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SUBJECT: CAROLINE ROBERTS URGENT - Potential for Leicester Royal Infirmary Hospital made liable in the event of her death after discharging her.

Urgent safeguarding and patient safety escalation for very severe myalgic encephalomyelitis patient, CAROLINE ROBERTS.

Re: Caroline Roberts, Leicester Royal Infirmary Hospital.

Ward: 26

Bed: 3

Dear NHS trust CEO, Mr Richard Mitchell, health professional staff involved in the care of Caroline Roberts, PALS, and safeguarding team.

I'm writing to you with concern for a patient who is rapidly deteriorating in your care at Leicester Royal Infirmary Hospital.

Very severe myalgic encephalomyelitis (ME) patient Caroline Roberts has been an inpatient with you this last week, due to inability to maintain adequate nutrition and hydration. She is severely disabled by very severe ME, hypermobile ehlers danlos syndrome (hEDS), mast cell activation syndrome (MCAS), and fluoroquinolone toxicity.

Caroline has been admitted to stroke ward 26, bed 3 as there was no other room available. It is our understanding that this entire week she has not received any effective treatment to improve her nutrition or hydration. She is instead continuing to decline dangerously.

We understand that today Caroline was finally seen by a dietitian. However, the dietitian gave Caroline a shake containing lactose. As Caroline is lactose intolerant we do not consider this to be effective treatment for her nutrition issues. Caroline's MCAS and very severe ME mean that consuming this shake would cause a life threatening allergy reaction.

We understand that the hospital is pushing for Caroline to be discharged home today. However, Caroline has deteriorated significantly and it would be extremely dangerous to discharge her now. She is so frail that her risk of mortality from just transporting her home is extremely high.

Throughout this admission Caroline has not been given adequate adjustments for her disabilities in accordance with the Equality Act 2010, which places duties on NHS organisations to make reasonable adjustments for disabled patients. Along with failure to provide adequate treatment nutrition and hydration care, this has contributed to Caroline deteriorating into a life

threatening post exertional neuroimmunological exacerbation/ post exertional malaise (PENE/PEM) crash. The issues reported to us by Caroline, her partner/ legal carer Jack McDonald, and family include:

- Not recognizing that Caroline's very severe ME requires a low stimulus environment, such as a darkened quiet room.
 - Instead Caroline has been left with a sheet tented over her head that still lets light through. As Caroline has severe light sensitivity this is worsening her PENE/PEM.
 - Instead staff are entering noisily and ignoring Jack and family members who ask them to please be as quiet as possible. As Caroline has severe noise intolerance this is worsening her PENE/PEM.
- Not recognising that Caroline's very severe ME, and hEDS, requires staff to be extremely careful with physical contact, and moving her.
 - Instead staff are performing unnecessary repeated neurological examinations on her. This is occurring even when Caroline or Jack have asked them to stop and leave her alone to rest. This is worsening her PENE/PEM.
- Not recognising that Caroline's very severe ME, MCAS, and fluoroquinolone toxicity requires careful attention to medication ingredients, and drug contraindications.
 - Instead, staff have removed all drugs not prescribed by the hospital and locked them away. This includes OTC allergy medications and sodium cromolyn, which are essential to prevent life threatening MCAS episodes.
 - Instead staff are pushing generic drugs and food containing ingredients that could cause a life threatening reaction for Caroline. This includes oral paracetamol that contains lactose, and a creamy chicken protein shake containing lactose. Consuming either would have caused a life threatening allergy episode.
 - Instead staff are pushing generic drugs that will exacerbate Caroline's fluoroquinolone toxicity. This includes oxycodone, pregabalin, and duloxetine. Such exacerbation risks life threatening complications of hEDS and severe ME.
- Not recognising Jack McDonald as Caroline's legal carer and partner who is essential to reduce the significant exertion of communication for Caroline.
 - Instead staff members continue to force Caroline to overexert to explain her ongoing medications, multiple times a day. This is worsening her PENE/PEM.
 - Instead staff members are taking offense when Jack refuses to let them give Caroline harmful medication that could cause Caroline an immediate life threatening episode.
 - Instead one staff member has threatened to have Jack evicted for not letting them into Caroline's room. As Jack did this to protect Caroline from further deterioration, this is especially concerning.

As advocates supporting Caroline and Jack, we have urged them to appeal 'Martha's rule' and get in contact with patient advice liaison services (PALS), to stop further harm and life

threatening complications. However, it seems the only action taken was a dietician consult which resulted in inadequate support for Caroline's nutrition needs.

As advocated we are urging you to please step in before Caroline is discharged in a condition where her mortality risk will only continue to rise. We ask you to please request a second review with the following actions as a matter of urgency as part of the review of Caroline's care:

- Immediate acceptance for Dr Charles Sheperd, Dr William Weir, and Dr Nigel Speight, of the ME association, to step in and provide their expert opinion on what must be considered and done for Caroline Roberts. This can only happen if a lead clinician contacts Dr Charles Sheperd at the following email address:
charles.shepherd@meassociation.org.uk
- Immediate implementation of reasonable adjustments appropriate for a patient with very severe ME.
- A second opinion review of Caroline Robert's risk of malnutrition, dehydration, and mortality.
- Urgent safe-guarding review.
- A multidisciplinary meeting with the treating team, safeguarding representatives, and the patient's caregiver.
- Staff to review the severe ME learning hub module: [NHS Severe ME learning module](#)

We are deeply concerned that Caroline Roberts is a highly vulnerable patient admitted because she could not maintain nutrition or hydration and has spent approximately one week in hospital without resolution of the presenting problem, while experiencing ongoing deterioration.

We ask that this matter be treated with urgency as Caroline's mortality risk continues to increase. Unfortunately, there have been multiple cases like Caroline where hospitals without knowledge of how to treat severe and very severe ME patients, have caused significant and life-threatening declines. This was the case with 27-year-old severe ME patient Maeve Boothby O'Neill – who tragically died in 2021 as a direct result of inadequate care by Royal Devon and Exeter Hospital.

We also urge the hospital to engage and accept advice from ME experts Dr Charles Shepard, Dr William Weir, and Dr Nigel Speight. Members of Caroline's multi-disciplinary team have a duty to engage with this information.

Most importantly, please acknowledge that as the patient, Caroline and her partner Jack are proficient in Caroline's condition. And therefore, we ask that your staff respect decisions to refuse treatments and examinations they know will cause her to deteriorate further and actively listen to her and Jack when they communicate the care she needs.

Yours sincerely,

[NAME]