

FOI REF: 23/892

26<sup>th</sup> January 2024

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## FREEDOM OF INFORMATION ACT

I am responding to your request for information under the Freedom of Information Act. The answers to your specific questions are as follows:

**I am writing to all hospitals in UK and Ireland which provide intrathecal therapy services to enquire about their practice or policy for managing patients with pumps, when they cannot attend the clinic for a refill. This situation usually occurs because of intercurrent acute illness or pressure sores, but sometimes because of inadequate hospital transport services.**

East Sussex Healthcare NHS Trust does not provide an intrathecal therapy service, therefore we do not hold this information.

**What is the address of your base refill clinic, with postcode?**

Not applicable.

**1) How many adults with pumps for spasticity/dystonia do you manage with intrathecal baclofen?**

Not applicable.

**2) How many adults with pumps for pain do you manage with intrathecal opioids?**

Not applicable.

**3) How many children under the age of 18 with pumps for spasticity/dystonia do you manage with intrathecal baclofen?**

Not applicable.

**4) How many children under the age of 18 with pumps for pain do you manage with intrathecal opioids?**

Not applicable.

5) **Approximately how many pump refills does your service do each month at your usual locations?**

Not applicable.

6) **Do you accept people attending on a stretcher for refills?**

Not applicable.

7) **How often do you refill pumps away from your base hospital clinic?  
Eg. Once/month, once/year, once in 5 years?**

Not applicable.

8) **What is the furthest you have travelled from your clinics to refill a pump, in miles or time, in the past 3 years?**

Not applicable.

9) **For the first time, a patient is unable to attend the clinic by wheelchair or stretcher for a planned refill, because of acute illness or transport failure. They are expected to recover and be fit to attend refill clinics in the future. They are 90 minutes drive from your usual refill service base and there is no more local service which could refill the pump before it runs out. Would you plan:**

a) **No refill and when pump runs dry advise local doctors to manage withdrawal symptoms with medication by another route?**

Not applicable.

b) **Staff from base clinic travels to refill pump at patient's home or local hospital, before it runs dry?**

• **Who would travel?**

○ **Doctor who runs the service?**

○ **Doctor in training who is rotating through the service?**

○ **Nurse who refills pumps in clinic?**

• **Do you arrange second person to travel to chaperone, check procedure or open vials to maintain sterility? No. /Yes, then who?**

• **Or a video call to check procedure/programming?**

• **When refilling away from usual clinic, would you ask pharmacy to prepare a sterile syringe with the total drug to be injected into the pump, or would you aspirate from separate vials at their home, as is usually done in clinics?**

Not applicable.

**c) Patient transferred to your hospital for in-patient management and refill?**

Not applicable.

**d) Other? Please explain.**

Not applicable.

**10) If you have refilled it once while they are acutely unwell, but subsequently the patient is unable to attend the out-patient clinic by wheelchair or stretcher for any future refills, and resides 90 minutes drive from your usual refill service base, and there is no more local service which does home refills to take over long term management, would you plan:**

**a) No visits for further refills or dose reduction?**

Not applicable.

**b) No further refills but home visits to reduce ITB dose in stages before pump runs dry?**

Not applicable.

**c) Regular home visits to refill pump until end of battery life, but pump not replaced?**

Not applicable.

**d) Regular home visits to refill pump indefinitely and pump replacement at end of battery life?**

Not applicable.

**e) Patient travels by stretcher ambulance, admitted overnight for regular refills?**

Not applicable.

**f) Other? Please explain.**

Not applicable.

If I can be of any further assistance, please do not hesitate to contact me.

Should you be dissatisfied with the Trust's response to your request, you have the right to request an internal review. Please write to the Freedom of Information Department ([esh-tr.foi@nhs.net](mailto:esh-tr.foi@nhs.net)), quoting the above reference, within 40 working days. The Trust is not obliged to accept an internal review after this date.

Should you still be dissatisfied with your FOI request, you have the right of complaint to the Information Commissioner at the following address:

The Information Commissioner's Office  
Wycliffe House  
Water Lane  
Wilmslow  
Cheshire SK9 5AF

Telephone: 0303 123 1113

Yours sincerely

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