



## Report from a visit to the Lymphoedema clinic

Speke, Liverpool, 15/09/22

### Introduction

On 15 September 2022 two Healthwatch Liverpool staff members visited the lymphoedema clinic in Speke, Liverpool. The visit had been arranged in advance with Mersey Care NHS Foundation Trust, the organisation that runs the clinic.

We worked with Mersey Care staff to design questionnaires so that we asked everyone the same questions. Most of the questions were prepared by lymphoedema service staff. We hoped to speak to patients attending the clinic in person, but as there were not many in-person appointments on the day we also spoke to patients by phone and left questionnaires with Freepost envelopes for staff to give out.

We heard from 19 patients in total: we spoke to 6 people in person, 8 by phone, and received 5 completed questionnaires in the post. Please note that not everyone answered all the questions, although most people did.

Patients we heard from came from Liverpool (10), Knowsley (4), Sefton (1), St Helens (1) and Wigan (1). For 2 people we did not receive this information.

We would like to thank the patients who were willing to talk to us about their experiences of the clinic, and the Mersey Care staff who helped to facilitate the visit, as well as the nurses who were there on the day for their help and support.

This report explains what people told us.

### What is lymphoedema?

The NHS website defines lymphoedema as

“a long-term (chronic) condition that causes swelling in the body's tissues. It can affect any part of the body, but usually develops in the arms or legs” (<https://www.nhs.uk/conditions/lymphoedema/>)

It is estimated that more than 200,000 people may have lymphoedema in the UK.

There are 2 main types of lymphoedema. Primary lymphoedema is a genetic condition and is less common than secondary lymphoedema. Secondary lymphoedema can be caused by certain treatments for specific cancers, or by long-term conditions such as rheumatoid arthritis.

The NHS treatments that are available to patients can depend on which area they live in; for example, we were told that there are more NHS treatment options available in Blackpool compared to Liverpool.

Mersey Care currently manages 3 Merseyside lymphoedema clinics, in St Helens, Sefton and Speke, Liverpool. The Speke clinic is the only one that is open 5 days per week.

## What people told us

### **We asked: What do you think is good about this clinic?**

Twelve respondents gave positive comments about the staff and staff attitude; people said staff were helpful, friendly, knowledgeable, supportive and caring. One person said that staff try hard.

“Helpful staff that make you feel at ease”

“Very helpful and supportive, you can ask anything, they're there to guide you. I'll phone them sometimes and when I'm upset they'll listen”

Care and treatment was the second most mentioned topic, by 7 people. Comments included:

“I found out that I had lymphoedema myself. They advised to wear stockings for 12 hours, they help, it's worth it”

“It's excellent, you can ask them anything, they explain everything properly to you. Chris and Sue did the Doppler and ultrasound, accurate readings”

This was followed by several other topics that received 2 mentions, including the information provided, efficiency, and good parking availability at the Speke clinic.

One person said that nothing was good due to the lack of treatments offered:

“Nothing. I have been attending for 2.5 years and am going private to get things done. Lymphatic drainage is not provided, they only provide a sleeve to compress your arm. It's a terrible service, but staff try very hard”

### **We asked: What could be improved?**

We received 17 responses to this question with a variety of topics mentioned.

3 people said there was nothing that could be improved, and 1 said they weren't sure:

"Not sure - it's only my second visit. I've been very impressed so far, creams and stockings were issued quickly"

Where people felt improvements were possible and/or needed, available treatments, funding and staffing were mentioned most.

