

## Appendix 1



# Scrutiny review: Urinary Incontinence

Review of the Health Select Commission

*May – July 2014*

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## **Executive Summary**

### **The aim of the review:**

The review group consisted of the following members:

Cllr Judy Dalton (Chair)

Cllr Maureen Vines

There were three main aims of the review which were:

- To ascertain the prevalence of urinary incontinence in the borough and the impact it has on people's independence and quality of life.
- To establish an overview of current continence services and costs, and plans for future service development.
- To identify any areas for improvement in promoting preventive measures and encouraging people to have healthy lifestyles.

It would also aim to support the following Council priority from the Corporate Plan:- Helping people from all communities to have opportunities to improve their health and wellbeing.

### **Summary of findings and recommendations**

The review focused primarily on prevention rather than the costs of current service provision, but recognised that preventative work contributes towards achieving savings for services, for example by reducing admissions to hospital or residential care. Centralisation of continence prescribing has improved outcomes for service users and future service development with greater emphasis on prevention should also produce both further savings and better outcomes. Awareness raising of the importance of good bladder and bowel health and being physically active, plus doing pelvic floor exercises as a preventive measure, could lead to fewer people having their quality of life diminished through urinary incontinence and result in lower future demand for services.

The review conducted was a spotlight review and formulated six recommendations as follows:

- 1 RMBC Streetpride and partner agencies such as SYPTTE should ensure all public toilets in the borough are clean and well equipped to meet the needs of people who have urinary incontinence, including suitable bins for the disposal of equipment and disposable products.
- 2 RMBC Sport and Leisure team should establish greater links with the Community Continence Service in order to support people to participate in appropriate sport and physical activity.
- 3 RMBC Sport and Leisure team should liaise with other sport and leisure activity providers to consider building more pelvic floor exercises into the Active Always programme and wider leisure classes
- 4 There should be greater publicity by partner agencies, coordinated through the Health and Wellbeing Board, to reduce stigma associated with incontinence and to raise public and provider awareness of:
  - a) the importance of maintaining good bladder and bowel health and habits at all life stages (through media such as screens in leisure centres and GP surgeries, further website development, VAR ebulletin and a campaign during World

Continence Week from 22-28 June 2015)

b) healthy lifestyle choices having a positive impact on general health but also helping to prevent incontinence, such as diet, fluid intake and being active

c) the positive benefits of pelvic floor exercises as a preventive measure for urinary incontinence, including the use of phone apps for support

d) the need to include the impact of incontinence due to medication, such as diuretics, within a patient's care

- 5 RMBC Neighbourhoods and Adult Services should work with care homes to encourage more staff to participate in the training offered by the Community Continence Service and to increase staff understanding of the impact of mobility, diet and fluid intake on continence.
- 6 That the Health Select Commission receives a report from Rotherham Clinical Commissioning Group in 2015 on the outcomes of the project considering future service development of the Community Continence Service.

## **1. Why members wanted to undertake this review?**

This review was requested by the Health Select Commission and as such an initial report was received at its meeting in June 2014. The key focus of Members' attention was to establish the extent to which preventive measures are promoted in Rotherham to reduce urinary incontinence, given the impact it has on people's quality of life.

There were three aims of the review, which were to:

- ascertain the prevalence of urinary incontinence in the borough and the impact it has on people's independence and quality of life
- establish an overview of current continence services and costs, and plans for future service development
- identify any areas for improvement in promoting preventive measures and encouraging people to have healthy lifestyles

## **2. Method**

A spotlight scrutiny review was carried out by a sub-group of the Health Select Commission consisting of Cllrs Dalton (Chair) and M. Vines. Following background research an initial report to the Commission provided an introduction and set the context. Evidence for the review was then gathered through a focused round table discussion with health partners and the Council's Sport and Leisure Team.

Members would like to thank the following officers who provided the review with evidence:

Stuart Lakin – Head of Medicines Management, Rotherham Clinical Commissioning Group  
Joanne Mangnall – Continence Advisor, Community Continence Services  
Chris Siddall – Sport & Leisure Manager, Leisure and Green Spaces, RMBC

## **3. Background**

An article in the Nursing Times in 2013 highlighted that around 14 million people in the UK have a bladder control problem. Causes of urinary incontinence can be physical or neurological; resulting from injury, illness or disability, but many forms can be cured, improved or managed. Good continence care and assessment helps to reduce hospital and residential care admissions and may reduce the need for continence products through interventions such as physiotherapy or medication. When continence products are required a good service ensures people have the most appropriate products, with their needs periodically reviewed.

