

Continence Promotion Services in **Barnet**



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ACKNOWLEDGEMENTS

We would like to acknowledge the staff at the Central London Community Healthcare (CLCH) NHS Trust involved in continence promotion service for supporting this engagement project. We would like to thank the nurses at Finchley Memorial Hospital for helping Healthwatch Barnet access patients and providing us with an insight into how the continence promotion clinic is run and answering our questions. Finally, we would like to thank the Healthwatch volunteers who highlighted this issue and the patients who took the time to participate in our engagement and speak about their experiences using the continence clinic.

INTRODUCTION

Healthwatch Barnet is part of a national network led by Healthwatch England, which was established through the Health and Social Care Act in 2012, to give service users of health and social care services a powerful voice both locally and nationally. We are the independent voice for people's views on Barnet services, both good and bad. We listen to local people and feedback patient experience.

Although most common amongst people over the age of 45, bladder and/or bowel problems can affect anyone at any point in their lives. It is estimated that around 14 million people in the UK have some degree of urinary incontinence, while bowel problems affect up to 1 in 10 people (1). Despite its prevalence, many people do not seek help. This can be for a range of reasons, including: acceptance that it is a normal part of aging or occurrence after childbirth; lack of knowledge around treatment options; and/or embarrassment. Bowel and bladder issues are often perceived as uncomfortable topics to discuss. According to the Department of Health, *identifying* people with a need is a key barrier in ensuring access to continence services (2). Receiving products and information around exercises and lifestyle changes, can greatly improve the quality of life for people with incontinence.

BACKGROUND

Continence Services in Barnet

Central London Community Healthcare (CLCH) provide continence promotion and stoma services in Barnet for anyone over the age of 18 who is registered with a GP in Barnet. The clinics take place at Finchley Memorial Hospital on three separate days, and are run by specialist nurses. One session was previously offered at Edgware Hospital but due to lack of take up, all three are now based at Finchley Memorial Hospital. They define their service as one that:

'Offers a comprehensive range of support to help people self-manage and remain independent, or to adapt and modify their lifestyles to adjust to increasing dependence.'(3)

In addition, the website states the service provides support for people with *'complex continence issues'*, however it does not specify who that term applies to.

Referrals to this service can be made by a range of people including: GPs, district nurses, health visitors, social services and other healthcare professionals. Patients can also self-refer using the CLCH referral form, which can be accessed online (Appendix I). Patients can either email, fax or post their completed referral form to the continence promotion service.

METHODOLOGY

Following feedback from Healthwatch Barnet volunteers, we decided to carry out an engagement with continence promotion service users in the borough. Healthwatch Barnet met with the Central London Community Healthcare (CLCH) NHS Trust, who deliver the service in Barnet, and Barnet CCG to understand the service that is offered.

Healthwatch Barnet spoke with patients accessing the adult continence promotion services at Finchley Memorial Hospital, where we carried out a short survey with either a carer or the patient themselves. Continence promotion is an important area that rarely receives attention. The aim of the survey (Appendix II) was to gather patient experience around the referral process, access to the service and treatment. Between April/May 2018 we attended 5 clinics, and were also able to meet the two nurses in charge of delivering the service.

FINDINGS

We spoke with 18 patients and/or their carers accessing the continence service, eight male patients and 10 females. Seven of these patients were attending the clinic for the first time, while most of the other respondents had been three or more times. We found that four of the patients were accompanied by a family member or carer, as they had more complex needs, including: Parkinson's, a learning disability, impaired mobility and someone who had recently suffered a stroke. However, we found that most patients were able to get themselves to the clinic and were therefore unaccompanied. Two of the respondents required an interpreter, as English was not their first language.

Finally, at most clinic sessions we attended, one or two patients were unable to make their appointment and/or cancelled last minute. We therefore found some of the sessions were not full. The nursing staff felt this could have been due to the dates we attended or difficulties patients experienced in travelling, due to their complex conditions. The nurses also explained they regularly had telephone conversations with any patients who needed follow-up appointments, but could not make it to the clinic in person.

The Referral Process

The vast majority of respondents had been referred by their GP to the continence promotion service and one patient had been referred by a healthcare worker who had visited their house six-months after a stroke. One patient who was being affected by continence issues had been able to self-refer to the service, following some research into the area. They had a positive experience in doing so:

"I called the clinic and was asked why I think I need it and what my symptoms are. I have an interest in urology, which helped me find the self-referral phone number. I was given an appointment straight away." (Male)

We asked patients if they felt they had received enough information about the service when they had been referred by their GP. Three patients did not answer this question, either because they could not remember or it was not relevant. Five people felt it would have been helpful to have received more information, for example, about the clinic and what to expect. One of these patients said they felt their GP practice had not given them enough information or handled their referral properly, as they were just phoned by the district nurse and told to go to the clinic. They felt they were not explained enough about the clinic or asked questions about their current health or home situation, which they found 'frustrating'. The comments on what further information patients would have liked can be found below:

"...not given any leaflets or booklets on continence care services. Probably would have liked more information. Would have liked to know more about the service." (Female)

"What to expect to get from being referred to this clinic. I was just told to go." (Female)

“...a little more information would have been good idea, like how long will I be committing to this clinic (though I know that the GP wouldn’t know how long) and what does the clinic do exactly.” (Female)

Views on Treatment Information and Appointments

We asked patients if they understood their treatment and had received enough information during their appointments. Patient preferences for more information prior to attending the clinic was again reflected in their answers. Some participants were relieved following their first appointment, and felt they now had enough information:

*“Yes [understood my treatment and got enough information], only once attended the clinic today. Before that I had no idea what I was coming to.”
(Male)*

“Yes, once I attended the appointment I did.” (Male)

All of the patients we spoke with understood their treatment and the information provided after they had attended their first appointment. One patient explained they knew what they came for (to get products) but got ‘good advice anyway’.

All of the patients felt listened to during their appointments and for many this was down to the nurses, as can be seen in the positive comments about the nurses:

“Nurse is very accommodating and nice.” (Male)

“Nurse is excellent, she is very good at listening.” (Male)

“Very friendly service.” (Female)

“If I say the exercises are not working for me then she will give me some other advice.” (Female)

Booking Appointments and Access to the Service

Nearly everyone we spoke with found the process of booking an appointment straightforward. Most people were contacted by the continence team with an appointment time and date and if they needed to change it they could get in touch and do so easily. People also mentioned getting reminders and confirmations by text or phone. One person said the process could be confusing at times, as they felt that appointment letters needed to be more specific about the service they were accessing, so it would be quicker to speak with who you needed to when you called the hospital:

“Sometimes can be difficult. You call the hospital and keep getting referred on to someone else. Would be easier when you received the appointment letter if it said specifically what the appointment was for (sometimes it just says Urology)” (Female)

Two people felt the hospital reception staff were rude when they called to change their appointment slot due to other hospital appointments. Both respondents said the reception staff sounded annoyed at them for wanting to change their appointments, and one of the

respondents (a carer) said this had made her apprehensive to access the service as she feared the person at the end of the phone would be involved in the service delivery. However, she was pleasantly surprised by how kind the continence nurse was:

“We were sent a letter with the appointment originally but I had to change it because I had another hospital appointment on that day. I felt when I called to change it the lady on the phone was not very nice or happy about me changing it and was a little bit rude. She sounded annoyed and mad at me” (Female, carer)

Most of the respondents had a main point of contact or a direct number for the continence team and only one person said they did not. A number of these patients said they are able to ask for their nurse, or leave a message and were called back, which was helpful.

“When I want to get in touch I call the number of the clinic that I was given and ask to speak to my nurse by name or leave a message” (Male)

“I can ring the unit, then the nurse gets back to you” (Male)

“I am able to call the nurse directly” (Female)

Travelling to the service was found to be easy for people who lived nearby to the hospital or those who were able to drive to the clinic. Concerns were raised around whether they would have to start paying for parking, as it was free at the time of the engagement. A woman, in her 80s, said she worried about not being able to drive her husband in the future. Five patients mentioned difficulties in getting to Finchley Memorial, as they had to take a number of buses and the long walk to the hospital from the bus stop was a problem.

“Take a couple of buses and it is a long walk to the hospital” (Female, travelling from Hendon)

“Using the bus to get the hospital is a nuisance and my foot hurts so usually I get a ride from someone or take a taxi” (Female)

“My daughter drives me here, and takes me to the clinic in a wheelchair. But one day if she can't bring me, it will be a big problem as even though I could take a cab, it's the amount of walking from the parking to the room which is very difficult with my crutches” (Female)

Language was an issue for two of the patients accessing the service. However, these patients had found solutions that they felt adequately accommodated them. A female patient used her mobile phone, with her daughter on loudspeaker throughout the appointment. She explained that she did not want to use up NHS resources by getting an interpreter. Another patient usually took a friend, but if they cancelled then they were just able to manage on their own. Our understanding was that these patients were aware of translation services available in the hospital.

“I thought I might use the translation services but in the end, I didn't feel I needed it” (Female)

Patients did not wait long for their appointments once they arrived at the hospital. Only one person said they had to 'sometimes' wait for a long time in the waiting area. Another said on one occasion they had waited in the wrong area, before they were found by the continence nurse. This emerged as an issue with the way patients were directed to the continence clinic and the signage at the hospital, rather than an issue with the continence clinic itself.