"Everything. There is no funding, you have to fight for treatment"

"Lymph drainage massage, getting trained up on that. Staffing issues. They're doing everything they can"

2 people mentioned that which nurse you saw had an impact:

"It depends on the staff. I learned more from (named staff member) in the past 6 months than the 18 months before. I felt very let down"

3 people mentioned waiting times. The location of/ distance to the clinic was also mentioned by 3 people, including this comment:

"The distance to the clinic. I lost confidence driving during lockdown. PTS (Patient Transport Service) criteria have now changed, they don't accept me anymore"

2 people made comparisons with when the service was run by Marie Curie in the past. One commented that

"they (Marie Curie) had more understanding when it's linked to cancer. It's not a place that really looks after people with cancer. (...) There was more staff at Marie Curie"

### **We asked: Was the length of time from the referral by your doctor to the date of your actual appointment with the service**

- Very satisfactory
- Satisfactory
- Not Satisfactory
- Very dissatisfactory

13 people responded to this question; 5 said the waiting time had been 'very satisfactory', 5 'satisfactory', 2 'not satisfactory' and 1 'very dissatisfactory'. Not everyone had been referred by their GP; several people told us they had been referred after a hospital appointment.

### **We asked: How long did you have to wait for your appointment?**

Responses varied from ½ hour (which we assume was about the wait at the appointment itself) to 1 year. 2 people said they had not waited long, 2 had waited less than a month, and 8 people had waited between 2-4 months.

2 people didn't know. 2 people said the GP hadn't referred them, and 1 said it was not applicable.

### **We asked: Did you find the facilities at the outpatient clinic**

Easily accessible: 18 people said 'yes', 1 said 'no'.

Welcoming: 17 said 'yes', 1 said 'no'.

Comfortable: 17 said yes they did.

Close to your home: here 11 people said 'yes', but 7 said no.

11 people also left comments in response to this question. There were 5 comments about the location (4 negative, 1 positive), 5 about transport to the clinic (2 positive, 2 neutral, 1 negative), and 4 about the building and its facilities itself (2 positive, 2 negative). Comments included:

"I live in Huyton, so it's easy to get to"

"Taxis are costing a lot, the taxi cost me £20, and I had to go 3x per week when I was wrapped"

"It's not as accessible to me as Marie Curie was, that was a quick bus ride away. Here is 40 minutes on the bus, but that'll be easier once I get used to coming here"

### **We asked: Did the clinician introduce themselves?**

All 19 respondents said yes, the clinician had introduced themselves.

### **We asked: What type of information did you receive at the clinic?**

14 people said they had received both written and verbal information, 4 had received verbal information, and 1 written information.

17 people said this information was adequate for their needs, but 1 person said it wasn't. 18 people said the information was understandable, and 16 people found it helpful, although 2 said they didn't find it helpful.

Comments included:

"A photocopy about one part of my arm, don't get shown how to do things, for example how to massage, I did it the wrong way, was told to look it up on YouTube by staff"

“With (named member of staff) I receive whatever information he has. With others I have had to ask. A scan changed my knowledge, but that was private though, not NHS”

In response to the question **Were you given the opportunity to ask questions/discuss concerns?**, all 19 respondents confirmed that they had been given this opportunity.

**We asked: does the lymphoedema clinic help you with:**

Providing ongoing support: 18 said ‘yes’, 1 ‘no’

Providing helpful information: 17 said ‘yes’, 1 ‘no’

Helping to reduce complications caused by swollen limb 14 ‘yes’, 3 ‘no’

Enabling you to live with lymphoedema 14 ‘yes’ 2 ‘no’

Comments included:

“It’s pro-active, they gave me a ball and exercises to do. I’m not as frightened about lymphoedema now, the stockings are helping. I have got new ones because the swelling reduced, and I’m now walking when I couldn’t walk before”

“For the ‘enabling you to live with lymphoedema’ I wouldn’t hold the clinic responsible. For ‘helping to reduce complications caused by a swollen limb’, they don’t do manual lymphatic drainage, there are no resources, more are needed. It’s managing, not improving. A lot comes down to the nurse you get; you get information, but with some you have to ask, it ranges from excellent to dire”

“I’m struggling to get psychological support. Personally I find it very hard. Also, the weight management, you can get bariatric surgery but not liposuction”

**We asked: How satisfied are you with the service provided by the clinic?**

14 people said they were ‘very satisfied’, and 1 person each said they were ‘satisfied’, ‘not satisfied’ or ‘very dissatisfied’.

