National Service Framework for Children, Young People and Maternity Services

Continence

Every Child Matters – Change for Children
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**Document purpose**  
Best Practice Guidance

**Gateway reference**  
8797

**Title**  
Continence

**Author**  
DH

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**Target audience**  
PCT CEs, NHS Trust CEs, SHA CEs, Care Trust CEs, Foundation Trust CEs, Medical Directors, Directors of Nursing, Local Authority CEs, PCT PEC Chairs, NHS Trust Board Chairs, Special HA CEs, Allied Health Professionals, GPs, Directors of Children’s SSs

**Circulation list**  
Continence issues form a part of the National Service Framework for Children Young People and Maternity Services. This exemplar describes a patient journey and the considerations which apply to each stage in addressing the issues.

**Cross reference**  
National Service Framework for Children

**Superseded documents**  
N/A

**Action required**  
N/A

**Timing**  
N/A

**Contact details**  
Noel Durkin  
Child Health and Maternity  
211 Wellington House  
133-155 Waterloo Road, London  
SE1 8UG  
0207 972 4152  
www.dh.gov.uk/childrensnsf

**For recipient’s use**
Introduction

The National Service Framework (NSF) for Children, Young People and Maternity Services has been published alongside supporting material, which includes a series of exemplar patient journeys. Whilst it is not the role of the NSF or the exemplars to provide detailed clinical discussion on individual childhood conditions, exemplars illustrate some of the key themes in the NSF.

Several factors influenced the selection of exemplar conditions, for example: large numbers of children and families affected, significant cause of illness and distress, wide variability in standards of practice or service provision and suitability for highlighting the NSF themes. Such themes include the importance of responding to the views of children and their parents, involving them in key decisions, providing early identification, diagnosis and intervention, delivering flexible, child-centred, holistic care. Care is integrated between agencies and over time and is sensitive to the individual’s changing needs. It is also acknowledged that not every child with the same condition will follow the same journey or have the same type or severity of condition as the one which is illustrated.

The primary audience for the exemplars is professionals from a broad range of backgrounds including education, NHS, social services and the voluntary sector (although they could also be of interest to parents and older children). The exemplars may be useful in a number of ways, for example, to:

- Highlight further references, which relate to evidence in the NSF and elsewhere, including key clinical guidelines;
- Stimulate local debate and assist multi-agency partners to re-evaluate the way they collaborate on, commission and deliver children’s services, for this and other conditions, to the benefit of children and their families;
- Provide an aid to examining and improving local clinical & non-clinical governance;
- Provide a multi-disciplinary training tool for staff working with children and young people to raise awareness of specific issues and stimulate discussion;
- Canvass the views of children and families on specific children’s issues (for example via focus groups), provide a non-threatening mechanism to open discussion, such as good and ‘not so good’ aspects of the current service; and
- Provide a starting point or template for debate, prior to development of new local strategies for managing complex childhood conditions.
# Beth's Continence Difficulties

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<td><strong>Identification of Problem</strong></td>
<td>Beth, aged 7 years, has wet herself at school on several occasions. Beth's mother tells her teacher that this has never happened at home, but she does go to the toilet more often than her siblings and she still wets the bed at night. Beth seems happy at school, and there are no family problems at home. Beth's mother offers to provide a change of clothes for Beth at school and Beth's teacher agrees to inform her of any further problems.</td>
<td><strong>Standard 1</strong> early identification and intervention</td>
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<td><strong>Seeking Advice</strong></td>
<td>Beth's mother has noticed that Beth's urine has recently developed a strong smell in the morning. Having been alerted by the class teacher, Beth's mother also notices that although Beth's underwear is not wet, her pants sometimes have a stain on them. She discusses the problem with her husband, and they decide to ask their GP for further advice.</td>
<td><strong>Standard 6</strong> multi-agency co-operation between partners, ensure timely access to appropriate services</td>
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| **GP Visit 1** | Beth's mother takes her to see the GP a few days later. He listens to her concerns about Beth's wetting difficulties and her strong smelling urine. The GP takes a history (1,2) and examines Beth. This includes an examination of the back for any lumbosacral problems. He also asks Beth to bring in a urine sample for analysis. The GP also asks about Beth's bowel habits. Beth and her mother say that Beth has never been that regular (every 2-3 days), but this was a family trait. The GP could see no signs of | **Standard 3** listening to the children and their parents, information about services and treatment | Incontinence Management Royal College of Physicians 2001 www.guidelines.co.uk  
| | | **Standard 1** early identification and intervention | NICE Guidelines on Urinary Tract Infections 2007 www.nice.org.uk  |

