CARE ENGLAND

Representing independent care providers

Challenging Continence non-provision by CCGs: Care England Guidance and Top Tips

This short paper highlights sources of information and advice you can use to support you in discussions with local CCGs, should you be faced with any problems in accessing continence products for your residents or any diminution of supply from CCGs.

Official statements supportive of the NHS responsibility to provide continence products and services for care home residents:

- The Government's *Essence of Care* guidelines published in 2010 state that best practice in this area is a situation in which:

  'People and carers have access to 'needs specific' products and devices to assist in the management of bladder and bowel incontinence'

  It goes on to say that the indicators for best practice are:

  - People's need for continence products and devices are anticipated, and product information and assessment is offered or initiated in a timely fashion
  - People's needs and preferences for continence products and devices are assessed and choices met (as appropriate)
  - People's needs and preferences for continence products and devices are evaluated and reassessed regularly
  - Sufficient time is given to enable people to communicate their needs and preferences
  - Explicit or expressed valid consent is obtained from people prior to treatment or care
  - People have access to expert knowledge and skills
  - Products and devices are adequate, safe and of good quality
  - Use of services is monitored, for example, by regular audit.

- In a letter to Martin Green, Chief Executive of Care England, dated the 8th November 2010, the then Care Minister Paul Burstow said:

  '*It is only right that people should have prompt and effective access to continence products*', before going on to say that '*we expect pads and other continence supplies to be provided in quantities appropriate to the individual's continence needs'.*

- Association of Directors of Adult Social Services (ADASS), former President Richard Jones, wrote to Care England in January 2011 in response to our concern that PCTs (the previous incarnation of CCGs) were stopping the provision of continence products in some areas and said:

'Our understanding is that it is the PCT's responsibility to provide continence supplies to people assessed as in need of them and this applies equally to people at home and in care homes. We would want to encourage people to challenge these developing positions in terms of PCT responsibility for continuing and health related care costs. It also runs counter to evidence which shows that continence problems result in admissions to hospital and incur higher costs down the line. If people are assessed and proper provision is made at an early stage, some of these admissions could be avoided together with the distress, disruption and associated risks that admission to hospital can bring'.

- In a response to a letter from Mumsnet, who were concerned about caps on the number of continence pads being supplied to children, the Prime Minister said in a letter dated 16th August 2010:

  'I would be concerned by any restriction along the lines set out. The best practice guidance, Good Practice in Continence Services, which was issued in 2000 by the Department of Health, recommends assessments by suitably trained individuals for incontinent patients and makes clear that the supply of continence products should reflect the outcomes of this assessment. Where patients are assessed as needing incontinence pads, which includes nappies, the guidance states: Pads should be provided in quantities to the individual's continence needs. Arbitrary ceilings are inappropriate'.

- In her foreword to the All Party Parliamentary Group's report entitled, Cost-Effective Commissioning for Continence Care published in 2011, the Chair of the Group, Baroness Greengross stated:

  'Continence problems can affect any member of the population, young or old. Incontinence can have a profoundly negative impact on a person's quality of life creating isolation, loss of dignity and other health and emotional problems. The wider cost implications of not providing adequate continence care are significant. Patients should be able to expect and receive prompt assessment and care to enable them to carry on living full and active lives. At a time of great change in the NHS we feel it is vital to bring this issue to the attention of all commissioners and policy makers'.

- In a response to an email from Care England dated 9 May 2013 regarding NHS community services charging care homes for continence products, the Department of Health said:

  'We have contacted NHS England, London Region and have made it clear that, in the Department's view, care and nursing home residents have the same rights to receive NHS services as those living in the community. We understand that the continence products are not actually provided to the care and nursing homes, but to the residents of those homes. They are delivered to the homes because that is where the residents live. We also understand those residents are not charged by the homes for the products.

  Were those residents living in their own homes in the community, they would be entitled to receive NHS services (including materials/disposable items, such as dressings, continence products, etc.) free at point of delivery. The fact that those residents live in care homes does not in any way remove or alter their rights to receive such services. Where a trust is providing free continence products to patients who live in the community, it cannot charge those who live in care homes for the equivalent products'.

- In the Department of Health publication, *Transforming Primary Care*, published in April 2014, the DH when talking about primary care services, say:

  'Ultimately, people want to know that they have access to high quality services at all times. For example, people should expect the same standards from NHS services and providers regardless of whether they are in their own home or in a care home'.

