

Analysis of Continence Service In Teesside

Feedback

September 2017



Introduction

Local Healthwatches have been set up across England to create a strong, independent consumer champion with the aim to:

- Strengthen the collective voice of citizens and communities in influencing local health and social care services to better meet their needs.
- Support people to find the right health and social care services for them by providing appropriate information, advice and signposting.

Healthwatch Stockton-on-Tees works with local people, patients, service users, carers, community groups, organisations, service providers and commissioners to get the best out of local health and social care services. This doesn't just mean improving services today but influencing and shaping services to meet the needs of the local communities tomorrow.

Healthwatch Stockton-on-Tees is steered by a Board of volunteers, commissioned by the Local Authority and accountable to the public. Healthwatch Stockton-on-Tees are the only non-statutory body whose sole purpose is to understand the needs, experiences and concerns of people who use health and social care services and to speak-out on their behalf.

Healthwatch has:

- The statutory right to be listened to; Providers and Commissioners must respond to Healthwatch within 20 days of submission of requests for information or reports.
- The statutory power to Enter & View publicly funded health and social care services.
- A statutory seat on the Health and Wellbeing Board.

Current continence service provision in Teesside

The current continence service is a Teeswide service which is funded by local Clinical Commissioning Group's (CCG's). Each locality advertises their continence services differently on their websites. Hartlepool and North Tees NHS Foundation Trust advertise on their website that the specialist nurses in the continence advisory service provide advice, care and support for men and women who have bladder and bowel problems, after assessment working to manage the service user's symptoms.

Rationale

Healthwatch works closely with both the voluntary and public sectors to assist in the delivery of its statutory activities and priorities. These close relationships ensure that the public voice is heard during the service planning processes making sure local services better meet the needs of the people using them. Through engagement with the Live Well Dementia Hub and Stockton Dementia Advocacy Service, and individuals who use the service in Stockton, it was brought to the attention of

Healthwatch that the continence service provision is not meeting the needs of service users. Local Authority representatives told Healthwatch that they also felt that information gathered could inform change as issues about the service provision are frequently brought to their attention.

Aim

To investigate public awareness and experiences of the Teeswide continence services.

Objectives

- To research and gain an understanding of the views and experiences of Teesside residents regarding the continence services. Healthwatch Stockton-on-Tees was particularly interested in the views and experiences of the residents of the Borough of Stockton.
- To work collaboratively with organisation to capture intelligence and gather the view and experiences of individuals who access the continence service.
- To inform commissioners of the findings and highlight recommendations for change to improve the service both now and in the future.

Methodology

Healthwatch staff and the Stockton Dementia Advocacy Service Lead designed a questionnaire to gather the awareness, views and opinions of members of the public, carers and service-users of the continence services. The questionnaires were circulated via email, social media and face to face at the Healthwatch Annual event and the Stockton Dementia Advocacy Service celebration event. The questionnaires were also circulated more widely with the support from the LiveWell Dementia Hub and the Halcyon Centre, Thornaby, and other organisations across Teesside, such as Age UK and The Bridge at Hartlepool.

Following analysis of the data gathered, Healthwatch Stockton-on-Tees has provided recommendations to the Local Authority areas in Teesside who commission the continence service to improve the provision.

Results **Please note quotes from individuals are highlighted in pink.*

Healthwatch Stockton-on-Tees received 29 responses, 17 of which were completed by service-users, carers or family members of those living with dementia. Individuals completing the survey were asked if they were aware of the continence service prior to them needing assistance. 55% were aware of the service. Of those who knew about the service the majority had been informed by professionals; 1 individual sought the information themselves from their local health centre.

Individuals were asked following their initial continence services enquiry, how long they had to wait to receive a continence assessment;

- 16% received the assessment within days.
- 58% waited a number of weeks.
- 26% waited a number of months.

8 respondents commented about the length of time they had to wait. It was evident from these comments that those who had been in hospital, were satisfied with the service and had received an immediate assessment. Others made the following comments:

“Didn’t need one.”

“I phoned up because I buy the pull-ups, but they don’t supply these.”

“By telephone only.”

“Over 2 months.”

The survey asked if individuals accessing the service had received all of the information they needed at initial assessment.

- 56% answered yes.
- 44% answered no.

The survey also asked “What other information would have been beneficial at the time of the assessment?”

The following comments were received;

“Further explanation of the process or ordering and the consequences if I didn’t order on time.”

“I buy my own pads.”

“No. More information on the options available would have helped.”

