



Tackling Incontinence Amongst Women of Child-bearing Age in Merton

March 2014

A report of the Healthier Communities and Older People Overview and Scrutiny Panel, Chaired by Cllr Suzanne Evans

Foreword by the task group chair

There was tremendous support for investigating this issue among members of the Panel. For many of us it was all too personal: we had either suffered ourselves or seen members of our family struggle to cope with this condition, one which is not only debilitating and distressing but also taboo, especially for women of childbearing age.

My own experience of living with incontinence following the birth of my daughter turned out to be typical. It took me five years to pluck up the courage to go to my doctor to ask for help, and only then after an 'accident' I found particularly embarrassing. But once I had done so, and my doctor had assured me the problem could be solved, the relief was immense. I remain incredibly grateful to the staff at St George's hospital who, to use colloquial terms, gave me my life back.

However, in preparing this report the Panel uncovered many barriers faced by women when it comes to getting access to incontinence services. This is unacceptable, especially given how hard it is for them to report the problem in the first place.

It is also very short-sighted. Incontinence has huge impact on health and social care services. Those who suffer are less likely to lead active, sociable lives. Working may become problematic. In any age group, incontinence is a key factor in relationship breakdown. It can often be a trigger for abuse. As women get older they are more likely to suffer falls and need residential care. Yet if incontinence was addressed earlier, many of these subsequent problems could be avoided.

The panel believes that if our recommendations are followed, more women will come forward for treatment, and sooner. Not only will this dramatically improve their quality of life, the NHS and our social care services will also benefit financially in the longer term.

Suzanne Evans

Chair, Incontinence amongst women of child bearing age task group

Recommendations:

No	Recommendation	To be implemented by:
1.	That midwives and health visitors follow up first, second and third degree tears following childbirth to check for signs of incontinence	NHS England
2.	That health visitors ask women ‘trigger questions’ after childbirth to identify the onset of incontinence.	NHS England
3.	That women are warned incontinence may be a problem following childbirth and that pelvic floor exercises are important to help prevent it.	MCCG
4,	That women should be given realistic information about the efficacy of pelvic floor exercises and advised what other options may be available in extremis.	MCCG
5.	That women are advised they should not hesitate to contact either their GP or the continence service if they experience any problems with incontinence at any time in the future	MCCG
6.	NHS Trusts should place greater emphasis on early detection and prevention of continence issues. We suggest perhaps establishing local/regional clinical champions?	MCCG
7.	The Director of Public Health should investigate how easily accessible and free training can be rolled out to unpaid carers to help them deal with continence	Merton Council

8	Incontinence issues should be prioritised as part of the Falls Prevention Strategy	MCCG
9.	Merton Clinical Commissioning Group should develop a clear pathway for unified continence services across the borough.	MCCG
10.	That MCCG and local acute NHS Trusts look into what role pharmaceutical companies may be able to take in hosting events to raise awareness on incontinence issues	MCCG
11.	That commissioners and the continence service seek to involve patient participation groups in raising awareness of continence issues	MCCG
12.	That an information leaflet is produced to advertise continence services	MCCG
13.	That e-information leaflets and posters advertising continence services should be distributed in discreet locations such as Lavatory cubicles in local public buildings where women can access them privately.	MCCG

Introduction

1. This review looked at the services available to people suffering from incontinence. This is a common condition that can affect people of all ages. Urinary incontinence (UI) is defined by the International Continence Society as ‘the complaint of any involuntary leakage of urine’ and is wide ranging in its severity and features. Although rarely life-threatening, UI and or faecal incontinence can seriously influence the physical, psychological and social well-being of affected individuals.
2. The impact of the condition on the families and carers of women with incontinence may be profound; it is often cited as a major reason why relationships between carers and the people they are caring for breaks down, and a key cause of admissions to residential or nursing homes; incontinence is second only to dementia as an initiating factor for such moves.¹
3. The resource implications for the health service are considerable. Figures from 2010 suggest the total incontinence-related expenditure for the UK was more than £420 million; £80 million of which was spent on absorbent products, such as incontinence pads alone (Royal College of Nursing). The Bladder and Bowel Foundation estimates incontinence costs the NHS £7,178 per 1,000 people in England.²
4. Incontinence also has a major impact on the quality of life of those who suffer. It restricts employment, educational and leisure opportunities. There may be considerable financial implications because of the soiling of clothes and bedding which; leads to extra laundry and renewal costs.
5. A number of factors led the task group to conduct this review. Incontinence is an issue that resonated amongst the group both from their own experiences as well as those of loved ones. The Chair and cabinet member had both suffered from the condition and had to face not only the challenge of dealing with it but also summoning the courage to seek medical help, such is the level of stigma around the condition in relatively young or middle aged mobile and otherwise healthy women. Another task group member cared for a family member who had the condition.
6. Age Concern UK were concerned about the low level of resources available to support people and a lack of awareness about what help is available to tackle this problem.