- On the NHS Choices website, people who are incontinent are advised that they would be able to receive treatment on the NHS should they receive an assessment stating that they are. The relevant sections says:

  'Your GP can assess whether you have incontinence, decide which type of incontinence you have, give general advice on controlling symptoms of incontinence, provide information on pelvic floor exercises and bladder retraining, and give treatment for incontinence with prescribed medicines.

  If lifestyle changes and treatments don't solve the problem, your GP can refer you to a continence adviser or specialist'.

- In June 2014, after we forwarded a letter from Norfolk NHS Trust on to the Department of Health, which was sent to one of our members, the Department replied, stating:

  'Care and nursing home residents, whether publicly supported or self-funding, have exactly the same rights to receive NHS treatment free at point of delivery as those living in their own homes or in the community. If the NHS is providing continence supplies to patients who live in their own homes, it should not deny the same service to those who are resident in care and nursing homes. It is the Department's understanding that continence products are not supplied to care and nursing homes themselves, but to the residents of those homes. The products are sent to homes, rather than to individual residents, because that is where residents actually live'.

Guidance and other evidence that we suggested you use in contest with your CCG:

- Obtain a copy (Care England can signpost you to this) of LAC 2001 (26), which describes the NHS responsibility for funding nursing care in care homes. Paragraph 50 says with effect from 1st October 2001 continence products should be made available by the NHS to residents of nursing homes who are also receiving NHS Funded Nursing Care", and refer your PCT to this document.

  http://webarchive.nationalarchives.gov.uk/20130107105354/http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/documents/digitalasset/dh_4012619.pdf

- Obtain a copy (Care England can signpost you to this) of Department of Health FNC Guidance LAC 2003 (7), 12 March 2003. This Department of Health Guidance on NHS Funded Nursing Care, under the heading 'EQUIPMENT AND CONTINENCE', section 3.1, states that:

  "Apart from nursing care, the NHS also becomes responsible for the supply of continence aids for all care home residents from April 2003."

- In addition, the Funded Nursing Care Practice Guide says in paragraphs 50 and 51:

  50 –'residents of care homes, including those providing nursing care, should have access to professional advice about the promotion of continence.'
  51- 'As well as prevention and advice services, the continence service should also include the provision of continence products, subject to a full assessment of an individual's needs. Continence products or payments should be made available by the NHS to care homes for residents who are also receiving NHS –funded nursing care, if required.'

  http://webarchive.nationalarchives.gov.uk/20130107105354/http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/documents/digitalasset/dh_106225.pdf

- Obtain a copy of the document published on 19th April 2000 entitled 'Good Practice in Continence Services', PL/CMO/2000/2 see www.dh.gov.uk

- Refer your CCG to the Age UK Fact Sheet FS1O, which says that the NHS should be providing continence products free of charge, section 13.5. says:

  'The NHS is responsible for providing continence services to residents in homes providing nursing care and for meeting the cost of any continence supplies (such as continence pads) that those residents are assessed as requiring, including any equipment needed.

  Community health services such as continence supplies and district nursing should be provided to residents of care homes that do not provide nursing care using the same criteria as for people living in their own homes'.

  http://www.ageuk.org.uk/Documents/EN-GB/Factsheets/FS10_Paying_for_permanent_residential_care_fcs.pdf?dtrk=true

- Refer to Age UK factsheet 23 which states in paragraph 3.1

  'If after an assessment it is agreed that pads or other products are necessary to manage your condition, they should be available from the NHS. What is available varies, as each area has its own eligibility criteria and contract to supply products including pads'.

  http://www.ageuk.org.uk/documents/en-gb/factsheets/fs23_help_with_continence_fcs.pdf?dtrk=true

- From the Age UK leaflet ' Managing Incontinence' the following paragraph has been extracted;

  'If problems develop while you're in a care home, the cause should be identified by your GP or district nurse and a treatment plan added to your care plan.

  If you're eligible for continence products, a supply should be arranged for you and you should not have to pay for them…'

  http://www.ageuk.org.uk/Documents/EN-GB/Information-guides/AgeUKIG15_Managing_incontinence.inf.pdf?dtrk=true

- Check that the CCG is following NICE guidelines for clinical treatment of incontinence:

  'Lower urinary tract symptoms: The management of lower urinary tract symptoms in men' May 2010

  http://www.nice.org.uk/guidance/CG97

  'Urinary incontinence: The management of urinary incontinence in women' October 2006
  http://www.nice.org.uk/guidance/cg40

  'Faecal incontinence: the management of faecal incontinence in adults' June 2007
  http://www.nice.org.uk/guidance/CG49

  The guidelines do refer to what products could be provided (and at what point in the individual's care pathway etc).

