

## Incontinence - 5 September 2017

*Motion made, and Question proposed,* That this House do now adjourn.—(Stuart Andrew.)  
9.05 pm

### **Mrs Madeline Moon (Bridgend Lab)**

Incontinence is not an issue that is often discussed in the Chamber. Society sees the condition as a taboo, which is hidden from public view while sufferers cope in private. However, an estimated 14 million people in all age groups will, at some point in their lives, experience a problem with bladder dysfunction. A further 6.5 million will have bowel dysfunction.

It is generally assumed that incontinence is a condition that affects older people, but that is only half the story. The National Childbirth Trust estimates that almost half of all women experience urinary incontinence after childbirth; there are around 700,000 births a year, so as many as 350,000 women could face this problem. NHS figures suggest as many as 900,000 children and young people experience some form of problem.

More than 300,000 people are diagnosed with ulcerative colitis and Crohn's, otherwise known as inflammatory bowel disease, and the most common age for diagnosis is between 18 and 30. Those conditions affect the digestive system to different degrees, but one in 10 people will experience regular incontinence. A 2012 survey by Crohn's and Colitis UK found that 61% of people had not sought medical advice for the incontinence. Like all other conditions that have associated problems with incontinence, that leads to social isolation. Crohn's and Colitis UK surveyed 1,000 young people on their experience, and 75% said that their condition made socialising impossible because of always needing to know of the proximity to a toilet. On a very simple level, given how many local authorities are closing access to public toilets, is it not time that we looked at alternatives? It is surely not beyond our wit in this House to look at issues such as rate relief, so that hotels, restaurants, pubs and cafes provide access to their toilets for those who urgently need to have that.

### **Melanie Onn (Great Grimsby Lab)**

I draw the House's attention to my entry in the Register of Members' Financial Interests. Does my hon. Friend agree that businesses with a high footfall could do an awful lot more to support their customers' needs in respect of incontinence issues, and consider additional aids such as the Crohn's and Colitis UK "Can't Wait" card—a facility to enable individuals who suffer from incontinence issues to access the toilet facilities of businesses that would not ordinarily allow people to use them, but which support their customers as and when they might need it, to avoid any emergency situations?

### **Mrs Madeline Moon (Bridgend Lab)**

I thank my hon. Friend for her work in this area. That most certainly would help, and it is so simple; it is not a huge thing to do. Another example is simply having a shelf in toilets where someone with a colostomy or ileostomy can place the clean bag, so it is readily available while they remove the full bag. That would make things so much easier and healthier, by ensuring there is no cross-infection. Instead, people often have to scrabble on dirty toilet floors, trying to access what they need.

All the figures I have to hand today are estimates—as one patient group pointed out to me, the collection of statistics in this field is patchy at best, and putting a true figure on the scale of the problem is very difficult—but we will not tackle taboos until we start talking about them: we must destigmatise the subject so that no one faces humiliation if they admit to a problem. We need to bring this issue out into the open once and for all, so that people no longer suffer in silence and we can reduce the long-term health implications and additional costs for the NHS.

An analysis of calls to the Bladder and Bowel Foundation's helpline in 2015 suggested that half the people with a continence problem had never spoken to a healthcare professional. Another study found that only one in three families seek help for children and young people with a continence problem. Imagine the long-term impact on a child's health of having to try to manage such a problem at school, with all the stigma of being the smelly kid and all the fear of having an accident during a lesson.

### **Jim Shannon (Strangford DUP)**

I congratulate the hon. Lady on bringing this subject forward; it needs to be aired and she is doing that very well today. I thank her for that. Does she agree that young people suffering from ulcerative colitis, Crohn's disease and other inflammatory bowel diseases need more help and support to deal with the lifestyle changes that these illnesses can bring? The latest statistics show that 75% of those young people say that they cannot have an active social life because of their condition, and I believe that restaurants, shops and councils have a responsibility to do more to help them to lead as normal a life as possible.

### **Mrs Madeline Moon (Bridgend Lab)**

I would ask every Member to consider the impact on their life of suddenly having a desperate, urgent need to access a toilet while at work or walking down the street, and there not being one available. Of course we must do more; no one can assume that incontinence is not coming their way or coming to a member of their family. As a society, we have to take responsibility for ensuring that people can access toilet facilities wherever they are and whenever they need them.

