

FOI_1574_2023-24 – FOI Request concerning Policy for Managing People with Intrathecal Drug Delivery Pumps

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. I am using Freedom of Information Requests to ensure a high response rate, and because my hospital does not regard this as research and hence this method does not require any regulatory approval.

<https://www.solent.nhs.uk/our-services/services-listings/intrathecal-baclofen-service-southampton/>

I propose to summarise these responses and write a report for publication in a medical journal. This information will inform service design and planning, particularly when key staff are retiring. It will also update a list of active services.

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

SO16 4XE (Western Community Hospital)

- 1. How many adults with pumps for spasticity/dystonia do you manage with intrathecal baclofen?**
52
- 2. How many adults with pumps for pain do you manage with intrathecal opioids?**
10
- 3. How many children under the age of 18 with pumps for spasticity/dystonia do you manage with intrathecal baclofen?**
0
- 4. How many children under the age of 18 with pumps for pain do you manage with intrathecal opioids?**
0
- 5. Approximately how many pump refills does your service do each month at your usual locations?**
13
- 6. Do you accept people attending on a stretcher for refills?**
Yes
- 7. How often do you refill pumps away from your base hospital clinic? Eg Once/month, once/year, once in 5 years**
About once every 2 years if admitted to a hospital and unable to attend clinic
- 8. What is the furthest you have travelled from your clinics to refill a pump, in miles or time, in the past 3 years ?**
20 miles
- 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 run dry advise local doctors to manage withdrawal symptoms with medication by another route.

No

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

Yes

In which case, who would travel?

Physio who runs the service

Do you arrange second person to travel to chaperone, check procedure or open vials to maintain sterility and if so who? Or a video call to check procedure/programming?

Yes if possible, but if not we rely on local clinical staff to assist

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?

We would aspirate from separate vials at their home

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

N/A

d) Other, please explain.

N/A

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

b) no further refills but home visits to reduce ITB dose in stages before pump runs dry.

c) regular home visits to refill pump until end of battery life, but pump not replaced.

d) regular home visits to refill pump indefinitely and pump replacement at end of battery life.

e) patient travels by stretcher ambulance, admitted overnight for regular refills.

f) Other, please explain.

We have never experienced this and do not envisage why (barring an acute illness) a patient would not be able to attend for refills. However, should that be the case, then I think option b would have to be considered, although if on a small dose we would probably also consider admitting them to our unit for a more rapid dose reduction and so that we could ensure we could titrate up oral medications.