- The National Service Framework for Older People 2001 refers to the subject and Standard 2: Person-centred care says;

  'NHS and social care services treat older people as individuals and enable them to make choices about their own care. This is achieved through the single assessment process, integrated commissioning arrangements and integrated provision of services, including community equipment and continence services'.

  http://webarchive.nationalarchives.gov.uk/20130107105354/http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/documents/digitalasset/dh_4071283.pdf

- There is an All Party Parliamentary Group for Continence Care chaired by Baroness Greengross and details about the group can be found at the following link:

  http://www.appgcontinence.org.uk/

  The APPG has produced guidance called 'Cost-effective Commissioning for Continence Care' which you might well choose to send to your CCG. This guide shows the impact that good commissioning practice can have on people's lives and outcomes. The guidance states that:

  'High quality integrated continence services should include: … Effective and safe provision of care in a range of settings e.g. patient's home, care home, community clinic or hospital.' (p.10)

  The guidance advises CCGs to plan ahead to manage demand for continence products, which may be useful for care providers in stating why CCGs do not have an excuse to not provide continence aids:

  "In managing the demand for continence services it is important to take note of factors which can affect demand such as:
  - *An ageing population*
  - *The opening of new-build, large care homes who will require a steady supply of expertise and products."*

- The circular LAC (DH) (2011)1 makes the following reference to the Personal Expenses Allowance (PEA).

  'The PEA is intended to allow residents to have monies for personal use. Councils, providers of accommodation and residents are again reminded that the PEA should not need to be spent on aspects of board, lodging and care that have been contracted for by the council and/or assessed as necessary to meet individuals' needs by the council or the NHS. Councils should therefore ensure that an individual resident's need for continence or chiropody is fully reflected in their care plan'.

  http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/documents/digitalasset/dh_123875.pdf

- Inform Care England if you believe residents in care homes are being treated differently regarding the supply of continence products to those people living in their own homes. Care England will follow this up with the DH.

- Ascertain from your CCG if adults and children are being treated differently and present the case for possible discrimination to the Equality and Human Rights Commission. http://www.equalityhumanrights.com

- To meet the requirements of the Equality Act 2010 advice has been produced for the NHS entitled 'Achieving age equality in health and social care – NHS Practice guide May 2010'. Chapter 13 looks at continence services and says;

  "Making continence services a priority and ensuring that an integrated continence service is in place would be an effective means by which local health organisations could demonstrate their commitment to age equality."

  It goes on to suggest a number of quick wins which include:

  "Review policies in rationing of continence pads in community, hospital and residential care settings."

  http://age-equality.southwest.nhs.uk/downloads/guides/age-equality-nhs-practice-guide-ALL-chapters.pdf

- The Royal College of Physicians conducted a National Audit of Continence Care, published in September 2010:

  https://www.rcplondon.ac.uk/resources/national-audit-continence-care

  This was commissioned by The Healthcare Quality Improvement Partnership. Some of their headline findings include:

  - The great majority of continence services are poorly integrated across acute, medical, surgical, primary, care home and community settings, resulting in disjointed care for patients and carers
  - Healthcare professionals are not consistently providing assessment, diagnosis and follow-through according to standard practice or

- Making care plans to achieve treatment goals and sharing these with patients and (where relevant) carers
- Quality of care (assessment, diagnosis and treatment) is worse in older people (patients aged 65 years and over as compared with those aged <65).

Their overall finding is that, *"People of all ages, and vulnerable groups in particular (frail older people, younger people with learning disability) continue to suffer unnecessarily and often in silence, with a 'life sentence' of bladder and/or bowel incontinence."*

- Essence of Care (2010) has benchmarks to support good practice in continence services

  http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/@ps/documents/digitalasset/dh_119971.pdf

- Consider how you might work with local charities representing users of services

- Consider asking local Dignity Champions to support you in ensuring residents get the service and supplies necessary to meet their assessed needs.