¹ Urinary continence service for the conservative management of urinary incontinence in women, NICE Guidance, 2008

² Prevention and Early Intervention Continence Services, Health and Social Care Partnership.

7. As members felt this group had been overlooked in previous discussions of the subject and because they were less likely to report symptoms due to shame or embarrassment, the task group decided to focus on women of child bearing age, those between the ages of sixteen and forty four, not least because, urinary incontinence often occurs following pregnancy. This contributes to making it about two to three times more common in women than in men. Also the task group felt that if services can be improved for this age group, there will be a direct knock on effect on older age groups where it is more prevalent. This supports the task group's commitment to the prevention agenda – identifying problems at an early stage and addressing them before they become worse, which creates unnecessary suffering and requires more invasive and expensive interventions later on.
8. This review also looked at how to raise awareness of incontinence and tackle the stigma that prevents people seeking help. As a first step the Chair of this task group and the Cabinet member for adult social care and health spoke jointly about their personal experiences in an article for the local newspaper. (See Appendix A)

The task group's terms of reference were:

- Looking at health pathways for treatment of incontinence amongst women of child bearing age
- Influencing current policies and strategies to increase the priority for this service such as the CCG's public health and the health and wellbeing strategy
- Looking at ways to tackle the stigma associated with continence issues
- Looking at ways to raise awareness of the problem and encourage people to seek help

What the task group did?

The task group held three meetings to consider a wide range of evidence and heard from:

- Continence nurse at St Helier hospital
- Community Nursing Manager, Sutton and Merton Community Services
- Acute Therapies Service Manager, Sutton and Merton Community Services
- Women's Health Physiotherapist, Sutton and Merton Community Services
- Assistant Director, commissioning, NHS South West London

The task group also:

1. Secured an article in the Wimbledon Guardian highlighting the problem with quotes from the Healthier Communities and Older People Scrutiny Panel Chair and the Cabinet Member for Adult Social Care and Health.
2. Conducted an online survey of incontinence in Merton which provided a small sample of people's experiences, while the survey was open to all areas

across London, it was still possible to extrapolate responses from Merton residents. Links to the survey were placed on:

- Mumsnet
- The Bladder and Bowel Foundation
- Merton Council website
- The Pelfix Technique

The findings and deliberations of the task group

Services for people who suffer from incontinence in Merton

9. We spoke to a number of front line clinicians who provide treatment for people suffering from incontinence to get a picture of services available for Merton residents, especially women in our target group. We found there are a range of services available;
10. The Continence Service is part of Sutton and Merton Community Services. There are two part time continence nurses and a senior nurse who works as a continence advisor . Their work includes clinical services such as assessing people for treatment as well as specialist support to individuals and training for other staff. We were told that there is a limited budget of £700,000 for continence services across the two boroughs. We found the team are passionate about their work and do the best they can with the limited resources available.
11. Continence services have been improved following a review in 2010. This led to the employment of the continence advisor who provides specialist advice and training for staff. There is also improved advice and delivery service on incontinence products.
12. There is a part-time continence nurse at Epsom and St Helier hospital who runs a continence clinic providing diagnosis, physiotherapy and advice on managing the condition.
13. The women's health physiotherapist is based within community services and provides exercises to strengthen the pelvic floor muscles for the treatment of incontinence. She sees five new cases a week. The waiting list for this service is currently three months long.
14. St George's hospital which also serves Merton residents has Urologists that treat incontinence problems.