“We felt that my dad’s needs weren’t properly assessed at the home.”

“No; a dedicated continence team is required.”

“Explanation of how to handle the problem. i.e. toilet regime, dietary information could help, how to anticipate the patient’s needs.”

“Not given enough information on which pads to use or how to fit properly.”

“Could I be provided with pants, and if not, where could I get them?”

“I don’t know because I knew nothing.”

Feedback gathered identifies that a high percentage, 61.5% of respondents were not shown the range of pads, to suit their specific needs. The following feedback was received:

“No information given, no consideration given, wrong size and not given options, orders are usually slow.”

“No, we were more or less told this is what you’ll be getting. We were not told about bed sheets, which were needed at the time and generally felt in the dark and on our own with things.”

“I left it to my daughter to sort out as she was aware of sizes.”

“I always buy them.”

“Sample pads never arrive. Told an example would be put in the post.”

“We just went ahead and bought pads and still do.”

“We were sent a sample pad to determine which size was appropriate, but could not read the sample.”

“Started with small pads which were a bit small, so used them up and waited until I’d run out of smaller ones to order bigger ones.”

Survey respondents were asked “How many continence pads did you receive after your initial assessment?”

- 11.1% said they did not receive enough pads.
- 33.3% said they received too many.
- 55.6% said they’d received sufficient.

Individuals were asked to comment on their experience, regarding the number of incontinence pads they received after initial assessment. Comments included:

“As small ones were too small and too many, but used them up anyway.”

“1 and it was paper thin.”

“2”

“Not enough – now enough pads – but pull-ups after initial assessment adequate. Not enough netty knickers for pads – pull-ups now withdrawn.”

“None, we have never had an assessment.”

“Too many – will still have a lot of pads when renewal date comes. But if I do not reorder by the date stated, order will cease.”

“Sufficient – a box full.”

“Sufficient – but my husband has to have 4 a day now and I only need 2 but now I need more.”

“It took a number of contacts to get it right and I didn’t know how many and was asked questions – e.g. how many do you think you’ll need?”

“No assessment.”

“We do not receive a supply from the incontinence service. The person has to continue to purchase the products until they are on the system and the delivery is made, many times the person will have to wait up to 24 weeks.”

“Bought myself”

“Never had any”

“Not enough – I think only about 2 or 3.” “Sample pads never arrive, then person has to wait until the care home’s next delivery, until they get their next supply.”

78% of individuals completing the survey confirmed that following assessment they received pads which were the correct size and absorbency, 21% felt they had not. The respondents who did not feel they received the correct size and absorbency, were asked if they required a reassessment and how long they waited for it. The following comments were received:

“No longer 9.5 available for night and I am in bed 10.5 per night. In the assessment nothing is solution focused – just how it is.”

“Haven’t received any.”

“Did not fit properly and uncomfortable for dad to wear due to the pressure sores. We were more or less told, this is all you get. The pants that we ended up using, we had to buy for dad ourselves.”

“They do not stick and I could really do with the pants.”

“Don’t know because I could not deal with the pads.”

Healthwatch Stockton-on-Tees asked friends, family members and carers how much they spent on extra continence items, per week. 15 people responded to this question and 3 of those people had no additional costs.

54% spent under £10 per week.

46% spent over £10 per week.

Respondents who spent over £10 per week made following comments:

“Over £25 I have to spend to get the sheets laundered.”

“Around the £10 mark. 14 pants are approximately £6. Net pants bought from online shop, they come loose and don’t stick sometimes.”

“£25 a week on pull-up knickers and laundered bed sheets.”

“Pull-ups at 75p each plus bags and wipes.”

“£150 per week.”