1. Questions and investigations relating to child physical/sexual abuse should always be considered (The Royal College of Paediatrics and Child Health Child Protection Campaign (6.112.g(i)). It is clear that in this case there are no associated worrying indicators for child physical/sexual abuse, so no need for questions or investigations.
2. Examination of the anogenital area would be indicated if there was a history of recurrent discharge, signs of post micturition dribble, the child was unresponsive to management, or there were, additionally, any indicators for child physical/sexual abuse.
constipation. He explains to Beth and her mother that bedwetting in young children is quite common, and gives them information about drinking regularly during the day (6-8 glasses a day), with the last drink one hour before bedtime. He also suggests that Beth's mother speaks to the school nurse for further monitoring, as well as information and support.

### School Nurse Interview

A few days later, Beth's mother arranges to speak to the school nurse. The school nurse listens and suggests that Beth, supported by her mother, keeps a diary record over four days of how often Beth goes to the toilet, what she drinks during the day, and when she is wet at night. She also advises Beth's mother that the bedwetting was not Beth's fault, as it is not something she has any control over. She reinforces the need for a regular fluid intake. She also gives Beth's mother details about ERIC for further information and support, plus resources such as bedding protection.

### Telephone Call From GP Surgery

Several days later, Beth's mother receives a telephone call from the GP to inform her that Beth has a urinary tract infection. The GP arranges a prescription for a course of antibiotics.