Follow-up Appointments and Prescribed Products

Nearly everyone we spoke with felt they had sufficient follow-up appointments, and had the option to call and book an appointment or ask a question if they were concerned. Only one person said they had not been told when their next appointment would be. One patient mentioned they liked being able to come every 6 months, as it stopped them feeling cut-off from the service. Patients returned for a follow-up between 3 months to a year from their previous appointment, depending on their situation.

"I have been given a review appointment in a year, but can call back anytime if I have any questions" (Male)

"When I feel I need an appointment, which is not scheduled, I just call and ask for one" (Female)

Eight patients had either not been prescribed continence products or were yet to receive their first order. Patients who had been prescribed continence products, had not had any difficulties in accessing these. Two patients said that in the past they had forgotten to apply for the products on time and therefore had not received their delivery on time.

Patient Suggestions for Improvement

Patients were asked if they had any suggestions to improve the continence promotion service. Most people said they were happy with the service as it was and had no suggestions. Some respondents said that better signage was needed in the hospital, especially around the continence clinic. Others mentioned more information and education for people before they access the service, including online videos. Finally, one person said that the transport to and from the hospital needed to improve and suggested a bus that picks up patients in the area.

"It's an excellent service" (Female)

"So far so good" (Male)

"Good service, good staff. Quite happy with the service. Just more information would be helpful" (Male)

"A video on the website to educate people on how the bladder works would be good" (Male)

"Only bus/transport issues to the hospital. A hopper bus that picks up patients in the area would be a good idea" (Female)

CONCLUSIONS

We had anticipated a high demand for the continence promotion service in Barnet, and found the clinic at Finchley Memorial quieter than expected. Despite this, the 18 patients we spoke with had positive feedback on the service. Once patients accessed the service they felt listened to, had very good relationships with the continence nurses and had sufficient follow-up. Some of the issues that emerged, were to do with a lack of information provided prior to the appointment and practical difficulties in the management of the clinics. This included signage in the hospital and some staff attitudes when booking appointments. Difficulties around public transport to Finchley Memorial Hospital have been raised a number of times in the past. We found that public transport was an issue for patients accessing the continence service, in particular the long walk from the bus stop to the hospital. More needs to be done to ensure the hospital is accessible. Finally, two people needed an interpreter and were not currently using one. It would be good to know what options had been offered to them.

Numbers of self-referrals to the service were low and only one patient we spoke with had self-referred. It would be beneficial to ensure anyone who may need to know about the service and how to get self-refer and access it. Related to this, we found the website with the referral criteria and information could be difficult to find and that the sweeping statement of 'complex needs' in the service description could put people off. Finally, the positive experiences of those who access the service could be promoted to encourage people who have a need, to use the service.

RECOMMENDATIONS

Following this engagement, four clear recommendations emerged.

1. **Improve the information that is available to patients prior to their first appointment at the continence promotion clinic.** This could be through leaflets provided by GPs and/or access to videos and information online.
2. **Increased promotion of the service.** Increased awareness of the continence service could be achieved by making it easier to find the referral information online and sharing patient experiences of the service. This could in turn encourage more people who need to, to self-refer.
3. **Ensure signage at Finchley Memorial Hospital is clear.** More signage around the continence clinic would ensure patients are waiting in the correct area and prevent missed/late appointments.
4. **Ensure interpreters are available and offered to patients.** Patients who require interpreters for their appointments should be offered this service and efforts made to ensure they do not feel they are a burden on the NHS Trust for using it.

RESPONSE FROM SERVICE MANAGERS AT CENTRAL LONDON COMMUNITY HEALTHCARE (CLCH)

We have received the following response from the Service Managers at Central London Community Healthcare.

1. Information leaflets about the service will be produced.
2. Information Posters for display at GP practices and health sites across the Borough will be produced.
3. There are ongoing issues with signage across Finchley Memorial site. There are also issues of patient confidentiality where some patients do not want other people to know which clinic they are attending.
4. All patients are asked if an interpreter is required when appointments are made and arranged when required. We sometimes have issues if patients who initially decline interpreting services, then contact the service a day or two before their appointment. We will always try and book an interpreter but sometimes due to late notice this can be difficult. In this case we will offer to defer the appointment so an interpreter can be sourced, but sometimes the patients decline this and personally arrange for someone to interpret for them.
5. The team will also address the interaction with reception staff to try and improve patient experience.

RESPONSE FROM BARNET CLINICAL COMMISSIONING GROUP (BCCG)

Barnet CCG appreciates the time that both Healthwatch and Barnet residents have given to discussing and surveying this important service area.

The CCG, as part of the wider communications and engagement programme promoting independence and wellbeing, will continue to work proactively with the providers and wider stakeholders across the borough to further raise awareness of the local continence service offer.

