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New guidance to improve continence care

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- How continence services should be organised

Author Kathy Oxtoby is a freelance health writer.


Guidance to help improve the care and experience of children and adults with continence problems was published by NHS England in November 2015. Excellence in Continence Care provides a framework that enables commissioners to work in collaboration with providers and others to make a step change so that safe, dignified, efficient and effective continence care is consistently provided.

This article looks at the potential impact of continence problems on health, and summarises the guidance on how health professionals can improve the experiences of people with continence needs.

Continence problems are sometimes debilitating, often embarrassing and can be life-changing. They can have a considerable psychological impact and affect personal and sexual relationships, and body image. Physical harm related to complications and treatments for continence problems, such as pressure ulcers, urinary tract infection, catheterisation and faecal impaction can all lead to admission to hospital and care facilities for extended lengths of stay – sometimes permanently.

Problems with the bladder affect more than 14 million people in the UK, and about 6.5 million have bowel problems (Buckley and Lapitan, 2009). In addition, 900,000 children and young people reportedly experience bladder and bowel dysfunction (Hicks et al, 2007). Incontinence is a symptom of an underlying problem that requires investigation, but there is variation in what people can expect when they visit a health professional for help. The Healthcare Quality Improvement Partnership and Royal College of Physicians undertake regular audits on continence care; the latest revealed that, despite the amount of guidance available, the quality of continence care remains variable across the country and poorer overall for older people (Wagg et al, 2010).

An ageing population, the greater prevalence of bladder and bowel problems and the wide range of care groups affected mean continence services need to be given a greater priority in healthcare. Many continence problems can be cured or managed more effectively. Improving continence care provision through integrated services brings many benefits, including:

- A better quality of life and greater independence for patients if solutions can be found that are appropriate to individual needs;
- Less reliance on pads and products can be fostered by finding and using alternative treatments;
- A reduction in admissions to hospitals and care homes;
- Fewer complications, such as urinary tract infections, faecal impaction and skin breakdown (NHS England, 2015a).

New guidance

In November 2015, NHS England published new guidance to help improve the care and experience of children and adults with continence problems. It collates up-to-date evidence-based resources and research to support commissioners and providers of health services (NHS England, 2015a). The guidance also takes into

Continence problems can affect people psychologically as well as physically.

1. Over 14 million people in the UK have bladder problems, and 6.5 million have bowel problems
2. Despite guidance being available, continence care varies in quality
3. An initial continence assessment is best carried out by staff trained in continence care in a community setting
4. People with bladder and bowel problems should be helped to self-manage their condition as the issue can often be resolved
5. People with more complex problems or who have not responded to treatment should be referred to a specialist service
account people’s diverse needs, from assessment, diagnosis and treatment, to recovery where possible.

The purpose of this guidance is to:
» Improve the experiences of people with continence needs;
» Promote consistent practice;
» Drive advances in clinical outcomes;
» Encourage equal access to services and treatment for all;
» Promote greater collaboration between health and social care, through working in partnership with the third sector, including voluntary and charity groups.

NHS England involved patients, public advocates and clinicians to help develop the guidance. By talking to those using continence services about their experiences, the organisation aimed to ensure people would have a greater role in assessing and managing their continence, and in the way services are designed.

The case for action
Effective community-based continence services can save valuable NHS resources while restoring dignity to patients and improving quality of life (All Party Parliamentary Group for Continence Care, 2011).

Establishing “what good looks like” will help all involved to understand services and help health professionals to understand what they should be delivering when it comes to standards and outcomes. The new guidance outlines the measurable principles for continence services commissioned for adults, children and young people (Box 1).

Essential elements of a continence service
Services for adults should ensure that:
» People with continence needs are identified and supported to identify their need for intervention, agree shared goals, ensure they can access the required assessments and treatments, manage their condition as a partner in care and have a good care experience;
» Patients and their family and carers feel they are treated with empathy and respect, are listened to and heard, are involved in decisions about their care, have access to personal budgets where appropriate, receive education and information to protect their health and manage their condition;
» Patients receive a service that is integrated, organised and clear, provides timely access to help, expert assessment and diagnosis, effective treatment and referral to more specialist services where necessary;
» Those with long-term conditions, disabilities and complex needs should be supported to plan their care and treatment, have a point of contact, have an identified care coordinator, have planned care with ongoing support. Services for children and young people (0-19 years) should provide:
» Treatment for all, including those with learning or physical disabilities;
» Community-based care for those with wetting (daytime and bedwetting), constipation and soiling problems;
» Leadership via a paediatric continence nurse specialist, with input from a multidisciplinary team (NHS England, 2015b);
» Effective referral and care pathways to secondary/tertiary care, education, child and adolescent mental health services and social services.