### Pharmacy Visit 1

Beth's mother collects the prescription from the surgery and takes it to the local pharmacy. The pharmacist checks that Beth has no known allergies and advises her to ensure that Beth takes the full 5 day course of treatment.
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<td><strong>Parent/Teacher/School/Nurse Meeting</strong></td>
<td><strong>Standard 6</strong>&lt;br&gt;co-ordination of health, social care and education services to meet individual needs</td>
<td>Managing bowel and bladder problems in schools and early years settings.&lt;br&gt;Guidelines for Good Practice, PromoCon 2006&lt;br&gt;www.promocon.co.uk&lt;br&gt;Access to education for children with medical needs, DfES 2001&lt;br&gt;www.dfes.gov.uk/sickchildren/&lt;br&gt;ERIC School Campaigns “Water is Cool in School”&lt;br&gt;www.wateriscoolinschool.org.uk&lt;br&gt;“Bog Standard”&lt;br&gt;www.bog-standard.org</td>
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<td>Beth’s parents, with the teacher and school nurse, meet one month later to review her progress in school. The teacher reveals that Beth is having fewer wetting accidents, but is leaving class more often to go to the toilet. The school nurse reviews the diary Beth and her mother have kept. This reveals that Beth is going to the toilet 10-12 times a day. Her mother has also noticed that Beth’s underwear is often damp by the time she gets to the toilet. The school nurse discusses the importance of Beth wiping properly from front to back after urinating and washing her hands after every visit to the toilet. She also checks; that the school toilets are clean and well maintained and that pupils have good access; the school has palatable drinking water facilities and allows pupils to have water bottles on their desks. She reinforces the fact that drinking water-based, non fizzy fluids, is extremely important. She further suggests that it might be helpful for Beth to be referred to the local paediatric continence clinic.</td>
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<td><strong>Paediatric Continence Clinic Visit 1</strong></td>
<td><strong>Standard 3</strong>&lt;br&gt;involving young people in their care&lt;br&gt;<strong>Standard 6</strong>&lt;br&gt;an integrated community-based paediatric continence service, informed by Good Practice in Paediatric Continence Service, insures that accessible, high quality assessment and treatment is provided to children and their parents/carers in any setting, including, for example, children looked after and children at boarding schools. Children with special needs and/or disabilities have equal access to investigation and treatment programmes</td>
<td>Good Practice in Paediatric Continence Services – Benchmarking in Action NHS Modernisation Agency 2004&lt;br&gt;Factor 2 – Access to Professional Advice re Continence and Bladder and Bowel Care. DH 2002&lt;br&gt;Nocturnal Enuresis and Daytime Wetting: A Handbook for Professionals, Butler R , Swithinbank L, ERIC 2007&lt;br&gt;www.wikipedia.org/wiki/Bristol_Stool_Scale</td>
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<td>Six weeks later, Beth and her mother are seen in the nurse-led paediatric continence clinic. The specially trained paediatric continence nurse reviews Beth’s history, checks her blood pressure and a dip stick urine for infection. They review the diary again. The nurse notes that Beth’s fluid intake is quite poor during the day and Beth admits that she does not want to drink in case she has an accident in school. She drinks more in the evening when she gets home, and admits to taking a large drink from the bathroom just before going to bed. Beth also explains to the nurse that she gets very little warning when she needs to go to the toilet, and will often have a small leak of urine. She is very upset about wetting the bed, as it prevents her staying overnight with friends. The nurse suggests that Beth keeps a record of how much and what she drinks and measures her voided volumes for 48 hours. This will give evidence of the capacity of her bladder. Beth’s mother has also noticed that Beth is opening her bowels less (every 3-4 days). The nurse shows Beth a stool chart. Beth indicates a Type 2 stool. The nurse undertakes an abdominal examination and palpates a faecal mass on the left side.</td>
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**Journey**  
She discusses with Beth and her mother about the advantages of good levels of exercise and a high fibre diet (5 fruit and veg a day) and reinforces the importance of a proper fluid intake. This would help to increase her bladder capacity and prevent constipation. Beth taking her own water bottle into the classroom might be a way forward. She explains the need for Beth to go to the toilet regularly during the day to retrain the bladder. Beth agrees to try this and they plan to meet again in four weeks time to review her progress. The nurse gives Beth’s mother a telephone number she could ring if she had any queries between visits.

**Continence Clinic Visit 2**  
Beth and her mother return to clinic to see the nurse 1 month later. They report that Beth has increased the amount she is drinking and is now managing over one litre per day. However, she is still having accidents and remains constipated. Beth is disappointed by the lack of progress, and for the past few days has been refusing to drink or go to the toilet regularly. Her mother is finding this frustrating, and is concerned that she and Beth are fighting more often.

Beth has kept her voiding chart, which shows that her bladder capacity is low for her age and confirms that she is visiting the toilet frequently through the day. The nurse feels Beth’s tummy again and finds she still has a faecal mass palpable in the left iliac fossa suggesting significant constipation.

The nurse draws a picture of Beth’s bladder and explains how the bladder should work. She helps Beth to understand the concept of a bladder which has a small capacity and is “overactive”, thereby causing her to have accidents. The nurse also explains why constipation can prevent the bladder from expanding properly to hold an adequate amount of urine. Constipation can also “irritate” the bladder causing frequency and the underlying reason for a urinary tract infection. The nurse discusses with Beth and her mother the need for laxative medication to help her control the constipation. It was agreed that the nurse would ask the GP