15. In response to questions from us, staff from the continence service were clear that they spend the majority of their time responding to people who request their services and they have very little time and resources to focus on the prevention agenda. Most people who access continence services are elderly, although the service is open to all age groups. Staff are not able to do preventative work or reach out to other groups who may need help due to limited resources.

16. Although we recognise that there have been some improvements to continence services since the review of 2010. We do not believe that many of the fundamental problems have been addressed. Amongst the issues identified in the review were:

- A lack of standardised referral/advice/treatment pathways within primary care to specialist care
- A lack of consistent information to patients
- Specialist physiotherapy continence is patchy and limited
- Insufficient continence education for front line staff
- Poor data from home delivery service of containment products so unable to get a clear picture of current incontinent needs.

17. An NHS Sutton and Merton briefing report presented to the panel³ states that 'the service review recommended the provision of a comprehensive continence service, supporting screening or urinary and faecal symptoms, assessment management and evaluation of management. This service provision with the correct highly skilled workforce would be promoting continence through accurate assessment rather than containing it through poor assessment.'

18. It also stated that 'the new model of care will challenge the current reactive service which only provides continence products and very little advice and support.'

19. We also found out that the staffing levels for treatment of incontinence across Sutton and Merton are below the recommended guidelines set out by NICE. It was very apparent to the task group that the service is not adequately resourced to meet need within the borough.

Under- reporting of continence problems

20. Existing research, previous reports to scrutiny, anecdotal evidence and personal experiences made it clear that many people do not seek help for

³ NHS Sutton and Merton - Briefing on the Continence Service – Healthier Communities and Older People Overview and Scrutiny Panel January 2010.

their incontinence. Some studies reveal that it can take the average woman five years to go to her general practitioner for help⁴.

21. A report to the health scrutiny committee in 2010 highlighted that accurately quantifying the real need and potential demand for services is difficult because:
 - Definitions of incontinence vary
 - There is so much stigma and misunderstanding of the condition that people who might benefit from treatment do not seek help
 - Some people with continence problems are unaware that anything can be done to help them, and so do not seek help
22. Data from a Leicestershire study has been used to estimate the local need for continence services within the NHS Sutton and Merton area. Over 11,000 people were estimated to have “bothersome” incontinence symptoms, and of these it was estimated that 4,450 would actively want help.
23. Recent figures show that 3,105, individuals are currently receiving incontinence pads from NHS Sutton and Merton, which could mean that there are at least 1,500 people who still need help.
24. The task group concluded that the low priority placed on incontinence needs to change. Incontinence has a huge impact on quality of life and is a major factor in falls amongst older people and those with long term conditions. Women of child-bearing age with young children, may struggle to keep active because of symptoms. It plays a role in mental health issues, leading to problems such as depression, anxiety, agoraphobia etc. If incontinence is left untreated and worsens the cost to the NHS and Adult Social Care becomes even greater.
25. Despite much talk of prevention, task group members concluded that in fact the service was already struggling to cope and probably could not manage if more emphasis was placed on the preventative agenda and more people came forward to get help.
26. We spoke to the Assistant Director for Commissioning at NHS South West London, were informed that commissioners were not aware of an unmet need within the service. Although we spoke to the service as it was going through a major period of transition (February 2013) , this reinforced our conclusions that this service is given a low priority by Commissioners as it is not life threatening.

⁴ Graham Allen MP Report to Parliament on incontinence 24 October 2007.