Lower Urinary Tract Symptoms include problems storing or passing urine, which may lead to urinary incontinence. There are several types of urinary incontinence with varying symptoms, but stress incontinence and urge incontinence are the most common, thought to be responsible for over 90% of cases, and people may have symptoms of both. Stress incontinence is when urine leaks if the bladder is under pressure, for example when coughing, sneezing or laughing, usually as a result of weakness or damage to the muscles that are used to prevent urination, such as the pelvic floor muscles and urethral sphincter. Urge incontinence occurs when people feel an intense urge to pass urine and urine leaks before they reach a toilet. It is usually due to over activity of the detrusor muscles that control the bladder.

Continence is typically achieved during early childhood; however both men and women are at risk of developing urinary incontinence at any stage of their life. Women can develop problems following pregnancy and childbirth and research tells us urinary incontinence affects about twice as many women as men. Whilst urinary incontinence

does become more common with age it should not be viewed as an inevitable consequence of ageing.

## 4. Findings

### 4.1 Prevalence of urinary incontinence

The Joint Strategic Needs Assessment shows that incontinence affects 19% of people over 65, rising to a third of those aged over 85 years. Rotherham has an ageing population, ageing faster than the national average, with the number of over 65s projected to increase by 7,500 (16%) by 2021 and the number aged 85+ by 1,500 (27%). This suggests a significant potential increase in future demand for continence services, unless more preventative work takes place across all age groups.

Based on data from the Royal College of Physicians the number of people in Rotherham with a continence problem would be estimated to be 12,500, but statistics show the Community Continence Service (CCS) is aware of or working with approximately half this projected number.

- The present clinical caseload the service is actively working with numbers around 1600 people.
- The caseload for stress/urge incontinence and bladder problems is approximately 220, mainly women (which is the norm) plus 54 with mental health problems such as dementia.
- 528 people with indwelling catheterisation and 618 with intermittent catheterisation (following conditions such as MS, stroke, spina bifida, post childbirth or detrusor muscle failure).
- 4276 are prescribed pads, 2884 of whom are female and mainly aged over 50 (see table below for detailed breakdown).
- 1 in 100 adults wets the bed.
- Rotherham has no paediatric continence service, although there is a children's service in Sheffield. School nurses deal with bed wetting and the Child Development Centre with toilet training.
- More boys than girls aged under 18 use pads, for example due to disability or developmental delay.

Members were provided with a snapshot profile by age and gender of current Community Continence Service users who are prescribed pads (all data is as at 8 July 2014).

	0 - 18		19 - 34		35 - 50		51 - 66		67+	
	Male	Female	Male	Female	Male	Female	Male	Female	Male	Female
<b>Community</b>	257	145	46	57	39	113	120	253	662	1432
<b>Residential</b>			3	6	3	8	9	13	126	557
<b>Nursing Bed (Self-funded)</b>			2	2	7	5	11	40	107	253
<b>Total</b>	<b>257</b>	<b>145</b>	<b>51</b>	<b>65</b>	<b>49</b>	<b>126</b>	<b>140</b>	<b>306</b>	<b>895</b>	<b>2242</b>

**Total Males: 1392**

**Total Females: 2884**

**Overall total: 4276 people**

## 4.2 Impact of urinary incontinence

### Health, wellbeing and participation

Incontinence is likely to have significant health and emotional impacts and to affect people's ability to take part in paid employment, education, or social and leisure activities. It may also damage family and intimate relationships. Social isolation, depression, low self-esteem and self-confidence and/or reduced independence are commonplace in many cases. Members heard anecdotally how some people plan their lives around the location of public toilets so they feel confident enough to leave home and go out.

"I've recently been using the continence service after experiencing issues, and I have to say it has been marvelous, absolutely life-changing. I can use the toilet normally again, and feel like I'm alive again!"  
*Service user on patient opinion website*

### Stigma

Embarrassment is a significant barrier that deters people from seeking professional help. On average people wait two to three years before they do so and often elderly people will not admit to having a problem. It may also mean many people either cope with the problem as best they can or purchase off the shelf products, rather than having an assessment to find out the cause of the incontinence and how best to treat or manage it.