APPENDIX I

Adult Continence Self-Referral Form

Please return the form to: Continence Promotion Service

Finchley Memorial Hospital, Granville Road, London N12 0JE

TEL: 0208 349 7465 FAX: 0300 008 3170 Email: CLCHT.ContinenceBarnet@nhs.net

| | | | |
|---|---|--|--|
| PATIENT | | GP | |
| Forename | | Name | |
| Surname | | Address | |
| Address | | Telephone | |
| Telephone | | Date of Self-Referral | |
| DoB | | | |
| Where did you hear about the service? | | Do you have other specific needs? E.g. Transport, wheelchair access. | Yes <input type="checkbox"/> No <input type="checkbox"/> Please specify: |
| Gender | Male <input type="checkbox"/> Female <input type="checkbox"/> | Language | |
| Interpreter required | Yes <input type="checkbox"/> No <input type="checkbox"/> | Ethnicity | |
| NHS number if known | | | |
| PRESENTING SYMPTOMS | Yes | No | Please give details or circle/delete appropriately. |
| Urgency in needing to pass urine or faeces? | <input type="checkbox"/> | <input type="checkbox"/> | Urine. Faeces. Both. |
| Need to pass urine more frequently than others/before? | <input type="checkbox"/> | <input type="checkbox"/> | |
| Waking through the night to go to the toilet or not waking and soiling the bed? | <input type="checkbox"/> | <input type="checkbox"/> | |
| Leakage of urine when you feel you are desperate for the toilet. | <input type="checkbox"/> | <input type="checkbox"/> | e.g. at home, when outdoors, approaching your front door, when you see running water |
| Urine leakage with activity. | <input type="checkbox"/> | <input type="checkbox"/> | e.g. leak with cough/laugh/run/sneeze/walk/lifting |
| Faecal symptoms | <input type="checkbox"/> | <input type="checkbox"/> | e.g. leak from the back passage/unable to control wind |
| Constipation | <input type="checkbox"/> | <input type="checkbox"/> | e.g. strain to open bowels/infrequently pass hard stool/give yourself perineal support/manual evacuation |
| Difficulty passing urine | <input type="checkbox"/> | <input type="checkbox"/> | |
| A lump or heavy/dragging sensation inside the vagina | <input type="checkbox"/> | <input type="checkbox"/> | |
| Pain on passing urine | <input type="checkbox"/> | <input type="checkbox"/> | |
| Pain on sexual intercourse | <input type="checkbox"/> | <input type="checkbox"/> | |
| Other | <input type="checkbox"/> | <input type="checkbox"/> | |
| Do you suffer from regular Urinary Tract Infections Yes <input type="checkbox"/> No <input type="checkbox"/> | | | |
| If so when was the last urine sample given? Date - | | Result: Antibiotics Prescribed? Yes <input type="checkbox"/> No <input type="checkbox"/> | |
| ANY OTHER INFORMATION RELEVANT TO THIS PROBLEM (inc. bladder/bowel investigations / examinations) | | | |
| | | | |
| Have you received assessment / treatment for this problem before: Yes <input type="checkbox"/> No <input type="checkbox"/> | | | |
| If yes, please specify: | | | |
| MEDICATION – please list current medication | | | |
| | | | |
| RELEVANT PAST MEDICAL HISTORY i.e. medical conditions/past surgery/number of children (year born) and type of delivery/ gynaecological conditions. | | | |
| | | | |
| OFFICE USE ONLY | | Nurse Assessment | |
| Date received: / / | | Inappropriate | <input type="checkbox"/> |
| Date triaged: / / | | Other | <input type="checkbox"/> |
| Triaged by: | | | |
| Urgent <input type="checkbox"/> | Routine <input type="checkbox"/> | | |

APPENDIX II



Continence Care – Patient Experience

1. How were you referred to continence services?
 - a. Via GP
 - b. Self- referral
 - c. Other (please state)
2. If you went to your GP first, and were referred here, were you given enough information about the continence service? Y/N
 - b) What additional information would have been useful at that point?
3. Thinking about your last appointment:
 - a) Did you understand your treatment and feel you had enough information?
 - b) Did you feel listened to?
4. Do you have a main point of contact within the continence care team?
5. Did you find the process of making an appointment straightforward?
6. Have you had to wait long in the waiting area for your appointment(s)?
7. Have you had any issues in accessing the service here (translation difficulties; access issues etc.)?
8. If you have been prescribed any products, have you had any issues with obtaining these?
 - a) Not prescribed
 - b) Yes – please tell us
 - c) No
9. Do you feel you have had sufficient follow-up appointments/advice?
10. Do you have any suggestions to improve the experience of continence services for people like you?

Extra Information

1. Date of interview:
2. First appointment? Y/N
3. If no, number of previous appointments attended:
4. Patient gender:

REFERENCES

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