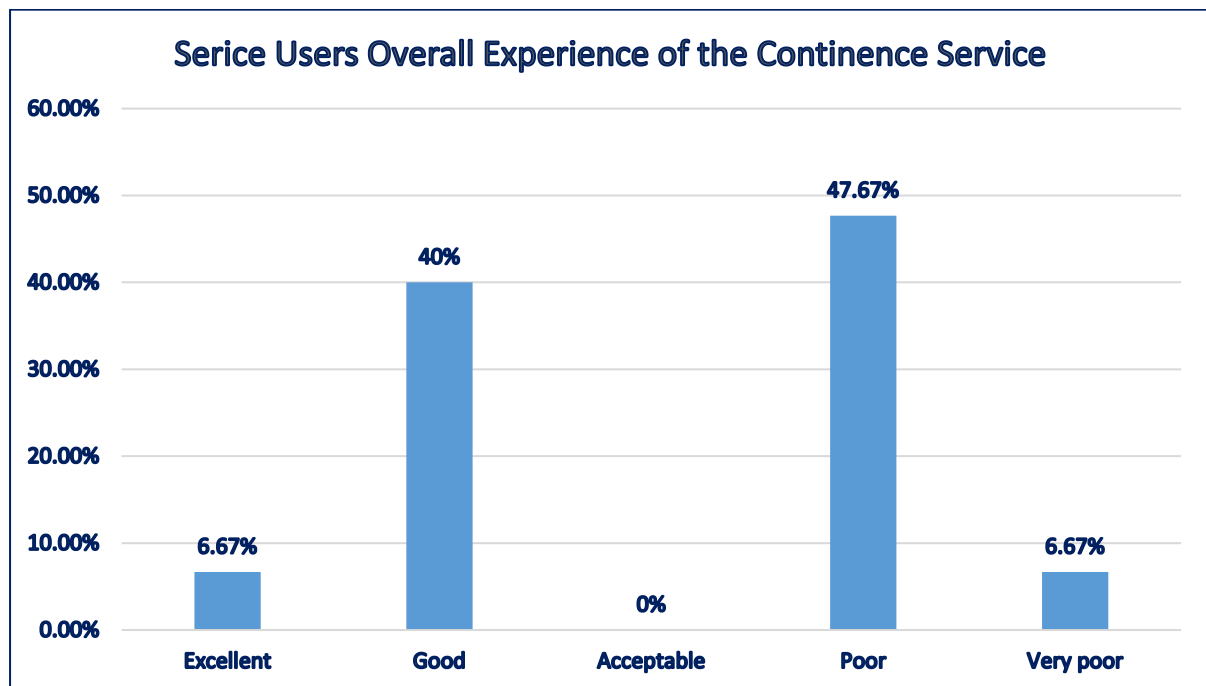
“£120”

“We ended up buying everything ourselves so dad was comfortable. Tena pads/sheets/bed pads and chair pads etc.”

“Mattress x2 per year = £200, Duvet x2 per years = £50, gloves/bags for disposal = £10 per week.”

86% of people completing the survey did not receive any financial support to help with the cost of extra items.

Healthwatch Stockton-on-Tees asked service-users to rate their overall experience of the continence service. Result can be seen on the graph below:



Additional comments received about the service, included:

“At no point did we get a face-to-face appointment.”

“You provide a good service and I am very grateful.”

“We felt the service was inadequate and we feel that my dad’s needs were not fully assessed i.e. taking into account that he is wheelchair-bound and immobile. No follow-up. Left feeling on our own and very stressed.”

“Nothing received yet. I’ve been using StayDry for men (medium waist size) super absorbent, for the past 4 years.”

“On occasion it is acceptable, but if I am late or early ordering, or highlight a duplicate delivery, the staff skip everything and then I start again.”

“Feels very unhelpful like they are reading from a script.”

One relative commented that they buy pull-ups for ease, which encourages the use of the toilet rather than pads.

Healthwatch Stockton-on-Tees asked people completing the survey, how they thought their journey from assessment to support and information, could be improved.

“More flexibility, more advice, clearer advice when something goes wrong.”

“More advice offered.”

“I was shown the range of continence pads but they were too big and bulky. Declined service and using Tena Lady from the shops.”

“Better communication and follow-up.”

“Size wasn’t right and the amount of pads sent was too many.”

“Having a pad that works and actually sticks properly.”

“No face-to-face appointment.”

“Better communication from the continence team, via email; telephone service is disgraceful probably down to staffing levels. No consistency in reviews, especially for people who are confined to home.”

“I didn’t know what to do for a long time, and then it was too far to go. Then waited months for nurse to come. Pads did not stick to pants and now spend £15 per week on pants.”

“There are more comfortable products on the market but not on the NHS.”

Conclusion:

Healthwatch Stockton-on-Tees acknowledge that the views included in the report represent a small number of people living with or caring for someone with continence issues.

68% of those who responded to the questionnaire were either living with or caring for someone with dementia. 32% of those responding were from the general public. Just over half of those who completed the questionnaire were aware of continence services prior to contacting them. The majority of those who were aware of services found out about the provision from a health professional.

Most people asked received a continence assessment within weeks of contacting the service. It did appear that those who were referred following a hospital discharge received an assessment quicker than those referred via community services. It should be noted however, that the numbers were very low for this evidence.