**Children’s NSF Theme**  
Standard 4 respecting and involving young people in their care  

**Evidence/Links**  
IMPACT Paediatric Bowel Care Pathway 2005, Norgine Pharmaceuticals  
www.childhoodconstipation.com  
Childhood Soiling: Minimum Standards of Practice for Treatment and Service Delivery, ERIC, 2001
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<td>to prescribe Movicol Paediatric Plain sachets initially 2 a day. She advises Beth and her mother that this dose may need increasing if it proves not quite enough over the next few weeks. She felt Beth should take as many sachets as she needed to produce a normal soft stool most days and she reinforces the previous information about a healthy high fibre diet, drinking sufficiently during the day and plenty of exercise. She suggests that Beth completes a special incentive chart to encourage her with this.</td>
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<td>Pharmacy Visit 2</td>
<td>The pharmacist explains that Movicol Paediatric Plain is now recommended as a first line treatment for constipation in children and can be mixed with a flavoured drink such as orange squash. He reassures Beth and her mother that it is a safe and gentle laxative that would start working over the next 3 – 4 days.</td>
<td>Standard 10 contribution of pharmacists to the effective and safe use of medicine for children</td>
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<td>Continence Clinic Visit 3</td>
<td>Beth and her mother return to the clinic 1 month later. Beth shows the nurse her charts which she has coloured in beautifully and demonstrates that she is now drinking much better. The nurse congratulates her on her hard work. Beth tells the nurse that she takes the Movicol in orange squash, it has worked well and she is now doing a soft poo every day. Although better than before, disappointingly, Beth is still having occasional wetting accidents in the day, associated with frequency and urgency and she is still wet most nights. The nurse feels that this now needs further attention, as these symptoms indicate that Beth has a condition called bladder overactivity in which the bladder contracts before it is full (this may also be a contributing factor to the bedwetting). She suggests to Beth that she should continue to drink good levels of fluid and go to the toilet regularly during the day. She also explains to Beth and to her mother that this condition often responds to treatment with an anticholinergic medication,</td>
<td>Standard 3 involving young people in their care Standard 10 Review of medication Standard 10 young people to be active partners in decisions about medications</td>
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Journey

which helps control the overactivity in the bladder muscle. However before she can arrange for this to be prescribed, given Beth’s history of urinary tract infections and some doubt as to whether she can fully empty the bladder, Beth needs referral for an ultrasound scan of her bladder to check that it is emptying properly. If not emptying properly the medication could make this worse and predispose her to a further urinary infection.

Scanning Department (this may be at the local hospital or in the community)

Beth has a drink as soon as she and her mother arrive at the appointment, enabling the scan to be taken at maximum potential fullness. The scan showed how much urine was in Beth’s bladder and how much was left in the bladder after she went to the toilet. Fortunately Beth’s bladder, although not holding a large amount initially, emptied completely. If the scan had shown a significant amount of urine left in her bladder it would be an indication of dysfunctional voiding and Beth would need referral on for more specialist investigations at the hospital, from a paediatrician and a nurse specialist.

Continence Clinic Visit 4

On return to the clinic, the nurse was pleased to report that Beth’s scan was normal. She arranges for Beth to start a course of oxybutynin treatment using a small dose of 2.5mgs in the morning and after school, with a double dose of 5mgs just before bedtime, as this might help her stay drier at night. She explains the possible side effects of this medication. Beth and her mother go away with more charts to record what happens to her wetting during the day as well as at night. The nurse encourages Beth to continue with her good drinking habits, regular toileting and to keep taking her Movicol Paediatric Plain sachets. She warns Beth and her mother that the new medicine sometimes makes the constipation worse and not to worry if she needed to increase the laxative dose.