"The first time I went to continence specialists nursing, Rotherham Community Centre, I felt nervous and embarrassed to talk about my condition, but within minutes I felt really at ease. The staff were so caring, polite and happy..."  
*Service user on patient opinion website*

### Disturbed sleep and falls

Incontinence may lead to disturbed sleep and/or increased risk of falls and injury if people are making frequent urgent trips to the toilet, especially at night. People with balance problems, people who are less mobile and/or lack physical strength or dexterity are more likely to fall if they get up to rush to the toilet. Identifying and treating incontinence may help to reduce the risk of falls and fractures amongst older people, but continence as a factor can get overlooked in assessing them.

"I have prostate cancer, and before using this service was getting up in the night up to 6 times to relieve myself. The continence prescription service was recommended by my district nurse, and after seeing them and being fitted up, things have been great ever since."  
*Service user on patient opinion website*

## 4.3 Community Continence Service

### General Service and Prescribing Service

The award winning CCS provides clinical advice, support and treatment to people in Rotherham who experience problems with bladder and bowel dysfunction. The service is responsible for supplying disposable absorbent products and prescribing all continence related equipment such as urinary catheters and drainage bags, using a standardised triage template to facilitate safe product ordering.

For the Prescribing Service people are seen within 48 hours and for the General Service the longest wait is four weeks. Once people are on the caseload they can self-refer in. Service users have the opportunity to discuss any product related problems with staff who will make home visits or hold telephone consultations. Annual reviews of patient needs

take place to check the suitability of their products and to spot any changes in clinical need.

In addition to support and product prescribing the service is also involved in preventative work:

- preventing catheter related A&E attendances and hospital admissions
- preventing patients from requiring long term catheterisation
- working with infection control to prevent catheter associated urinary tract infections

The General Service is staffed by the Continence Advisor plus a 0.6fte band 6 nurse, support worker and administrative worker. The Prescribing Service has 2.4fte band 6 nurses and support staff who cross over with the stoma service.

Referrals derive from GPs and other health care professionals, through self-referral and also from people learning about the CCS from other service users. The CCS works closely with the physiotherapist running the women's health clinic with two-way referrals in place. Publicity about the service is included on the TRFT website and in directories of local services and the CCG website contains detailed information and advice.

### **Centralised prescribing**

Rotherham transferred the prescribing responsibility for continence products from GPs to the existing nurse-led CCS in 2009, together with the financial responsibility for the prescribing budget. It is the only Clinical Commissioning Group (CCG)/Primary Care Trust to demonstrate a decrease in continence expenditure over the last five years. From 2009-2013 continence prescribing costs in England increased by 21.56% whereas in Rotherham costs decreased by 8.99%. The CCG estimates that if NHS Rotherham's continence expenditure had increased in line with national cost growth trends, costs in 2012/13 would have been 30% higher, thus resulting in a potential saving of £239,591. The current budget is approximately £670,000 p.a. and cost efficiencies have released resources to improve service provision through additional staff, funded entirely from the savings made from centralisation of prescribing. Members noted that incontinence pads are controversial and with tight savings targets in the NHS many CCGs are trying to ration them or to save money.

The continence service redesign revealed a number of people whose mobility and independence had been compromised due to unsuitable products. The project enabled the CCG to meet this unmet need and improve patients' independence. Feedback on the Patient Opinion website is very positive about the service and choice is probably enhanced through being able to access a wider range of products via the specialist knowledge of the continence nurses. Service users have said they like talking to the expert staff of the CCS rather than someone at their GP practice.

### **Future service development**

Input from the service user group informs service development and funding has been agreed from cost savings for a research/project nurse to continue the continence service re-design, to improve patient outcomes and release further efficiencies. This will develop further the work on preventing catheter associated urinary tract infections and on reducing the number of non-elective hospital admissions.

Another facet of the work that was welcomed by Members will be exploring the opportunity to develop an integrated incontinence referral pathway with the service as the single point of access, signposting people to urology or gynaecology if needed. There are approximately 450 GP referrals to TRFT urology and gynaecology outpatients each month and a number of these patients could be seen and managed in a community based clinic

either by a nurse or physiotherapist. Similar pathways developed elsewhere in the country are improving patient outcomes and reducing consultant referrals.

#### **4.4 Preventative measures**

Preventive work may take place on three levels:

- Primary prevention - educational work and promoting wellbeing across the whole community
- Secondary prevention - identifying people more at risk through early intervention
- Tertiary prevention - working to minimise disability or deterioration from an existing health condition

Preventative work currently undertaken and being further developed by the CCS focuses mainly on secondary and tertiary level prevention. Potentially the project/research nurse could also consider more educative work as part of the plans for future service development on prevention. In addition scope exists for wider partner agencies to contribute more to reducing urinary incontinence through primary prevention to support the existing work.