Comments varied and included:

“Clear information, compassionate, knowledgeable and addressing the gaps (drainage massage), and talking about psychological support”

“Mixed satisfaction: satisfied with what they can give me, but dissatisfied with the resourcing of this service so that it can truly be improving patients' lives”

“When seen the care is good, but the service isn't good enough, things aren't getting done properly. I've waited 2 years to get my arm wrapped, the discomfort, sleeves didn't arrive on time after wrapping, so I was in discomfort for more weeks than I should have been in”

**We asked: Would you benefit from a support group for patients also diagnosed with lymphoedema?**

11 people said 'yes', 8 said no.

Some people we spoke to had additional comments, including 3 who said it would not benefit them but believed it would benefit newly diagnosed people, and 2 who said it would be helpful and/or nice to see others in a similar position.

**We asked: Do you feel there is anything the clinic could do to provide a more appropriate support service for you? (e.g. different treatments etc.)**

7 people answered 'yes', 9 said 'no'.

12 people left comments about this question. 7 said they would like to see treatments like massage/ lymphatic drainage:

“Drainage massages, lymphatic drainage, but there is no funding or staff to do it. I wish there were more staff and more funding”

“(.....) do a massage. A practical demonstration would be helpful”

One person mentioned psychological support. 2 people mentioned additional equipment should be used, one a laser measuring tool to ensure consistency, another a massage machine that could be loaned to patients.

One person said they would like further information about how to prevent lymphoedema spreading to other parts of their body.

4 people said they did not know if/ did not think there were further treatments that would help them.

We were asked to include this **Lymphoedema Service Patient Satisfaction Survey – symptoms**.

Patients were asked to score their symptoms before and after attending the clinic. The underlined numbers in brackets reflect the number of people who gave that particular score. Again, not everyone answered all the questions.

a) Pain **before** attending the clinic:

**No pain**    1 (6)   2 (2)   3 (3)   4 (1)   5 (6)   **Extreme Pain**

b) Pain **since** attending the clinic:

**No pain**    1 (6)   2 (4)   3 (5)   4 (2)   5 (0)   **Extreme Pain**

c) Movement of your limb **before** attending the clinic:

**Poor**            1 (7)   2 (2)   3 (1)   4 (1)   5 (7)   **Good**

d) Movement of your limb **after** attending the clinic:

**Poor**            1 (1)   2 (2)   3 (4)   4 (4)   5 (6)   **Good**

e) Your understanding of lymphoedema **before** attending the clinic

**Poor**            1 (9)   2 (2)   3 (3)   4 (2)   5 (2)   **Good**

f) Your understanding of lymphoedema **after** attending the clinic

**Poor**            1 (0)   2 (2)   3 (1)   4 (6)   5 (9)   **Good**

Although individual answers varied, overall it is clear to see that the lymphoedema clinic had a positive impact on the pain people experienced, on increasing movement of the affected limb(s), and on people's understanding and knowledge of lymphoedema.

### **We asked: Have you needed to see a physiotherapist since attending the Lymphoedema Clinic?**

6 people told us they had, and 10 said they had not.

### **We asked: Do you feel your arm/leg has reduced in size since you started attending the clinic?**

12 patients said the swelling had reduced, 5 said it was the same, and 1 said it had increased.

**We asked: Would you be happy having a telephone assessment if it was thought to be appropriate?**

8 people said 'yes', 11 said 'no'. Several said they felt the affected part of their body had to be seen, and that phone consultations therefore would not be appropriate.

**We asked: Would you benefit from attending an evening or weekend clinic?**

4 people said they would like to attend an evening clinic, and 4 a weekend clinic.

**We asked: What do you feel about your experience at weight management clinic (if attending)?**

5 people said that they would like to attend a weight management clinic but this had not been offered. In addition 1 person who had attended in the past said they would like to go again.