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<td>Standard 7 provision of appropriate specialist care, as required</td>
<td>Improving the patient experience: friendly healthcare environments for children and young people, DH 2003 Nocturnal Enuresis and Daytime Wetting: A Handbook for Professionals, Butler R and Swithinbank L, ERIC, 2007</td>
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<td><strong>Pharmacy Visit 3</strong></td>
<td>The pharmacist confirms that there may be some other side effects from the oxybutynin, such as dry mouth or facial flushing, but as the dose was small this would be unlikely to cause Beth any problems.</td>
<td><strong>Standard 10</strong> contribution of pharmacists to the effective and safe use of medicines for children</td>
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<td><strong>Continence Clinic 5</strong></td>
<td>One month later Beth and her mother go back to see the specialist nurse. Beth shows her the charts she and her mother have been keeping. Beth is obviously delighted with her progress, as she has now been almost completely dry during the day for the past 2 weeks. Beth reports that she can now hold on to her wees until break and dinner time at school and no longer has to rush out in class time. Her teacher has noted and has praised her for this. The nurse checks that Beth’s constipation has not returned and discovers that, although Beth is still wet at night, she is having a few more dry nights in the week than before. She suggests Beth continues with the oxybutynin to complete a 3 month course, which would allow Beth’s bladder to adapt to the new “habits”.</td>
<td><strong>Standard 10</strong> review of medication, <strong>Standard 7</strong> appropriate specialist care, as required</td>
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<td><strong>Continence Clinic Visit 6</strong></td>
<td>Two months later Beth and her mother return with reports of continued good progress. Beth has now been completely dry in the day for some weeks and her day time frequency and urgency have resolved. Although she is drier than before at night she is still wet 3 or 4 nights a week and is upset because she doesn’t feel she can go for a sleepover at her friend’s house. The nurse explains it is now time to gradually withdraw the oxybutynin to see if Beth can now manage without a relapse of her daytime symptoms. She suggests starting with the morning dose and if all was well to try stopping the afternoon and then the night time dose, but to continue with her regular toileting regime. The charts that Beth has been keeping suggest that her bedwetting was due to a problem of arousal (or waking up to the sensation of a full bladder) at night. There was no indication of nocturnal polyuria (producing more than</td>
<td><strong>Standard 6</strong> participation and planning care and continuity of care, <strong>Standard 8</strong> information about the child’s condition, <strong>Standard 8</strong> children who require ongoing health interventions have access to high quality care</td>
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<td>Had Beth’s course of antibiotics or anticholinergic medicine not been effective, referral to a tertiary clinic would have been considered, with assessment by a general or specialist paediatrician and follow-through by a specialist paediatric continence nurse</td>
<td>The “Three Systems” Approach to the assessment and treatment of nocturnal enuresis Childhood Nocturnal Enuresis and Daytime Wetting: A Handbook for Professionals, Butler R, Swinthinbank L, ERIC, 2007</td>
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average amounts of urine at night, something usually caused by an insufficient production of the kidney regulatory hormone, vasopressin). The nurse explains the two main treatment approaches to Beth; 1) A medication called desmopressin which acts by reducing the volume of urine produced overnight, thus making it easier for the bladder to store the urine until the morning; 2) an enuresis alarm, which wakes the child on the first sensation of passing urine. The nurse discusses these options with Beth and her mother. Since Beth’s problem of bladder overactivity was now under control, it would be appropriate to consider the enuresis alarm as a treatment approach. The nurse explains this to Beth and describes how Beth could use either a body-worn or a bed alarm and how the alarm should be used. Beth is very keen to try and chooses an alarm on loan from the clinic. Her mother agrees to help Beth wake up when the alarm goes off in the night. Beth knew she was responsible for switching the alarm off and getting to the toilet. The nurse gave Beth some more charts to fill in to keep track of her progress and arranged to check with Beth and her mother on the phone a few days after starting the alarm, then after two weeks, to make sure the alarm was working correctly and there were no problems.

Beth and her mother came back to clinic one month later to report progress. Fortunately Beth had managed to stop the daytime oxybutynin without any recurrence of her daytime frequency and urgency. Beth was still using the alarm at night and her mother reported that Beth had found it very difficult to wake for the first week or so (she needed her mother to “prompt” her), but she was gradually getting better at this and now when the alarm went off Beth could get herself out of bed to the toilet. Beth showed the nurse her night time charts which showed she was having a lot more dry nights and the wet patches were much smaller. The nurse congratulated Beth and encouraged her to continue with the alarm as it could take 3-4 months to become completely dry.

