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MR EDWARD G. THOMAS Senior Coroner MR GRAHAM DANBURY Deputy Coroner, Dr FRANCES CRANFIELD, ALISON GRIEF, EDWARD SOLOMONS Assistant Coroners

12 August 2015

The Rt Hon Jeremy Hunt MP Secretary of State for Health Department of Health 79 Whitehall London SW1A 2NS

Your Ref: Our Ref:

Dear Mr Hunt,

Re: Eileen SMITH, deceased

I am writing to you under the provisions of Schedule 5 (paragraph 7) of the Coroners & Justice Act 2009 which came into force in July 2013. This re-enacted the provisions of the old Rule 43 of the Coroners Rules 1984. Attached to this letter is information concerning the new rules and regulations from which you will see requires a written response. Copies of this letter and the response received from you will be forwarded to the other interested persons identified at the inquest in accordance with the list attached.

In fact I am aware that you had some knowledge of Eileen's tragic death because the family wrote to you and you kindly responded in July 2014 both formally and informally.

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As you can see from the supplied documentation, Eileen had a learning disability the details of which are fully contained in the findings and in the documentation supplied at the inquest. Eileen was admitted initially to the Queen Elizabeth II Hospital Welwyn Garden City and then to the Lister Hospital, Stevenage. With Eileen was a purple folder which detailed her disabilities and her Health Action Plan. The Learning Disabilities Advisor from Health and Community Services of Hertfordshire County Council gave me a specimen purple folder which would have included Eileen's Service User Plan and her personal care needs. The home where Eileen resided also indicated that she never appeared cross or frustrated and never complained or showed signs of discomfort or pain. She clearly very happy at the home and had an active life; she was very supported by her family.

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The East and North Hertfordshire NHS Trust carried out a Serious Incident Investigation and produced a report detailing failings including gross failings of nursing care. A detailed action plan has been undertaken and I have been told that significant changes have been made to prevent this from happening again. A copy of the report has been sent to the Clinical Commissioning Group (CCG). The Trust has a policy concerning the care of adult patients with learning disabilities and has now produced a hospital communications book to assist in medical nursing staffs understanding of a person with learning disabilities. Towards the end of paragraph 14 of my findings I felt it was important to state that assumptions about the health of a person with learning disabilities could not be made by external appearances and that there should be communication particularly with those such as carers and family who may well be able to assist in helping the staff. This happened successfully on the first night of Eileen's admission when the Senior Sister who clearly had read the purple folder contacted the family who helped Eileen to understand that she could not keep wandering from her room.

As I have indicated to the other interested persons, my primary purpose in making a Regulation 28 report to you, is to ask you whether you could assist in the care of persons with learning disabilities. I was impressed by the purple folder, the passport that accompanies a patient to hospital. The information contained can give those unfamiliar with the patient some understanding of what to expect and not to make assumptions that when nothing is said that all is okay.

The East and North Hertfordshire NHS Trust have undertaken a programme to assist staff in achieving a greater understanding of patients with learning disabilities and the importance of the Learning Disabilities Nurse whose service was notified by the Senior Sister on duty on the first night.

The Health and Community Services of Hertfordshire County Council have informed me that their department produced "my purple folder" as they were aware that persons with learning disabilities can face obstacles in accessing support for their physical health needs including communication difficulties which impacts upon their ability to secure appropriate advice. There is no doubt in my mind that the "my purple folder" benefits all within the health and hospital environment and should be helpful in providing appropriate health care for learning disabled patients. The Hertfordshire County Council have suggested to me that each acute Trust should introduce or continue to use "Reasonable Adjustments Audit tool for each patient admitted with learning disabilities to assess the adjustments made during their time in hospital and learn from current practice in line with recommendations from guidance documents such as CIPOLD Report. They tell me that they are piloting such a tool in the West Hertfordshire NHS Hospital Trust (Watford General Hospital). They are planning to roll it out with the East and North Hertfordshire Hospital NHS Trust (Lister Hospital) in the near future.

They have suggested to me that training should be mandatory for all staff within an acute Trust:-

- Training as part of Trust Induction process on learning disability awareness and reasonable adjustments including the use of "my purple folder"
- Mandatory training on the role of paid/family carers in line with the Trust's Carers Policy to ensure collaborative working across the Trust
- Training for all on the learning disabilities admissions policy and reasonable adjustments including "my purple folder"

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 Training on Learning Disability Awareness the additional risk for patients with learning disabilities and how they can be supported

The Hertfordshire County Council also has indicated to me that they feel the following would be highly beneficial:-

- Identification of a lead medical representative who can advise and work collaboratively with Acute Liaison Nurses and clinical staff when a patient with learning disabilities is admitted to the Trust.
- Investment in communication aids for all clinical areas, Hospital Communications Book and Easy Read EIDO Leaflets to meet national information standards

I do not know whether "my Purple Folder" and "My Health Action Plan" are generally provided throughout England and Wales in respect of persons with learning disabilities being admitted to hospital but if it is not, then I would draw your attention to these suggestions in the hope that it may then assist those with learning disabilities who are then admitted for what for them is likely to be a strange and confusing environment. Comprehensive understanding of that patient will undoubtedly benefit the care of that patient and hopefully prevent similar fatalities to that of Eileen.

I heard so much about Eileen and was privileged to receive lovely photographs of her. She was clearly a happy and lovely lady and as I indicated I find it very sad that she died in such circumstances. I therefore hope that any other similar death can be prevented.

I look forward to hearing from you in due course.

Formally under Regulation 28 I require a response from you within 56 days of receipt which I calculate is the Friday 9th October 2015. I am retiring as Senior Coroner on the 31st October 2015 and would really appreciate a response within a reasonable timescale of that date to enable me to communicate your response with the interested persons. Please let me know if there are difficulties in complying with this timescale.

Many thanks for your anticipated assistance with this matter.

Yours sincerely

Edward G Thomas Senior Coroner