Only 2 respondents attended at the moment, with one commenting that

“Lack of information about lymphoedema, it's a gap. The Dr acknowledged that, they should have an understanding of underlying conditions”

Another said they had lost weight, but that this was due to depression more than because of the clinic.

**We asked: How long did you wait to receive your garments?**

Responses varied from 'less than 1 week' to 'months'. For most it took between 1 and 4 weeks.

Finally, we asked if people had **any further comments**.

15 people did; 5 people had positive comments about the service, including:

“I just think the clinic is good, it gives you reassurance. You can ask questions, and they are here if I get sick or something. If it wasn't here, I don't know what I'd do”

7 had further comments about phone consultations not being appropriate:

“I wouldn't want a phone consultation, they can't show you exercises over the phone, and questions pop into your head more when face-to-face”

3 people commented that the service needed more money, further treatment options and staff training:



“The clinic is fine but lacking in treatment options, there is no money. Staff need more training, and people need nurses to go out and see them”

## Conclusion:

Although we spoke to a limited number of patients, we had several long conversations and received some in-depth feedback. Most of this was broadly positive about the service, but some less so. We shared all the (anonymised) feedback with Mersey Care.

Overall, what patients thought of the service in part depended on what they knew about lymphoedema and available treatments; this had an impact on expectations, and the opinions about the treatments and care the clinic offered. Some patients who had attended the previous lymphoedema service when it was run by Marie Curie were still getting used to the changes.

Several patients praised individual staff. One of the nurses in particular was praised multiple times. Some patients felt that the care and treatment they received depended on the nurse they saw (in terms of their knowledge and attitudes).

Waiting times until the first appointment took place were mentioned, but not as a big negative – again, expectations played a role here. Apparently GPs were not always aware of the service, which did lead to longer waiting times for some patients.

There was mostly positive feedback about the facilities in Speke. Some people mentioned it was a long distance for them, and expensive if they had to travel by taxi. A few were pleased to learn that other clinics were opening, depending on where they lived.

Several patients mentioned wanting to learn more about (lymphatic drainage) massage. One patient mentioned that referrals to psychological support should be offered, for example IAPT services for people with long-term conditions. From speaking to patients we felt that it would be good if everyone was made aware that psychological support is available, even if they had not considered it themselves.

Referrals to weight management clinics weren't always being offered to patients who might want to attend. Clearly this has to be clinically appropriate, but maybe this is a conversation that should be had with more patients, although we recognise that it can be off-putting for some.

Patients were asked if they would benefit from a support group for patients also diagnosed with lymphoedema; we know that peer support can be

helpful when dealing with long-term conditions. Some patients said they would be interested, also to have speakers providing information/ training sessions (e.g. about massage). Others said it may be good for people recently diagnosed but would not be useful for them.

In terms of commissioning, some areas offer more NHS treatment options compared to the lymphoedema service here. A few patients had sought and found private treatments like massage or lymphoedema-specific physiotherapy, but many patients would not necessarily be able to pay for this.

### Recommendations:

Some of these recommendations are aimed at Mersey Care as the provider of the service, whilst others are aimed at commissioners (who plan and buy services for all of us). Some may be relevant to both the provider and commissioners.

#### For Mersey Care:

- One member of staff in particular stood out in the number of positive comments we received from patients about their knowledge and attitude. We recommend that the service looks at what this particular staff member does/how they work so that other clinic staff can learn from this.
- Offer all patients referrals/ signposting to psychological support services as a matter of course.
- Arrange a patient support group; several current patients we spoke to expressed an interest, and offer this to newly diagnosed people too.
- Ensure up-to-date tools are available for staff to work with, e.g. one patient had been measured with a laser measuring tool when attending a private appointment and felt that had been more consistent/ accurate.
- Review staffing levels in order to reduce waits and to enable more flexibility to cope with staff sickness.

#### For commissioners:

- Commission more treatments to support patients with lymphoedema such as lymphatic drainage massage. Look at what lymphoedema services in Blackpool offer.

- Together with the provider consider whether more clinics are needed at other locations to make these easier to access for patients.