### **Dr David Drew (Stroud Lab/Co-op)**

My hon. Friend is making a compelling case. She will be aware of ERIC—Education and Resources for Improving Childhood Continence—which has campaigned for many years for better availability of continence pads. These are still charged for at very high rates. If every school were to provide continence pads, a lot of children would have a much better experience at school.

### **Mrs Madeline Moon (Bridgend Lab)**

I thank my hon. Friend for that intervention. In particular, we should look at the need for teachers to understand the issue of incontinence. They need to understand that a child who constantly puts their hand up and says that they need to go to the toilet is not trying to get out of the lesson, and that it is perhaps an indication of a deep-seated problem that needs to be tackled. There is certainly a need to educate and build awareness of continence problems in schools. This relates to the little ones coming into the reception class—some of whom, increasingly and shockingly, have not been potty-trained and not learned to control their bowels and bladder—and as the problem continues throughout the school. Schools need to step in and ensure that parents and children have access to the help and advice that they need.

People should have the confidence to talk about the problem to GPs and to seek an early diagnosis and intervention. People should not have to assume that it is something they have to live with. It is estimated that people manage the problem themselves for an average of five years before seeking help. We also need to highlight the detrimental impact that incontinence can have on an individual, and the fact that existing policy responses exacerbate the situation. This is a quality-of-life issue. It affects sleep and mental wellbeing, and it can cause isolation. For a child, it can have a long-term impact on their self-esteem and on family relationships, and it often makes them vulnerable to bullying.

Access to toilets can become a determining factor in every journey and activity away from the home. The condition can also lead to more complex health problems, which are inevitably more expensive to treat, and some people even choose residential care so that they can have management of their problem. One specialist in the field summed the situation up by saying:

“The reality is that bladder and bowel continence needs can affect anyone at any age. It can reduce a person’s enjoyment of life, ability to live an independent life, reduce education and work opportunities and lead to further medical complications.”

Patient surveys have highlighted the limitations imposed on people’s lives by their conditions. For sufferers who responded to a survey, those restrictions and sleep deprivation were the worst aspects, with 93% saying that it had affected their mood, 63% saying that it had affected their ability to work, and 39% saying that it had forced them to take time off work. Frustratingly, there are solutions for many, but people all too frequently struggle to cope on their own, using incontinence products available in local chemists rather than seeking the help that could be available from the NHS.

### **Rosie Cooper (West Lancashire Lab)**

It is really important to note that people who rely on getting pads and looking after themselves are not getting the best service, and doctors and nurses are sadly not receiving training in this most important area. Shockingly, the pre-registration nurse curriculum does not include training for bladder or bowel incontinence, so it is all too easy not to address the real problem. We need that experience to help people; we should not just pad them up. People can be helped with exercise, for example, and there are many interventions that could help instead of them being told simply, “Go and buy a pad.”

### **Mrs Madeline Moon (Bridgend Lab)**

I commend my hon. Friend’s work for the all-party parliamentary group on continence care, which does invaluable work in this area.

I am going to jump to another section of my speech. It is shocking how many people go into hospital with no continence problems but may be incontinent or doubly incontinent and have major problems by the time they leave. It is far too easy for nurses and doctors to see the use of pads as the only solution. At some point, I hope the Minister will look at how we can gather figures from hospitals on how many patients enter with continence problems and how many leave with continence problems to get some idea of how great the problem is.

I chair the all-party parliamentary group on Parkinson’s, and the Minister will be aware that Parkinson’s UK has campaigned for many years due to the problems that people with Parkinson’s have when they go into hospital and their carefully timed medication regime is changed to fit in with drugs rounds on the ward. A perfectly mobile and continent person can

become immobile and incontinent due to NHS failure. That cannot be allowed to carry on. It is shameful that we are facing such problems in 2017.