The roles and responsibilities of team members are outlined in Box 2.

Empowering patients
NHS England advises that care needs should be integrated across healthcare, primary and secondary care, as well as care home settings and education settings so patients do not have to repeat often embarrassing stories to each part of the service. For example, parents of a child with wetting and soiling problems often have to travel to different clinics and tell the same story to different professionals. This results in fragmented care for conditions that are interrelated.

As well as improving experience of care, integrated services deliver better clinical outcomes (Wagg et al, 2010). People with bladder and bowel problems should be supported to self-manage their condition as, in many cases, the issue can be completely resolved.

Patient empowerment involves choice, and this may mean they decline a particular treatment option. Empowerment also requires access to information, advice and treatment, and patients having the right to achieve continence whenever this is possible. This helps to improve their quality of life, independence and dignity.

Delivering and receiving care
The NHS England (2015a) guidance states that: “[High-quality professional assessment is the foundation of continence care].”

Many children, young people and adults with continence needs can be cured but, where this is not achievable, a treatment and management plan can improve the quality of life for most. Guidance from the National Institute for Health and Care Excellence states that once “red flags” – warning signs of underlying conditions such as bowel cancer – have been excluded, conservative treatment and care should take place (NICE, 2007).

NHS England recommends that the initial assessment is undertaken by staff trained in continence care, and is best carried out in a community setting where treatments such as dietary advice, bladder retraining and pelvic floor muscle exercises can be offered. Where appropriate, these should be tried before referral to either a specialist continence service or secondary care for more in-depth diagnostics and/or surgical intervention.

First-line medication for continence or constipation can be prescribed in the
primary care setting, which can mean some patients do not need specialist referral. Those with more complex problems or who have not responded to treatment should be referred to a specialist service, for example urology or specialist physiotherapy. This approach ensures patients are assessed by the right professional in the right place at the right time, reducing inappropriate referrals and improving outcomes and experience.

Managing and containing continence

For patients whose condition does not respond to treatment, options to manage continence should be available.

Adults

An assessment to ascertain the need for containment products such as absorbent pads, pants and hand-held urinals should be carried out in the short term. Reassessment at regular intervals is required to ensure not only that products remain fit for purpose but, where possible, patients are enabled to return to standard toileting.

Containment products can offer security and comfort, helping patients to continue with their normal daily activities, thereby improving their quality of life. However, these products are costly, can affect patients’ dignity and do not offer a long-term solution. The guidance advises they should not be offered in the long term unless the patient has not responded to other treatments.

Indwelling urinary catheters can be distressing for patients and are associated with infection that can lead to complications, hospital admission and even death. As such, they should be removed as soon as possible. This is best done within an integrated continence service that can, for example, teach patients intermittent self-catheterisation. The need for other prescription products such as sheaths and faecal collectors must also be reassessed.

Children and young people

Children and young people with a bladder or bowel problem should be assessed by appropriately trained staff so the correct treatment and management programme can be put in place (Hicks et al, 2007). It must be the exception, rather than the rule, that children and young people are provided with containment products.

Case study

Jacqueline Emkes, a teacher based in Bedford, began to have recurring bladder infections following a hysterectomy in 2009. In 2010, she was diagnosed with an obstructed ureter. Two major operations resulted in continued pain and infection, and left her with no sensation in her bladder. She says: “When I developed bladder problems and was given self-catheterisation as a means to manage the problem, it became a huge burden during working hours. I avoided using the catheter in school or public places, which meant I suffered more infections. It took me ages to find out how to get help locally.

“It would help so many people if GPs and nurses had more training and could direct people to the right place, so they could get help quickly.”

In 2013, Ms Emkes met the criteria for a sacral nerve stimulator, which helped stimulate the bladder to empty more completely and meant her need to self-catheterise greatly reduced during the day. She had further bladder reconstruction surgery in 2015 and attended a pain clinic, as back problems and infections left her with almost constant pain. She is now waiting to receive a stimulator in the spine to help reduce her pain.

Ms Emkes says: “My life and that of my family has been greatly affected by my illness. I am left with limited working capacity and feel disappointed to have had to reduce my career. However, I am grateful for the support I have had. My GP, urological surgeons, the nurses, and a specialist bladder and bowel physiotherapist have helped me enormously.”

Conclusion

Increased preventative services, easily available information and advice, and integrated health and social care could have a significant impact on the number of children and adults with continence problems and the severity of the health and social difficulties they experience as a result.

This guidance highlights the need for health professionals to provide the best continence care, and it is vital they ensure patients receive support to manage their bladder and bowel problems. The guidance also has the potential to ensure continence care is consistent across the country. NT

References