44% stated that they did not receive enough information at the assessment regarding the service, equipment available or how to use the pads or what to do if something did not go as planned.

Over 44% felt they were supplied with either too many or too few pads.

Comments highlighted several common themes, namely, pads not sticking and pull up pants not been available via the continence service.

When asked how the service could be improved better communications was highlighted.

Recommendations:

Based on the intelligence gathered, Healthwatch Stockton-on-Tees recommend the following:

1. The continence service provides a follow up phone call one week after assessment to ensure the pads have arrived and that the person knows how to use the equipment and that the equipment/pads supplied are meeting their needs.
2. In line with the 2015 NHS document, Excellence in continence care: Practical guidance for commissioners, providers, health and social care staff and information for the public;

“Assessment to ascertain the need for containment products such as absorbent pads, pants and hand-held urinals can meet a person’s continence needs in the short-term. Reassessment at regular intervals is then required to ensure not only that products remain fit for purpose, but that where independence can be gained, a return to standard toileting is enabled for a quality of life with freedom from leakage and odour.”

Regular, planned follow up reviews be introduced to provide guidance and ensure the needs of the patient and carer are being met. Perhaps a phone call every 3 months or a pre-printed post card asking three simple questions regarding the supply, fit and effectiveness of the equipment/supplies (with a pre-paid return envelope).

3. A joint publicity drive be undertaken with all involved in the delivery of the service such as Public Health, Clinical Commissioning Groups and the Local Authority to publicise the service and try to reduce stigma.
4. A further study be carried out by the continence services to see if deviances exist between assessments instigated by a hospital trust to those from community services.
5. Healthwatch Stockton-on-Tees recommend that at assessment awareness is raised with the service user around financial benefits that may be available to them, which may support the cost of extra items, perhaps in the form of a leaflet or information sheet.

Acknowledgements:

Healthwatch Stockton-on-Tees would like to thank the following for their support in the circulation of the survey and the gathering of evidence for this report; North of the Tees Dementia Collaborative, LiveWell Dementia Hub, Dementia Voices Stockton and The Bridge, Hartlepool. Healthwatch Stockton-on-Tees would also like to thank the service users and Healthwatch Stockton-on-Tees members who gave their time to provide information on their views and experiences of the Tees-wide continence services.

Appendices



Dementia Voices
Stockton

healthwatch
Stockton-on-Tees

Dementia and Continence Survey (for those living with dementia, their family and carers)

Healthwatch Stockton-on-Tees has worked in collaboration with Dementia Voices Stockton to design this survey. Support has been received from the North of Tees Dementia Collaborative and The Hospital of God at the Bridge in Hartlepool, in the circulation of the survey to local service users.

Incontinence affects many older people, especially those living with dementia, their families and carers. Healthwatch would welcome your views and experiences on services, support and provision available.

1. Were you aware of any continence services available, when this became an issue?

- Yes
 No

If Yes, how were you made aware?

2. Following your initial enquiry, how long did you have to wait to get a continence assessment?

- Days
 Weeks
 Months
 Other (please specify)

3. When the continence District Nurse carried out the continence assessment, did you receive all the information you needed?

- Yes
- No
- If No, what other information would have been beneficial?

4. Were you shown the range of incontinence pads available, to suit your specific needs?

- Yes
- No
- If No, please give details below

5. How many incontinence pads did you receive after your initial assessment?

- Not enough
- Sufficient
- Too many
- Please provide further comments.

6. Were the pads you received the correct size and absorbency?

- Yes
 No

If No, did you require a re-assessment and how long did you wait?

7. How much do you spend per week on extra items? (e.g. wipes, gloves, extra pads, bedsheets etc.)

- Under £10
 Over £10
 If Over, please specify approximately how much in the box below.

Other (please specify)

8. Do you receive any financial support to help with the cost of extra items?

- Yes
 No

If yes please give brief details in the box below

9 How would you rate your overall experience, including your wait for assessment, your assessment and the product?

- Excellent
- Good
- Acceptable
- Poor
- Very Poor

Please give us details for your rating in the box below

10. How do you think your journey from finding out the issues to getting the support and information you needed could have been improved?

11. Please enter the first part of your postcode below.

For advice and support, or if you would like to speak to a member of the team to give further feedback, Healthwatch Stockton can be contacted on 01642 688312 and Dementia Voices Stockton can be contacted on 01642 527363.

Many thanks for taking the time to complete this survey, which may influence future service provision to better meet the needs of service users.