to be revised or the funding responsibilities altered.

The Continuing Healthcare team are sorry that the case coordinator did not review the documentation from Jan Arevalo, Specialist Epilepsy Nurse, nor those provided by Jim Ruddy, Chief Executive Office of Rushmoor Healthy Living. The team confirm that it is expected that any previously completed decision support tool will be available at the review and each of the domains and previously assessed need levels are considered by the reviewer. It is expected, in accordance with the National Framework for NHS Continuing Healthcare and also the service standard operating procedure, that reviews are inclusive of any relevant contemporaneous clinical records.

The views of the individual and also their representatives should be discussed and recorded within the review document. Whilst your comments are recorded on the assessment, it is acknowledged that limited action was taken to consider the documents which you felt were

relevant to the review. I apologise that the case coordinator's approach was not in line with the values promoted within the NHS Continuing Healthcare team for West Hampshire Clinical Commissioning Group.

The team would like to reassure you that the case coordinators do have protected administrative time in order that they can prepare for appointments and respond to any case queries. However, it is acknowledged that in this circumstance usual process was not followed for which the team would like to apologise.

I understand from your letter that you were not assured that due consideration was given to the frequency of Mrs Austen-Jones' seizure activity which led to the case coordinator's recommendation that care should be reduced. Whilst it is acknowledged that it is appropriate to ensure that care provision is appropriate in line with the West Hampshire Clinical Commissioning Group Choice and Equity Policy, this needs to be supported by appropriate clinical evidence in order to ensure that needs are met and safety is maintained. This is inclusive of any epilepsy care plan, risk assessments and contingency/emergency planning. The team's Professional Lead, who undertook the complaint investigation understands the risks associated with tonic-clonic seizures, refractory epilepsy, respiratory requirements and Buccal Midazolam and that each individual will require a measured and clinically sound response dependent on clinical requirements. The team will therefore respond to the training need highlighted around epilepsy care for all case coordinators.

With regards to the recommendation following clinical review, as discussed above, the role of the case coordinator is to highlight whether there has been a change in presentation which may lead to an increase or decrease in provision, as well as consideration as to whether a decision support tool review meeting is appropriate. 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. The team apologise that this was not effectively completed or communicated to you at the time of the meeting.

Given the concerns raised and the process challenges highlighted, the team would like to complete a further case review with an experienced case coordinator. We would also like to offer that this is a joint visit with the local authority social worker. The team will contact you by 12 January 2018 with a view to arranging the review and how you would like to proceed.

The Care Act advises that anyone in a caring role may be offered a carers assessment by the local authority. As case coordinators and registered professionals, it is appropriate that any need for a carers assessment is identified and an appropriate referral is made. Therefore should you like the team to organise this, please advise the team when they contact you.

In the meantime, if there are any adjustments or additional consideration which you feel would be beneficial to support a more positive review experience, please let the team know.

Please accept our sincere apologise for any distress the review process has caused you and your family. I understand that clinical assessments of this nature generally can cause anxiety, which have been heightened by the lack of confidence in the clinical recommendations being made.

I hope that the above information provides a satisfactory response to the concerns raised and addresses them all fully. I appreciate that you may have further questions or comments which I would be happy to reply to. Alternatively our Deputy Director for NHS Continuing Healthcare, Ciara Rogers, would be pleased to meet with you in order to discuss your concerns further.

Yours sincerely

A handwritten signature in black ink, appearing to read 'H Hauschild', written in a cursive style.

Mrs Heather Hauschild
Chief Officer

cc. Leo Docherty MP

If you're not happy with our final response to your complaint, and would like to take the matter further, you can contact the Parliamentary and Health Service Ombudsman. The Ombudsman makes final decisions on complaints that have not been resolved by the NHS, government departments and some other public organisations. The service is free for everyone. To take a complaint to the Ombudsman, go to www.ombudsman.org.uk/making-complaint or call 0345 015 4033. It is important that you make your complaint to the Ombudsman as soon as you receive our final response as there are time limits for the Ombudsman to look into complaints.