



30 September 2024

BY EMAIL: [REDACTED]

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Service

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Dear Mr Appleton

**MARGARET HUNTLEY (DECEASED)**

I am writing in response to the preventing future deaths report received at the Association of Ambulance Chief Executives and I respond as our Director of Operational Development and Quality Improvement on behalf of AACE.

On behalf of AACE, I would like to extend our sincere condolences to the family of Margaret Huntley.

It may be helpful for us to explain that AACE is a private company owned by the English and Welsh NHS ambulance services. Its purpose is to support its members, UK NHS ambulance services, in the implementation of national agreed policy and to act as an interface, where appropriate at a national level, between them and their stakeholders. It is a company owned by NHS organisations and possesses the intellectual property rights of the Joint Royal Colleges Ambulance Liaison Committee UK ambulance service clinical practice guidelines (the "JRCALC guidelines"). AACE is not constituted to mandate or instruct ambulance services however it has national influence via the regular meetings of ambulance chief executives and chairs along with a network of national specialist sub-groups.

We respond in relation to your matters of concern:

*There is a lack of understanding amongst (non-clinical and clinical) Ambulance Service staff as to the importance of steroid medication and the steps to be taken should a patient (a) report that they are prescribed steroid medication and/or (b) present with symptoms potentially consistent with steroid insufficiency/Addison's Crisis.*

Firstly, it is important to note that the education and training of paramedics is not within the remit of AACE or JRCALC.

Secondly, JRCALC guidelines are advisory and have been developed to assist healthcare professionals inform patients and to make decisions about the management of the patient's health, including treatments. This advice is intended to support the decision-making process and is not a substitute for sound clinical judgement. The guidelines cannot always contain all the information necessary for determining appropriate care and cannot address all individual situations; therefore, individuals using these guidelines must personally ensure they have the appropriate knowledge and skills to enable suitable interpretation. All our JRCALC guidance is updated on a regular basis. The guidance is available to all UK ambulance paramedics and is used on an App.

The JRCALC guidelines contain a specific guideline called 'Steroid-dependent patients'. This guideline details the assessment and management of patients that are dependent on steroids. We also have separate guidance around the indications for administering hydrocortisone which we know is carried on all ambulances.

[REDACTED]

We are engaging with the Addison's Disease Self-Help Group and the Pituitary Foundation so that they can provide information to patients with regard to ensuring their health care record contains information that they are steroid-dependent and explaining how people can be reassured about what happens and what can be done to ensure if emergency help is needed, such as a 999 ambulance, that they receive the best care possible.

In relation to the second matter of concern:

*There is not, within the NHS Pathways system or otherwise, guidance or processes for Ambulance Service staff triaging calls, including non-clinically qualified staff, to follow regarding (a) the importance of steroid medication and the need to establish, if a patient raises during a call that they are prescribed steroid medication, detailed information regarding that prescription to include the type of prescription and the reasons for it; (b) actions to be taken or processes to follow should a patient raise during a call that they are prescribed steroid medication.*

AACE are not responsible for the guidance or processes for ambulance staff triaging calls. NHS Ambulance Services are required to process 999 calls through an approved triage system and there are currently two different systems in use in ambulance trusts. We know that these systems are able to advise patients to take their emergency supply of steroids.

In relation to the third matter of concern:

*It is unclear as to whether Margaret Huntley had been issued with a Steroid Emergency Card and/or information around use of such a Card. I am concerned that there needs to be improved usage, and awareness, of Steroid Emergency Cards.*

Within our JRCALC guidance for steroid-dependent patients, we have an image of the NHS steroid emergency card. We included this particularly to help raise awareness amongst ambulance clinicians. In addition ambulance clinicians can often gain access to the patients' health care record where clinical information such as steroid dependency may be available.

In relation to the final matter of concern:

*It was confirmed in evidence that it is possible for GPs to request that an alert is placed on to the Ambulance Service's system(s) to alert Ambulance Service staff to specific patient health conditions, such as steroid insufficiency. I am concerned that (a) there is inadequate awareness of this ability amongst GP's; (b) this action is not routinely being taken by GPs.*

AACE do not support routine 'flagging' of patient addresses for steroid-dependent patients. We know that the majority of ambulance services have moved or are moving away from this due to a number of governance and risk issues. One example of an issue is that if a flag is placed against a patients address, the patient may have moved house or died, therefore, the validity of the flag becomes flawed. Or, if the 999 call is made from somewhere other than the flagged address, the flag is then not useful. We do however support important information being documented on the patients summary care record or care plan.

If you have any further questions please do not hesitate to get in touch.

Yours sincerely

  
  
Director of Operational Development and Quality Improvement  
