

Ref. No: 0550  
Date: 31/12/23  
Subject: Pumps for Spasticity / Dystonia

## REQUEST

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.

To help you identify the appropriate people to answer these questions, intrathecal pumps are usually managed by the neurorehabilitation clinic / spinal injuries service/ pain management service/ neurosurgery or neurology. Alternatively you could ask your procurement team who has ordered Medtronic Synchromed intrathecal pumps or Medtronic 8551 refill kits. In Southport District General Hospital I believe the spinal injury rehab clinics run the service.

1. What is the address of your base refill clinic, with postcode?
2. How many adults with pumps for spasticity / dystonia do you manage with intrathecal baclofen?
3. How many adults with pumps for pain do you manage with intrathecal opioids?
4. How many children under the age of 18 with pumps for spasticity/dystonia do you manage with intrathecal baclofen?
5. How many children under the age of 18 with pumps for pain do you manage with intrathecal opioids?
6. Approximately how many pump refills does your service do each month at your usual locations?
7. Do you accept people attending on a stretcher for refills?
8. How often do you refill pumps away from your base hospital clinic?  
E.g. once / month, once / year, once in 5 years.

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

10. 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.
- 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? If 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?

- c. patient transferred to your hospital for in-patient management and refill
- d. Other, please explain

11. 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

## RESPONSE

St Helens and Knowsley Teaching Hospitals NHS Trust and Southport and Ormskirk Hospital NHS Trust became a single legal entity known as Mersey and West Lancashire Teaching Hospitals NHS Trust on 1<sup>st</sup> July 2023, as such parts of the response may be provided in two sections relating to the hospital sites of each of the legacy organisations.

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

North West Regional Spinal Injuries Centre, Outpatient Department, Southport District General Hospital, Town Lane, Kew, Southport, PR8 6PN

### 2. How many adults with pumps for spasticity / dystonia do you manage with intrathecal baclofen?

50 adult patients are currently being managed.

### 3. How many adults with pumps for pain do you manage with intrathecal opioids?

Nil

### 4. How many children under the age of 18 with pumps for spasticity/dystonia do you manage with intrathecal baclofen?

Nil

### 5. How many children under the age of 18 with pumps for pain do you manage with intrathecal opioids?

Nil

### 6. Approximately how many pump refills does your service do each month at your usual locations?

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**7. Do you accept people attending on a stretcher for refills?**

Yes

**8. How often do you refill pumps away from your base hospital clinic?  
E.g. once / month, once / year, once in 5 years.**

Only in exceptional circumstances - at home or hospital.

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

50 miles

**10. 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.

No

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

Yes

**Who would travel? Doctor who runs the service? Doctor in training who is rotating through the service? Nurse who refills pumps in clinic?**

The doctor who runs the service.

**Do you arrange second person to travel to chaperone, check procedure or open vials to maintain sterility? If yes, then who? Or a video call to check procedure / programming?**

Yes – this is arranged as appropriate.

**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 carry out the procedure as it usually done in the clinic.

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

No

**d. Other, please explain**

N/A

**11.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**

N/A

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

Yes (depending on individual patient need).

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

Yes (depending on individual patient need).

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

Yes (depending on individual patient need).

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

Yes (depending on individual patient need). Patient would be seen as an outpatient if possible – if travel arrangements can be put into place.

**f. Other, please explain**

We always endeavour to perform the baclofen refill procedure and not allow the pump to run dry.