- The Royal College of Physicians has a booklet, 'Continence care – Keeping control.' This is aimed at improving continence care by providing information on the services people should expect from the NHS bladder and bowel service. Using plain language, developed in consultation with continence service users, the booklet details best practice in diagnosis, management, information provision and support, and what to do if the service does not meet these standards. The booklet will help people overcome the potential embarrassment of discussing continence care with healthcare staff, particularly when someone is attending or receiving a service for the first time and is not sure what to expect. Care homes may also find the information helpful. The booklet is available for download at:

  http://www.rcplondon.ac.uk/continencebooklet

- Consider contacting your local Healthwatch with a list of the official statements printed above to ensure that CCGs do not charge for services that should be provided on the NHS.

- Refer to this guidance: 'Excellence in continence care: Practical guidance for commissioners, providers, health and social care staff and information for the public', published on the 16 November 2015 by NHS England: https://www.england.nhs.uk/commissioning/wp-content/uploads/sites/12/2015/11/EICC-guidance-final-document.pdf. This guidance states that:

  "NHS England is publishing this guidance to help support best practice in continence care, promoting equal access to services and treatment for all. It is applicable to all children, young people, adults and the elderly, taking into account their diverse needs from assessment, diagnosis and treatment to recovery where possible. The purpose is to promote consistent practice, improve the experiences of people with continence needs drive advances in clinical outcomes and reduce health inequalities."

  "The groups of who is at most risk of continence problems are identified and a picture of 'what good looks like' is given to help people understand what a continence service should be delivering with regard to standards and outcomes."

"Robert Francis referred to continence as 'this most basic of needs,' his report highlighting significant concerns in this area of care (Department of Health, 2010). In the 'Hard Truths' report, the Government made a commitment to ensure that the fundamental standards of care that people have a right to expect are met consistently, whatever the setting (Department of Health, 2013.)"

"Regular audits by the Healthcare Quality Improvement Partnership (HQIP), the latest in 2010, show that despite the amount of guidance available, the quality of continence care remains variable across the country and poorer overall for the elderly."

- Care England, in 2015-16, sent out a series of Freedom of Information Requests to all CCGs, asking about their approach to the provision of continence aids to care home residents. The responses showed complete variability and widespread misunderstanding or their responsibilities. Our report on this information and individual responses from different CCGs is available on the members' section of our website, under 'FOI Requests and Responses' and then 'Continence FOI Request'. Please access this area, and use the information here for your own purposes.

  On the back of this information, in February/March 2016 Care England tabled a series of Parliamentary Questions about the responsibilities of CCGs in paying for continence aids to achieve final clarification on this issue. The results of these will be a Care England-initiated meeting of the Continence APPG (mentioned above). The results of our PQs and the notes of this APPG meeting, with evidence from across the sector, will also be available in this area of the members' section of the website.

- In March 2016, Care England received a response from the PQ to clarify the responsibility for continence funding and provision. After some confusion at the Department of Health, Lord Prior of Brampton confirmed that:

Correction:

Lord Prior of Brampton:

"The legislation under which NHS England and clinical commissioning groups (CCGs) commission services requires them to arrange for the provision of services for which they are responsible, to such extent as they consider necessary to meet all reasonable requirements.

For CCGs, this includes offering continence services as part of their obligation to provide community health. Although CCGs often focus on prevention and treatment, it is expected any standard continence service should include access to products. The criteria for the provisioning of continence products are set by individual CCGs To support CCGs, NHS England has recently published new guidance to help improve the care and experience of children and adults with continence issues. This encourages much greater collaboration between health and social care."

A copy of the guidance Excellence in continence care was attached.

- In Spring 2016, Ann Mackay MBE, Director of Policy at Care England, wrote to Jane Cummings, Chief Nursing Officer for England about the issue of continence aids non-provision. In June 2016, Jane Cummings replied:

  "We recognise that there will always be people including some people in care homes who have a need for a containment product and in these circumstances we would expect CCGs to have commissioned this…

  … In terms of how we are checking that CCGs are using the Commissioning Framework for Continence Services Excellence in Continence Care, there are several approaches here:

  • We are arranging for CCGs to have access to teams of expert clinicians, commissioners from areas we know have adopted the guidelines and people with lived experience to review their existing service against the best practice outlined in the guideline and make appropriate improvements.

  • We are exploring the potential for a mandatory data set to provide transparency about the continence service CCGs are commissioning.