Diagnoses are not made in a huge number of cases. Healthcare professionals do not provide consistent assessments, diagnosis and follow-through according to standard practice. Even basic things, such as an assessments of where the toilet is in relation to where someone sleeps, are not carried out by social workers. I cannot begin to tell the House how many times people are admitted to hospital as the result of a fall at night caused by them trying to negotiate the stairs to go up or down to a toilet that is on a different level from where they sleep. It is shocking that people face having to wear an incontinence pad because they cannot use the stairs or because there is a risk of them falling at night when accessing the toilet. We simply must get this sorted out.

Incontinence can cause additional problems. Urinary tract infections, pressure sores, anxiety, depression and falls cost the NHS a great deal of money, and we could save money by making relatively simple changes. I have not been able to find any comprehensive analysis of the cost to the NHS and other services that would demonstrate potential savings from early interventions. As far as I am aware, such an assessment has not been carried out. A series of parliamentary questions tabled last year revealed that data are not held by the Department of Health on the number of people admitted to hospital for catheter-associated urinary tract infections, for non-catheter-associated urinary tract infections or with urinary incontinence generally. If it existed, such information would help to clarify the extent of the problem. An estimate was offered in 2014-15, with NHS trusts reporting an annual cost of £27.6 million, which is almost certainly an underestimate.

Too many individuals are bearing the brunt of managing their condition. Buying a regular supply of pads costs anywhere between 10p a pad, for a child, and 60p a pad, depending on the type of pad required.

### **Melanie Onn (Great Grimsby Lab)**

My hon. Friend is being generous with her time. Does she think that now is the time for the Government to reconsider the VAT on these products?

### **Mrs Madeline Moon (Bridgend Lab)**

We need to reconsider the issue of VAT on a whole range of sanitary and continence products. As a society, we need to take responsibility for the facts of our daily life. For a person on any sort of restricted income, such as those on benefits, the costs even of simple laundry are huge when dealing with incontinence.

Some families are spending up to £100 a week buying incontinence products. It is ludicrous if they are not able to access those products through the health service or joint stores with local authorities. It is a postcode lottery whether or not a person can access the help and support they need, which is shocking. Think of the savings in sickness pay, in hours of work lost and in mental health and wellbeing if we started to tackle this problem.

It is time to raise a number of issues, including what happens when things go wrong.

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## **Jim Shannon (Strangford DUP)**

The hon. Lady has referred to people being caught short and, from my knowledge of people who have come to me with their problems, there is a lack of understanding from employers towards employees who have these problems, with people losing their jobs. Does she agree with me and other Members that there has to be a better understanding from employers of employees who have this problem?

## **Mrs Madeline Moon (Bridgend Lab)**

I recently had a meeting with employers in Bridgend, and the chief executive of CGI was present. That company is proactive in asking its employees what problems they have so that it can support, rather than punish, when those problems affect people's working situation. People with incontinence should feel confident that they will not lose their job if they say, "Actually, I have this problem. I am going to have to go to the toilet." Shockingly, I found another employer in my constituency that was deducting from employees' wages every time they left the floor to go to the toilet because it was time away from their telephone response service. Yes, we need to consider the whole issue of employment practice in relation to incontinence.

Between 2007 and 2015, 92,000 women in England are thought to have had vaginal mesh implants as a treatment for incontinence. As many as one in 15 women have gone on to have those removed because of complications. The individual testimonies of those affected are dreadful, and while dealing with the wider issue of incontinence we must not forget their plight. I commend the work of my hon. Friend the Member for Pontypridd (Owen Smith), who has brought this issue to the attention of the House, but it is also important that the Government carry out a full audit, establish a registry to determine how many women have been affected, suspend this treatment and look at how we can make sure that the damage and destruction of people's lives does not continue.

I know you have been generous with our time, Madam Deputy Speaker, as the House has concluded its other business so early, but I hope that the need for action on this has become obvious. First and foremost, we need to work collectively to raise the profile of incontinence as a public health issue, not as a personal failing—that is how it is seen. If I have an incontinence problem, it is seen not as my having a medical problem but as there being something wrong with me. That view needs to be turned around. People need to be able to talk to their GP. If we go into any pharmacy, we see a sign saying, "If you've got a cough and it persists, see your GP." There are signs saying, "If your mole is changing size, talk to your GP." We need to have something that says, "Suffering incontinence? Well don't suffer in silence, talk to your GP. You will be able to access help and support." We need to stop assuming that this is something that affects older people and to engage schools in understanding how it affects young people. We need to educate young people on bowel and bladder health. Why on earth do we not talk about this? Are we really so hung up that we cannot talk to young people about the fact that at some point in their life they may have a problem, tell them what they do about it and say what sort of help they can get?