The CCS held some patient facing events five years ago although these were not overly successful and the service has attended Older People's Day and Carer's Day events. Wider awareness raising and education about continence is likely to result in increased demand for services, which could have resource implications in the short term, until the results of greater focus on prevention impact on demand in the longer term.

#### **Lifestyle choices**

Healthy lifestyle choices have a positive impact and help to reduce the chance of urinary incontinence developing:

- maintaining a healthy weight;
- reducing alcohol and caffeine consumption (as these are irritants to the bladder) but ensuring an adequate fluid intake;
- having a good diet to avoid constipation as this sometimes exacerbates bladder problems; and
- keeping fit and active.

Healthy Lifestyles is one of the six priorities in the Health and Wellbeing Strategy so there is scope to link in to that workstream in terms of publicity and awareness raising about preventing incontinence, for example during World Continence Week.

#### **Physical activity**

Demanding exercise such as heavy lifting or marathon running may actually weaken the pelvic floor muscles and people with stress incontinence may be fearful of taking part in physical activity in case of mishap, with a knock on impact on their overall health and wellbeing. However core strength training targets all muscle groups that stabilize the spine, hips and pelvis, focusing on balance and stability during movement. This is of universal benefit but may particularly be helpful for anyone with reduced mobility or poor balance who experiences incontinence, as mentioned in 4.2.

Active Always is a comprehensive borough wide programme of physical activities for adults, coordinated through RMBC Active Rotherham (formerly Sports Development) in partnership with several NHS Rotherham services and community partners. The

programme offers a range of general activities plus specific ones to support people with a long term condition or after a rehabilitation programme (some by referral only from a GP or health professional). Falls Prevention – Active Otago Strength & Balance exercise sessions take place in seven venues, including Davies Court. Strength, coordination and balance form a key component of the Exercise after a Stroke class and Tai Chi.

The four leisure centres include Active Always activities within their programming as well as the wide range of activities for all age groups, such as workout classes in the studio or the pool, gym classes and sports.

### **Pelvic Floor Exercises**

Supervised intensive pelvic floor muscle training (also known as Kegel exercises) has been proved to relieve symptoms and may reduce the risk of developing stress incontinence. However research shows that the number of women who do the exercises as a preventative measure is quite low according to the CCS. Although exercises may be incorporated into the individual's daily regime, initial support helps to ensure they are done correctly, as research also shows some women experience difficulty with identifying the muscles and doing the exercises. Where people are intensely supported in classes they are also more likely to sustain the exercises. Physiotherapists are able to carry out quick tests to check whether there is an improvement after exercising.

Pelvic floor exercises, which are beneficial for both women and men, could potentially be included more widely within sport and activity programmes as a no-cost preventive measure, subject to staff being trained to deliver them. They are currently included in leisure centre activities such as Pilates and Aqua Pilates and are part of core strength training. Information about classes and activities does not explicitly mention which ones include pelvic floor exercises.

Downloadable apps for mobile phones provide information about how to do pelvic floor exercises. They usually incorporate a timer function to time the muscle contractions and to set as a reminder to undertake them. Detailed information about exercises for both men and women is also available on the internet.

### **Bladder training**

Another helpful method to reduce certain types of urinary incontinence is to retrain the bladder by gradually increasing the time between toilet visits to micturate. "Just in case" toilet trips might make people feel more secure but diminish bladder capacity.

### **Toilet facilities**

Access to clean, well equipped toilets, in schools and workplaces as well as in public spaces, was emphasized by the CCS. Toilets should contain suitable bins for the disposal of equipment and pads for both men and women. The biggest issue for the CCS service user group is clean, accessible public toilets, with some negative views expressed regarding the town centre, including poor design of the accessible toilet.

### **Nursing and care homes**

As stated above mobility, dexterity and core stability are all important as it can cause functional issues if people are not as mobile or are unable to walk or to balance on a toilet. These issues, coupled with fluid intake and diet, are all relevant in care homes. RMBC's Sport and Leisure team includes a disability officer and engages with care homes for sporting activities, such as New Age Kurling and Boccia in nursing homes and sheltered accommodation. Rotherham United also holds activities in care homes.

