

16 February 2026

Dear Lady Casey,

**Putting dignity in continence at the heart of adult social care**

We write, first and foremost, to congratulate you on your appointment to chair the independent commission into adult social care, and to extend our best wishes for success in this important endeavour.

We warmly welcome the commission's ambition to make adult social care more preventative, productive, and person-centered – to give greater voice and power to those who rely on care, as well as their families and carers. These goals are urgently needed.

Secondly, we urge you to ensure that any future proposals **place dignity at the heart of your recommendations** – especially in the care of people living with incontinence. For too many, continence care is the hidden frontline of indignity within the current system.

Incontinence can have a severe and lasting impact on patient's health, independence, and quality of life. It can lead to urinary tract infections, skin damage, increased hospital admissions, and profound emotional distress.

And with over **160,000 people** in care and nursing homes in the UK living with continence challenges – a number that is only set to rise alongside the ageing and disabled population – the system must respond better.

At the most basic level, people need, holistic assessment of their bladder & bowel symptoms, with guidance to possible treatment options, & referral to specialist healthcare professionals as needed. This may include assessment for continence products. Patients who are unable to be continent with appropriate treatment should be provided with the most suitable product for their needs, in sufficient quantities, with guidance & support on how to use them effectively.

However, we know that by having access to specialist continence advice, support and assessment, along with continence aids to meet need (i.e. pads, catheters, bowel wash outs, medication), continence can be much better managed, and dignity and quality of life for the patient improved.

But we know this is often not happening. A recent investigation by the *i* Paper<sup>1</sup> found patients are being “**robbed of their dignity**” due to a postcode lottery in continence product provision. FOI data revealed that over half of NHS trusts providing continence care products (such as absorbent pads) cap supplies at **three or four pads per day** – despite professional guidance, including from NICE<sup>2</sup> and the Association of Continence Professionals<sup>3</sup>, that is clear that products should be matched to assessed clinical need.

The impact is not abstract. One patient told us:

*“It is no exaggeration to say that without continence products, I simply wouldn't be able to lead a normal life.”*

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<sup>1</sup> [https://inews.co.uk/news/patients-robbed-dignity-hospitals-ration-hygiene-products-3425336?srsId=AfmBOoqEWngPUdV197ZuRFUf1LtBbPbF1rpVb2e8SlklbFvM\\_T6zd7vo](https://inews.co.uk/news/patients-robbed-dignity-hospitals-ration-hygiene-products-3425336?srsId=AfmBOoqEWngPUdV197ZuRFUf1LtBbPbF1rpVb2e8SlklbFvM_T6zd7vo)

<sup>2</sup> NICE guidance QS54, CG49 and NG123

<sup>3</sup> <https://acpcontinence.co.uk/national-guidance/>

Families, too, are affected. Nearly half<sup>4</sup> of those supporting a relative with incontinence report concerns about their loved one's **dignity and privacy**, and with over a quarter saying that it has led to family members taking on more caregiving responsibilities.

Yet this is not just a moral failure – it is also economically short-sighted. FOI responses from 50 NHS trusts further revealed a combined **overspend of £4.1 million** on continence care last year, clearly signalling that current budgets do not match patient needs – and will fall even further short as the ageing population grows.

We therefore ask that the commission:

- Explicitly recognise the need to **uphold dignity in continence care**, and
- Recommend action to ensure that **clinical need** – not budget or postcode – **dictates provision**.
- Work with us to identify what quality care and management for continence looks like and involve us in helping to shape the services that are needed.

We were encouraged to hear that your review will include a data-driven deep dive into the current system. As organisations and individuals with direct experience of continence care, we would welcome the opportunity to contribute evidence and insight to help ensure the review is as robust and well-informed as possible.

Thank you for considering this issue. We would welcome the opportunity to meet with you and your colleagues to explore this issue further.

Yours sincerely,

**Nik Hartley**, Chief Executive, Spinal Injuries Association

**Kate Steele**, Chief Executive, Shine

**Roland Watson**, Chair, Pain UK

**Sonya Carassik Ratty**, Chief Executive, Adapt & Live | Disabled Living

**Tracy Whitehouse**, Service Manager/Adult Specialist Nurse, Bladder and Bowel UK

**Georgina Carr**, Chief Executive, The Neurological Alliance

**Frances Lawrence**, Chief Executive Officer, Dementia Carers Count

**Dame Caroline Dinenage MP**, Officer of the All-Party Parliamentary Groups on Carers and on Women's Health

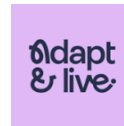
**Baroness Ritchie of Downpatrick**, Officer of the All-Party Parliamentary Groups on Dementia and on Access to Medicines and Medical Devices

**Mohammad Yasin MP**, Officer of the All-Party Parliamentary Groups on Adult Social Care and on Kidney

**Baroness Grey-Thompson**, Officer of the Women in Parliament All-Party Parliamentary Group

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<sup>4</sup> <https://docs.google.com/presentation/d/1oL-kOotDqOZlkb2raPf-lYmCh4JZee6A/edit?slide=id.p1#slide=id.p1>



**For more information, please contact:**

Ignacia Baudrand, Whitehouse Communications

[Ignacia.baudrand@whitehousecomms.com](mailto:Ignacia.baudrand@whitehousecomms.com)