Will the Minister give us an idea of what his Department plans to do to tackle the huge hidden problem of incontinence in this country? Will he agree to talk to the devolved Administrations so that we do not just set something up for England, but we all take responsibility for this? I am sure that the hon. Member for Strangford (Jim Shannon) and my hon. Friend the Member for Newport East (Jessica Morden) would agree that we must get this sorted once and for all.

When people seek help they need to feel that health professionals will be equipped to help them. It is also important that doctors are trained in this; it needs to be part of the core training

of all nurses and doctors. It should also be there for those who are training to be nursery nurses. We need to build that conversation and to do it soon. It is important that the General Medical Council takes responsibility for moving this forward. I am aware that in England the NHS published "Excellence in continence care" in November 2015, which sought to define what best practice should be and to make recommendations. The document was very welcome, but implementation has been slow. The executive summary even commented on that, saying:

"Over the years, some excellent research and guidelines have been produced for best practice continence care but this work has often stalled as it has not translated into a clear commissioning plan for a local continence pathway."

Will the Minister ensure that every local authority and every health authority has to have a clear continence pathway? That is not a big ask; they should be doing it already. Can we make sure that such pathways are now in place?

Continence services in the UK vary in quantity and availability, with a report in 2010 concluding that patients were faced with a "life sentence" of suffering due to non-existent or poor diagnosis, a lack of treatment plans and poorly co-ordinated care. Earlier this year, a Paediatric Continence Forum audit established that only 41% of clinical commissioning groups and health boards provide all four main continence services and product provision. That is absolutely shocking.

I hope I have convinced the Minister that he should take the opportunity to make a change in the quality of life for far too many people in this country. This is a problem area that we have neglected for too long.

9.30 pm

### **The Parliamentary Under-Secretary of State for Health (Steve Brine)**

I congratulate the hon. Member for Bridgend (Mrs Moon) on securing this debate. I completely agree that incontinence is a public health issue. I am the public health Minister, so it is appropriate that I am responding to the debate.

It is important that I reiterate some of the hon. Lady's points from the Government Dispatch Box. Incontinence is absolutely an issue with which too many suffer in silence, and we all need to learn to speak more openly and honestly about it. Think of the subjects that the House of Commons has discussed today, on its first day back after recess: it is incredible what the House can achieve and bring to public consciousness. The hon. Lady has certainly added to that today. By talking about incontinence, we draw back the veil and encourage others to come forward for assessment. I hope that somebody is watching or listening to this at home and decides that they are going to take the first step and ring their GP tomorrow morning, without shame or embarrassment.

As the hon. Lady said, there are 14 million adults in the UK with bladder-control problems and 6.5 million with bowel-control problems. She is absolutely right to point out that this is not just an older person's problem: it reaches across the sexes and across the generations. Incontinence has been touched on in previous debates—the hon. Lady has raised it in the House this year—but I am told that there has been no dedicated Commons debate on it since 2004, so it is now high time for one.

All continence problems can be debilitating and life-changing. They affect a wide range of care groups and can be a particular concern for the ageing population—although, as both the

hon. Lady and I have said, not exclusively. As the hon. Lady said, incontinence is not just a physical problem; it can be, and very often is, psychologically distressing. When continence care and support is done well, it makes an enormous positive difference to patients' lives.

As the hon. Lady acknowledged, some of the issues she raised go much wider than the brief of a mere health Minister, but I shall touch on some of the other points she made, as well as those for which I am directly responsible. We absolutely do need to develop the workforce of health professionals so that they are more informed and educated about continence issues across the board and are able to support and care for individuals in a safe, effective and dignified manner. We need to measure people's health outcomes robustly—without measurement it is hard to take action—to make sure that services continue to improve and that we can provide the best care possible.