Impact of incontinence on women of child bearing age

27. Urinary incontinence is more prevalent among women after childbirth, because of the damage caused to the pelvic floor during the birth process. One in four women experience it. The level of damage and severity of symptoms varies enormously; often muscles are weakened and women leak small amounts of urine when they cough, sneeze or exercise. At the other end of the spectrum – there can be severe damage resulting in uncontrollable urinary and faecal incontinence.
28. If services are improved for women of child bearing age, the task group felt a good practice model could be developed which could then be extended and applied to other groups. The Continence Nurse agreed that this approach could have a direct impact on reducing incontinence amongst older people, where it is more prevalent.
29. There are some services in place to support women in the six week period after giving birth. For example, women who experience third degree tears in childbirth will receive a check up with the women's health physiotherapist, in accordance with NICE guidelines. We were informed that after such a tear women are at higher risk of incontinence so it is important they are encouraged to do pelvic floor exercises which can improve symptoms in up to 70% of women. This is also in line with guidance from the Royal College of Gynaecologists and Obstetricians, although we were told this is not standard practice across the borough.
30. However the task group heard evidence that incontinence does not only result from third degree tears and limiting access to physiotherapy just for this group is a mistake. Despite the fact the task group was aware this goes beyond the current NICE guidelines, members felt strongly that women who experience first and second degree tears should also be followed up to both identify and pre-empt problems.
31. Although women receive postnatal support from health visitors and midwives, it is clear many are not asked questions about incontinence. Or if they are, the questions are asked too soon after childbirth, when it is not possible to assess whether or not a continence problem will either develop or become long-term due to the fact a woman is still recovering and her body is not yet back to 'normal'. The task group felt frontline professionals need more training and support to ensure that they ask women about incontinence issues, well

after the six week period given the problem can kick in a few years after childbirth.

32. One respondent from our survey has called for *“greater help from midwives. I had a third degree tear and had no information at all either before or after birth on pelvic floor exercises or how to treat incontinence. I had to seek help myself some months after the birth”*

33. The task group also heard that in many cases, pelvic floor exercises alone cannot solve the problem. Our concern is that they can be offered as a panacea ‘cure all’ by both medical professionals and voluntary sector support groups, and give women the unrealistic expectations about their efficacy. This means women with greater problems which are not resolvable by pelvic floor exercises may a) fail to seek further help and b) blame themselves for their inability to cure the problem. The point should be made very strongly that if pelvic floor exercises fail to solve the problem this is not the end of the line and that other interventions, including surgery are available.

RECOMMENDATIONS:

That midwives and health visitors follow up first, second and third degree tears following childbirth to check for signs of incontinence.

That health visitors ask women ‘trigger questions’ after childbirth to identify the onset of incontinence.

That women are warned incontinence may be a problem following childbirth and that pelvic floor exercises are important to help prevent it

That women should be given realistic information about the efficacy of pelvic floor exercises and advised what other options may be available in extremis.

That women are advised they should not hesitate to contact either their GP or the continence service if they experience any problems with incontinence at any time in the future

The Prevention Agenda

34. As members of this task group and the Healthier Communities and Older People Overview and Scrutiny Panel we cannot stress enough the importance of the prevention agenda. Time and time again we review health issues and find that resources are concentrated on treating the problem when it has escalated and that not enough emphasis is put on trying to prevent it in the first place or targeting treatment in the early stages.

35. We saw the continence service as being a prime example of this. The condition is clearly not prioritised, nor understood in terms of its wider implications. Current services are stretched and there are no clear treatment pathways. This has a huge impact on those suffering from incontinence and places a significant financial burden on the NHS.
36. An All-Party Parliamentary Group for Continence Care produced a guide for commissioners regarding implementing and monitoring an integrated continence service. The guide argues that the most cost effective continence services are clinically driven, patient sensitive and treatment focussed. This reduces associated complications further down the line such as urinary tract infections, pressure ulcers, and complications leading to hospitalisation. This report calls for one target on incontinence in the Joint Strategic Needs Assessment.⁵
37. The professionals we heard from who work in continence services told us we should target people at risk: those with mental health problems; women aged 16-44; and those with learning disabilities. We need to get healthcare professionals to ask the right questions to find out if people are incontinent and then to know where to send them to.
38. We need to put money into prevention and raising awareness, and recognise that it may take a few years to realise the benefits.
39. We know that as our population ages the impact of incontinence related problems will escalate. It is important to improve the service now not least because we know there is a link between incontinence and falls which can seriously distress and incapacitate the elderly and cause premature death.
40. Given the fact incontinence is a key factor in admissions to care homes and current policy is to continue to allow people to live in their own homes for as long as possible, the task group felt that tying incontinence into the prevention agenda and providing more support to carers would assist in minimising care home admissions.