Research carried out in Rugby<sup>1</sup> showed the benefit of education for staff as urinary

incontinence was less prevalent in nursing homes where nurses and carers had received continence training. The CCS do offer training to care home staff and in-house product training but take up is low and last year sessions were cancelled due to a lack of participants. Engagement is more difficult with private sector care homes and high staff turnover impacts on training and continuity of care.

### **Health professionals**

Although in general there is greater focus on incontinence management and containment, more attention is starting to be paid to needs assessment and continence promotion. Awareness raising is needed with health care providers to dispel the notion of incontinence being an inevitability due to age or certain conditions and to encourage promotion of continence and preventative measures. Nurses, occupational therapists, physiotherapists, midwives, health visitors and school nurses are all well placed to assist with this. Signposting people for early assessment or support should link in with the future service development plans for an integrated pathway.

## **5. Conclusions**

Rotherham has a good, award-winning community continence service, which is evident from service user feedback. Therefore the question is what more could be done on the preventative side to try and reduce the numbers of people who do become incontinent, particularly in relation to preventable stress and urge incontinence, as well as providing services and support for those who will continue to need continence products.

One such measure is to continue promoting healthy lifestyle choices to all sections of the community, which is already one of the six priority workstreams within the Health and Wellbeing Strategy. Public awareness about the importance of good bladder and bowel health and information to try and counter some of the stigma around incontinence are important. Raising awareness about continence promotion more widely with health professionals and care home staff will help with prevention. However it may well result in more signposting for assessment, rather than management and containment of incontinence, potentially increasing demand for services in the shorter term.

Another measure is to support and encourage people to do pelvic floor exercises and to consider ways to incorporate these more widely or more specifically within Rotherham's sport and leisure activity offer. The general benefits of core strength training were noted as helping with balance and mobility and current provision includes many sessions that focus on this area, including within the Active Always activity programme.

Members welcomed the plans for future service development of the Community Continence Service with greater focus on prevention, especially the workstream to consider developing an integrated continence care pathway, which should link in with services such as physiotherapy and fitness activities. Early assessment of a urinary incontinence problem, to identify its root cause and appropriate treatment should be facilitated by a single point of access, potentially reducing the numbers who are using incontinence products unnecessarily or inappropriate products, improving the quality of life for many people.

## **6. Recommendations**

- 1 RMBC Streetpride and partner agencies such as SYPTTE should ensure all public toilets in the borough are clean and well equipped to meet the needs of people who have urinary incontinence, including suitable bins for the disposal of equipment and disposable products.

- 2 RMBC Sport and Leisure team should establish greater links with the Community Continence Service in order to support people to participate in appropriate sport and physical activity.
- 3 RMBC Sport and Leisure team should liaise with other sport and leisure activity providers to consider building more pelvic floor exercises into the Active Always programme and wider leisure classes.
- 4 There should be greater publicity by partner agencies, coordinated through the Health and Wellbeing Board, to reduce stigma associated with incontinence and to raise public and provider awareness of:
  - a) the importance of maintaining good bladder and bowel health and habits at all life stages (through media such as screens in leisure centres and GP surgeries, further website development, VAR ebulletin and a campaign during World Continence Week from 22-28 June 2015)
  - b) healthy lifestyle choices having a positive impact on general health but also helping to prevent incontinence, such as diet, fluid intake and being active
  - c) the positive benefits of pelvic floor exercises as a preventive measure for urinary incontinence, including the use of phone apps for support
  - d) the need to include the impact of incontinence due to medication, such as diuretics, within a patient's care
- 5 RMBC Neighbourhoods and Adult Services should work with care homes to encourage more staff to participate in the training offered by the Community Continence Service and to increase staff understanding of the impact of mobility, diet and fluid intake on continence.
- 6 That the Health Select Commission receives a report from Rotherham Clinical Commissioning Group in 2015 on the outcomes of the project considering future service development of the Community Continence Service.

## **7. Background papers and references**

*Pharmaceutical and Medicines Waste* - Report to Health Select Commission March 2014

*Scrutiny review: Urinary Incontinence* - Report to Health Select Commission June 2014

Joint Strategic Needs Assessment

Ensuring Effective Continence Care - October 2013 Health Scrutiny Panel,  
North Lincolnshire Council

Warwickshire County Council January 2011 – Report of Adult Social Care Prevention Services Task and Finish Group

Nursing Times Discussion: Continence 10.07.13

Frontline magazine, Chartered Society of Physiotherapists 2.10.13

NHS Choices and Patient Opinion websites

Reference

1 - "Is policy translated into action?" National survey by RCN and Continence Foundation