A good-quality, patient-focused service begins with getting the specification and commissioning right from the outset. For services in England, NHS England published its commissioning framework for continence services, "Excellence in Continence Care," in 2015 to help to achieve this. Working with clinicians, third sector organisations and people living with the condition, NHS England brought together the most up-to-date evidence-based resources and research to support commissioners, health providers and professionals to make real and lasting changes to raise the standards of continence care. As well as outlining an individual's pathway from assessment to treatment and recovery when possible, the guidance advocates integration across primary, secondary and tertiary services, as well as across health, education—as mentioned by several Opposition Members—and social care. It is designed to ensure that commissioners work in collaboration with providers and others so that safe, informed, dignified—a key word—efficient and effective continence care is consistently provided to patients.

### **Dr David Drew (Stroud Lab/Co-op)**

The Minister will have heard my earlier intervention. Will he and his colleagues in the Department for Education commit to write to each school to make sure that they have an incontinence strategy? In particular—it is just a simple thing—they should provide incontinence pads for children who suffer from this terrible condition.

### **The Parliamentary Under-Secretary of State for Health (Steve Brine)**

Clearly, it is not my place to promise work tasks for Education Ministers, let alone other Health Ministers, but they will have heard what the hon. Gentleman said. I have a feeling that he will be following this matter up, no doubt through the all-party group. The chair of that group, the hon. Member for West Lancashire (Rosie Cooper), is sitting but two rows in front of him.

As well as outlining an individual's pathway from assessment to treatment and recovery when possible, the guidance advocates integration across the different areas. Strengthening the workforce's knowledge is absolutely key. In England, continence care and the importance of this issue to the comfort of patients is already an important part of the basic training offered to a wide range of clinicians and care workers and is part of the Nursing and Midwifery Council's training curriculum.

The commissioning guidance builds on that by setting out the minimum standards required along with the specific roles and responsibilities for every member of a patient's continence

team including the individuals themselves, their family—very important—and carers. It is important to acknowledge that, following assessment and with the right advice, self-management of a condition can improve outcomes considerably.

There will always be people, including some in care homes, who have a need for aids. A group of specialist nurses for adults and another group for children are currently preparing some consensus guidelines on commissioning continence products, which in due course the Excellence in Continence Care board will consider for endorsement as a supplement to the framework. Of course we need to make sure that commissioners are following the framework, and NHS England is taking several approaches to tackle this. Let me touch on a few of them.

### **Rosie Cooper (West Lancashire Lab)**

The Minister's comments are very welcome, but what pressure can he really apply to get clinical commissioning groups to implement NHSE's guidance and to get the GMC, the Nursing and Midwifery Council and medical schools to include training in continence? If we can get that right, those facilities will be there when people say that they have the problem. Then we will get the clinical intervention, not just the costly pads in response.

### **The Parliamentary Under-Secretary of State for Health (Steve Brine)**

I thank the hon. Lady for her intervention. I will take it away with me, and I will come on to the point about the CCGs.

I was just about to outline the approaches that NHS England wants to take to ensure that commissioners are following the framework. They include arranging for CCGs to have access to teams of expert clinicians, commissioners from areas that have adopted the guidelines and are following best practice, and people with lived experience to review their existing service against the best practice and make appropriate improvements. NHS England is also exploring the potential for a mandatory data set to provide transparency about the continence services being commissioned and encouraging CCGs to develop integrated commissioning arrangements to improve co-ordination, experience and use of resources. That is all very positive.

In addition, the National Institute for Health and Care Excellence—or should I say NICE as I am now getting to grips with all the acronyms—has produced a range of guidance for clinicians to support them in the diagnosis, treatment, care and support of people with continence problems, including the 2015 quality standards for urinary tract infection in adults, which sets out how treatment must be holistic in nature.

I understand that the Under-Secretary of State for Health, my hon. Friend the Member for Thurrock (Jackie Doyle-Price), recently replied to the hon. Member for Bridgend on the issue of paediatric continence data and the risk of losing the National Child and Maternal Health Intelligence Network, which provides a valuable data resource. Let me take the opportunity to reassure her that the ChiMat legacy website can still be accessed. Paediatric continence is a very important issue. I understand that Public Health England is grateful to the Paediatric Continence Forum for its productive collaboration over the years and that it wishes this relationship to continue. It has agreed that if PHE's infrastructure remains the best place within the health system to enable these reports and to make these data available at a local level, it will make every effort to recreate the paediatric continence needs assessments during its 2018-19 business planning process. I am the Minister responsible for Public Health England. I see its leaders regularly and I will raise it with them next time I see them.