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<td>Standard 4 transition, empowerment, self management and family support Standard 8 partnership and involvement of parents Standard 4 transition, empowerment, self management, family support</td>
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Journey

She told Beth that if she managed 14 nights dry in a row she could stop using the alarm. As Beth had not had any more problems with constipation, the nurse suggested she could now see if she could gradually reduce the dose of Movicol Paediatric Plain while making sure her constipation did not recur.

| Continence Clinic Visit 8/9 | **Standard 5**  
children and young people feel safe and supported  
**Standard 6**  
co-ordination of services between care providers | Guidelines on Minimum Standards of Practice in the Treatment of Enuresis, Morgan R., ERIC, 1996 |

Beth proudly reported that she had been dry at night for over 2 weeks and had stopped using the alarm. Since then she had managed to stay dry. She was however continuing to drink more and toilet regularly. Her mother reported that she had been able to gradually reduce and stop the laxative medication without any recurrence of constipation. Beth's mother mentioned that Beth appeared much more confident in herself and was looking forward to staying at her friend's house. The nurse gave Beth a big sticker and a special certificate to celebrate her achievement. She warned Beth's mother that there was a chance that Beth's wetting at night might recur and if this happened to bring her back to clinic, as she would respond well to a further course of alarm treatment. Beth is discharged from the clinic and the nurse writes to her GP to say that she has responded well to treatment for all her continence difficulties and is now dry day and night and free of constipation, without needing any on-going medication.
National Service Framework for Children, Young People and Maternity Services – Continence

Children’s NSF Continence Exemplar

Initial assessment, diagnosis and early management
Parents ask for advice from health professionals about wetting/soiling problems in child
Assessment of symptoms, examination and testing
Diagnosis & plan for care, assessment and review recorded
Referral to Paediatric Continence Service as appropriate
Care partnership with child and family
   – agreed plan for review of care
   – patient action plan
   – linking information and

Living with incontinence
*Child/family/health professional become partners in care
*Link to local support
*Contact for national patient groups

Differential diagnosis/underlying pathology referred on

Child with well managed continence problem able to cope with all usual home/school/social activities

Continence friendly environment
Improving access to clean drinking water and toilets

Acute problem/relapse
Child or parents notice change in voiding pattern/wetting
Stool frequency/Consistency/soiling

Advice on treatment and direction for immediate review
Protocol based care to restore continence and return to self care

Assessment & care at point of first contact
Primary Care – GP/SN/HV
Walk in centre
NHS Direct A & E

Referral to paediatric continence service

Revise continence action plan and agree review
Communicate with other professionals dealing with child

Refer for further assessment and action

Expert Patients/parents training in self care

Planned transition to adult services

School care
*Linking with school health service
*Continence policy in schools
*Training for school staff
Authors:
ERIC (Education and Resources for Improving Childhood Continence)
Rosie Kelly: Lead Nurse, Children’s Services, Ulster Hospital, Belfast, Northern Ireland
Mary White: Independent Specialist Continence Adviser
Dr Ursula Butler: Consultant Community Paediatrician, Sheffield Children’s Trust
June Rogers MBE: Paediatric Nurse Advisor and Director, Promocon (Promoting Continence and Product Awareness), part of Disabled Living
Penny Dobson (Ed) Director, ERIC (Education and Resources for Improving Childhood Continence) Chair; Paediatric Continence Forum
Reviewed by members of ERIC’s Clinical Advisory Committee: Chair: Dr Jonathan Evans, Consultant Paediatric Nephrologist, Nottingham University Hospitals NHS Trust and members of the Paediatric Urology Special Interest Group, Royal College of Nursing: Chair: Christine Rhodes, Clinical Nurse Specialist for Paediatric Urology, Nottingham City Hospital.

The Royal College of Nursing welcomes the exemplar on paediatric continence care, highlighting the importance of a multidisciplinary approach to supporting children, young people and their families.
National Service Framework for Children, Young People and Maternity Services – Continence is available to view or download from www.dh.gov.uk/publications

For more information about the National Service Framework for Children, Young People and Maternity go to: www.dh.gov.uk/childrennsf