  • The CCG assurance process enables NHS England to check how CCGs are meeting the health needs of their population and if you know of particular CCGs who are not commissioning continence supplies to people in care homes, please let us know which CCGs these are and we will use the assurance process to follow this up.

  • We continue to encourage CCGs to develop integrated commissioning arrangements with Local Authorities to ensure improved co-ordination, experience and use of resources.

  • We have an ongoing communication and education campaign to raise awareness about the Commissioning Framework for Continence Services.
  I hope this letter reassures you that the matters you have raised are important to us and the actions we are taking to ensure all people including those in care homes have their continence needs met."

- Care England replied to Jane Cummings, asking to see, and hopefully contribute to, the mentioned additional best practice guidance, and providing a list of offending CCGs for her to follow up through the CCG assurance process. Care England also asked her to re-affirm the message that CCGs should be providing, or reimbursing care providers at a fair and true rate for, continence aids. We have asked if she can assure this through the NHS bulletin. We await her response (27/06/2016).

- On 20 July 2016 Richard Fuller MP (Con) Bedford asked what steps the DH was taking to improve education and training for health and care staff on continence and toilet support. In response David Mowat MP, Parliamentary Under-Secretary of State at DH, said that " NHE England's Excellence in Continence Care guidance, published in November 2015, provides a framework that enables commissioners to work in collaboration with providers and others to make a step change to address shortfalls so that safe, dignified, efficient and effective continence care is consistently provided. This guidance is aimed at commissioners, providers,

health and social care staff and also provides information for the public. The guidance was produced in partnership with patient and public advocates, clinicians and partners from the third sector. A copy of the guidance can be found at the following link: www.england.nhs.uk/commissioning/wp-content/uploads/sites/12/2015/11/EICC-guidance-final-document.pdf

- In addition, the National Institute for Health and Care Excellence has produced a range of guidance for clinicians to support them in the diagnosis, treatment care and support of people with continence problems e.g. Urinary incontinence in women (September 2013), Faecal incontinence in adults (June 2007), Urinary incontinence in neurological disease: assessment and management (August 2012) and Lower urinary tract symptoms in men: management (May 2010).

- The Royal College of Nursing's *Continence care in care homes: A framework to gather and share key information.* The framework is designed to help staff to develop a continence care plan, by asking the right questions.

  Access here:
  file:///C:/Users/goldmans/Downloads/PUB-003139.pdf

  This framework consists of four sections:

  - A list of key questions to ask (gather information) about the resident's bladder and bowel control. Examples of different aspects to explore.
  - Documentation to record this information
  - Documentation to plan and review continence care for the individual resident in a format linked to the key questions
  - Brief information on the different aspects of continence care to enable you to provide good quality continence care in the form of "top tips".
  - This format allows all information to be recorded in a standardised way and stored together for easy

- Alistair Burt MP also wrote to Care England on 21 June 2016, stating the below:

NHS England, working with clinicians, third sector organisations and people with lived experience of incontinence published the commissioning framework for continence services, *Excellence in Continence Care*, in November. The framework outlines good practice for assessment, diagnosis and treatment, and sets out a number of principles for how services should be designed to take into account the needs of people with incontinence. These include integration across primary, secondary and tertiary services, health, education and social care settings. NHS England is overseeing an ongoing communication and education campaign to raise awareness about the framework.

In addition, separate groups of specialist nurses for adults and children are preparing guidelines on commissioning continence products, which NHS England's *Excellence in Continence Care* Board will consider for endorsement in due course.

There are many people in care homes who require a containment product and NHS England expects clinical commissioning groups (CCGs) to meet the needs of these people. It holds CCGs to account in providing these services in several ways. It is arranging for CCGs to review their existing services with the help of teams of expert clinicians, commissioners from areas that have successfully adopted the *Excellence in Continence Care* guidelines and people with lived experience of incontinence in order to make appropriate improvements.

It is also considering how a mandatory data set could be used to make clearer the information available about the continence services that CCGs commission.

The CCG assurance process enables NHS England to check whether CCGs are meeting the health needs of their populations. Anyone with concerns about the services commissioned by a particular CCG can raise these direct with NHS England, which can investigate the matter.

NHS England continues to encourage CCGs to develop integrated commissioning arrangements with local authorities to improve the experiences of people using health and social care services.

I hope this reply is helpful.

Care England
21 July 2016
For further information contact:
Ann Mackay, Director of Policy
amackay@careengland.org.uk