## ***The Parliamentary Under-Secretary of State for Health (Steve Brine)***

I would also like to use this debate briefly to mention transvaginal mesh implants, which the hon. Lady rightly raised in her speech. She was about to intervene to ask whether I was going to mention them. I know that some women experience severe side effects and complications post operation. I know that there has been considerable interest in this across the House. The hon. Lady mentioned the hon. Member for Pontypridd (Owen Smith) who shared a working group on it recently and is looking to set up an all-party group on the subject.

I have heard heart-breaking stories and I have talked to colleagues in and around the House who have been contacted by constituents about this. We have to make sure that we listen, not only to provide the best support but to inform health services so that they can reduce complications from the treatment. When complications do occur, we must ensure that they are treated promptly and effectively.

We must also remember that these procedures help thousands of women each year who are suffering the distressing effects of stress urinary incontinence and pelvic organ prolapse. Surgical procedures using mesh devices have provided an effective form of treatment that can be far less invasive than alternative surgical procedures. Let us not throw the baby out with the bathwater. In 2014, NHS England set up its mesh oversight group which, in partnership with clinicians, regulatory experts and patient groups, published its final report in July this year which helps to address the three major issues highlighted by clinicians and patient interest groups alike: clinical quality, data and informed consent. That answers the point made by the hon. Member for Bridgend about the devolved Administrations. Yes, we liaise with them, and I welcome the news that both Wales and Northern Ireland will be setting up their own working groups. We would like to see more collaboration on this topic across all the devolved Administrations, and we will give them every support so they can learn from what we have found in the NHS England working group. I hope that that answers that point.

The hon. Lady raised a couple of other issues. She made a really good point about non-domestic rates and public toilets. That issue is raised in the House more often than it should be—it should not need to be raised. I will make sure that my colleagues in the Department for Communities and Local Government hear her call. There is a discretionary relief scheme on non-domestic rates that councils can access, and I am sure that she has made her council aware of it. I encourage other Members to do so, because that is how the discretionary scheme can be used. It is exactly what it says on the tin—it is discretionary.

The hon. Lady made an excellent point about installing a shelf in public toilets. That would be welcome. As a parent of young children in the not too distant past, a shelf would have come in handy on lots of occasions. She made an excellent point about the changing of continence products. The hon. Member for Stroud (Dr Drew) made a point about ERIC. I was not aware of that, so I thank him for doing so and will look it up. He also spoke about the need for teachers to be informed about the subject. I urge him to pursue that with Education Ministers, but I am sure that they have heard tonight's debate, given that they have been mentioned.

The hon. Member for Bridgend made a really good point about hospital data on continence, access to tertiary care and exit from hospital care. My family and I have experienced the fight on Parkinson's on far too many occasions. I thank the hon. Lady for the work that she does on the all-party group and I look forward to meeting her in that capacity. I will ask officials to look at the very good point that she has made. She also raised VAT on sanitary and continence products. The Government have taken action on VAT on women's sanitary products within the realms of what is possible as a member of the European Union. We have invested that money in women's health charities, as she knows. On the wider point about

VAT, we are restricted as a member state, but we will soon be free, and we will be able to make those decisions in the House—taking back control, as someone once said.

Finally, the hon. Member for Strangford (Jim Shannon) made an excellent point about employers and their understanding of the issue. Employers should show every understanding in this area, and I expect them to do so—I do not think that I can be clearer than that.

To conclude, I thank the hon. Member for Bridgend once again for highlighting these issues. For all those who suffer from continence issues, it is important that we talk about the topic, treat it seriously and work together to overcome the taboo and stigma by speaking candidly about it. I genuinely believe that only by doing so can we truly provide patient-centred services, where patients are at the centre of everything we do. We work with the healthcare professionals, commissioners, providers, pharmacists and trusts to improve the advice and services offered to best meet the needs of the people who rely on and—let us remember—pay for these services.

*Question put and agreed to.*

9.45 pm

*House adjourned.*