Recommendations:

NHS Trusts should place greater emphasis on early detection and prevention of continence issues. We suggest perhaps establishing local/regional clinical champions?

The Director of Public Health should investigate how easily accessible and free training can be rolled out to unpaid carers to help them deal with continence

⁵ Cost effective Commissioning for Continence Care, All Party Parliamentary Group for Continence Care Report, 2011.

Incontinence issues should be prioritised as part of the Falls Prevention Strategy

Health Pathways and Co-ordination of Continence Services.

41. The panel is unanimous in agreeing that there can be no underestimating the importance of having a clear clinical pathway both in terms of patient experience and identifying issues at an early stage. Professionals need to be able to identify problems quickly and signpost people to the right service.
42. When we investigated what someone reporting an issue with incontinence may experience we found a very fragmented service across South West London, where some health care professionals are not even clear where to refer people to. The treatment that people receive depends upon which service they go to – their GP, the continence clinic at Epsom and St Helier or the Urology department at St George's.
43. The All Party Parliamentary report; *Cost Effective Commissioning for Continence Care* highlights: "There is no doubt that an integrated service saves money, it leads to early identification and treatment of symptoms, agreed referral pathway to specialists, reduced hospital admissions improved patient experience and alleviation of distressing symptoms.

RECOMMENDATION :

Merton Clinical Commissioning Group should develop a clear pathway for unified continence services across the borough.

Raising awareness and tackling stigma

44. Our research highlighted again and again the unfortunate truth that many people do not seek help for their incontinence, either because they do not know where to go or they are too ashamed or embarrassed.
45. We uncovered a number of prevailing and damaging myths around incontinence which; can also act as barrier to those who would otherwise seek help and treatment. Some of these myths include:
 - Incontinence can only be corrected by surgery
 - If pelvic floor exercises don't work, there is nothing else you can do
 - Incontinence is inevitable because it's hereditary

- Health professionals can see it as a 'normal' part of ageing
- Health professionals do not take it seriously or they dismiss it
- Having a caesarean rather than a natural birth always prevents the problem

46. We asked our front line practitioners how we could tackle these myths and were told we need to use a combination of training, positive feedback from clients and success stories to dispel myths around incontinence. Proactive treatments such as pelvic floor exercises and bladder retraining should be used much more widely. Also general awareness raising was necessary among the public, families and, indeed, some health professionals, that the condition can be treated and not just contained.

47. The new responsibility for local authorities for public health presents an important opportunity to raise awareness about how to get help for incontinence. We recognise that there are limited resources and tight budgets, so we considered low budget options for raising awareness of services which will also help to tackle the stigma and myths surrounding this issue.

48. We were told that pharmaceutical companies often play a role in offering information and advice on the range of continence products available. We would like Merton Clinical Commissioning Group (MCCG) and the Trusts to consider what role they could play in providing information to the public and training for professionals on continence issues. However we recognise that this needs to be managed with sensitivity and caution, not least because the task group felt strongly that some existing commercial forms of awareness raising can be counter-productive. For example, the well known Tena Lady TV advertisements could lead the uniformed to conclude that incontinence is as natural as menstruation and that pads are the only answer. This is another reason why positive public health messages need to alert women to the range of support options available.

49. In Merton we have a vibrant voluntary and community sector. We feel they could play an important role in raising awareness of incontinence issues and dispelling the myths and promoting success stories. We would like the commissioners and the continence service to take this forward as a matter of urgency.

50. We were surprised to find that there are no leaflets or strategically placed posters advertising the continence service. This is an important way to signpost people and let them know that the service exists and the task group felt that women needed to access such leaflets in places where they will not feel embarrassed about picking them, lavatory cubicles for example.

Recommendations:

That MCCG and local acute NHS Trusts look into what role pharmaceutical companies may be able to take in hosting events to raise awareness on incontinence issues

That commissioners and the continence service seek to involve patient participation groups in raising awareness of continence issues

That an information leaflet is produced to advertise continence services

That e-information leaflets and posters advertising continence services should be distributed in discreet locations such as Lavatory cubicles in local public buildings where women can access them privately.