September 2025

The impact of incontinence on families and support networks

Bladder & Bowel UK

Attends®

Key Findings

Foreword

At Bladder & Bowel UK, we believe no one should face the challenges of incontinence without dignity, understanding, and the right support. Incontinence affects over 14 million people in the UK, yet the impact on families and support networks remains largely overlooked. Every day, carers adapt their routines, manage complex needs, and navigate fragmented services, often without adequate support. This report gives voice to their experiences, highlighting the practical, emotional, and financial pressures they face.

Our mission is to improve life for everyone affected by bladder and bowel conditions. By listening to carers and understanding the realities behind closed doors, we can work towards better services, fairer provision of products, and greater recognition of the vital role carers play, and by doing so improve wellbeing for everyone affected. These findings are a call to action for policymakers, healthcare providers, and communities to ensure that bladder and bowel care is not left on the margins, but given the priority it urgently needs.

Sonya Carassik Ratty
Chief Executive
Bladder & Bowel UK |
Disabled Living

Executive summary

Incontinence care is one of the most challenging aspects of caring for someone. Families and support networks often provide essential, life-changing support to loved ones living with incontinence. But behind closed doors, many face exhaustion, financial strain and emotional burnout, with incontinence often acting as a catalyst for an unwanted move into a care home or supported living.

This report presents findings from 146 people with first-hand experience of caring for someone with incontinence. It explores how supporting someone with incontinence affects an individual's mental health, physical wellbeing, social life and finances. The report also highlights major barriers to support and the urgent need for more joined-up services.

Key findings include:

- Over half of respondents reported symptoms of anxiety or depression due to their caring responsibilities.
- Many carers feel isolated and trapped, unable to leave the house for more than short periods.
- A lack of supplies and delays in accessing Bladder and Bowel services are adding to the pressure.
- Financial costs - ranging from hygiene products to rising utility bills - are placing strain on already-stretched households.

Caring for someone with incontinence is relentless and invisible. We call on healthcare services, policy makers and charities to prioritise continence care and provide targeted, meaningful support for carers who are being left to cope alone.

Introduction

Incontinence is a common but often hidden issue, affecting over 14 million people across the UK – including children, working-age adults and older people. Despite its prevalence, it remains under-discussed and under-prioritised, largely due to stigma, embarrassment, and societal discomfort around intimate health.

But the impact of incontinence extends far beyond the individual. For many, it is their loved ones – parents, partners, adult children, siblings or friends – who provide the day-to-day care and emotional support. These unpaid carers take on intimate tasks, manage hygiene routines, adapt their lives around the person they support and navigate health and care systems, often with little guidance or respite.

This report explores the lived experiences of these carers. It highlights the emotional, practical and financial challenges they face – and what must change to better support them.

The research forms part of a wider project delivered by Bladder & Bowel UK, supported by Attends. It was born out of a need to better understand how incontinence affects not just individuals, but whole families and communities.

The campaign aims to:

- Shine a light on the social, emotional, psychological and economic toll of incontinence on carers and families.
- Explore what improvements would most benefit them.
- Start a conversation where people affected can find solidarity, reduce taboos and share coping strategies.
- Advocate for families and social groups currently struggling in silence.
- Remind policymakers that the burden of care too often falls unjustly and disproportionately on families – and that they urgently need better, more specialist support.

Methodology

This report is based on findings from an anonymous online survey conducted by Bladder & Bowel UK supported by Attends.

Aims of the survey:

- To understand the personal impact of supporting someone with incontinence.
- To identify unmet needs and gaps in support.
- To gather recommendations from carers themselves.

Survey structure:

- The survey included both quantitative (tick-box) and qualitative (open-ended) questions.
- Topics covered: emotional wellbeing, physical health, financial impact, access to services, and daily routines.
- Respondents were asked to share their experiences and suggest what would help.

Respondents:

- Majority identified as family members (e.g. parents, spouses, siblings).
- Carers supported children, adults, and older people with a range of health conditions.

Analysis:

- This report presents findings from 146 respondents, identified as having first-hand experience of caring for someone with incontinence, from a wider survey of more than 200 submissions.

Key Findings

Emotional toll on caregivers

> ***“It is hard to deal with faecal incontinence when the person affected is an adult, and the way he sees me as his wife has changed."***

Many carers reported feeling emotionally drained and alone. They spoke of exhaustion, isolation and a profound sense of loss. For many, their role had shifted from loved one to full-time carer, with serious consequences for their identity, relationships and mental health.

A striking 65% of respondents said the emotional impact of incontinence care was one of the most challenging aspects of their experience. Many shared how they had lost their sense of self and, in some cases, felt they were losing the person they loved. Some described ongoing struggles with depression, anxiety or even suicidal thoughts, highlighting the urgent need for better emotional and psychological support.

Shame and silence still surround the issue of incontinence, making it even harder for carers to speak openly or ask for help. This isolation can deepen the emotional toll, leaving many to cope without the support they need.

Q8

Emotional impact

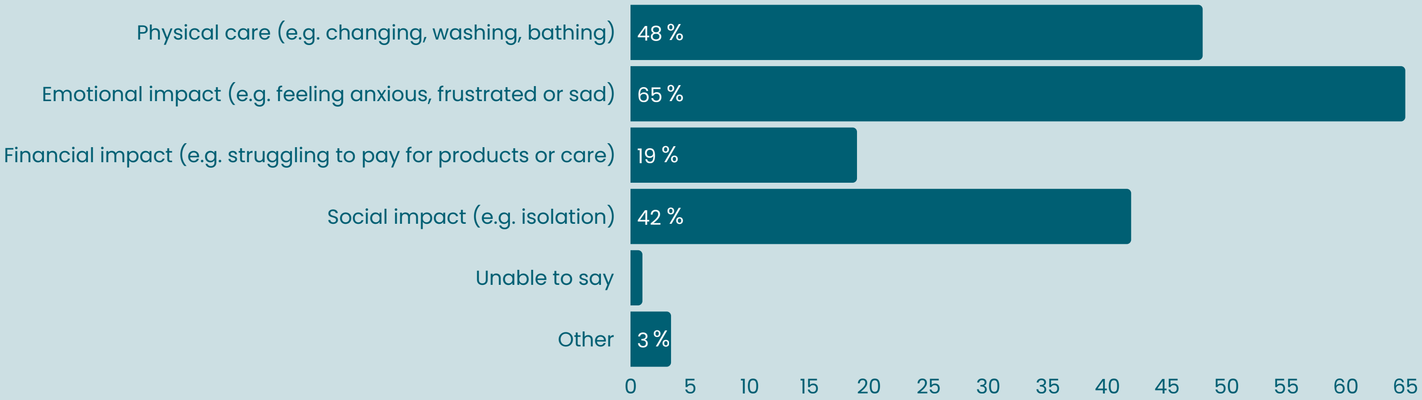
On a scale of 1-10, how significantly have you been emotionally impacted by the issue?

> ***"Dealing with a parent’s incontinence can be extremely frustrating and stressful, sometimes leading to a decline in the relationship."***

Q7

Most challenging area

Which of these areas have you found most challenging? (can choose up to two options)



Daily life defined by care routines

Findings from the research show that caring for someone with incontinence can impact almost every hour of the day. Many carers described how their time is dominated by practical tasks, including doing multiple loads of laundry daily and managing frequent night-time pad changes, which severely disrupt their sleep.

"The biggest change for me is not being able to work properly. Waking up three or four times a night to care for my son leaves me very tired, both physically and emotionally."

Participants also highlighted the physical demands of manual handling; lifting, rolling and cleaning, which can take a toll on their own health. In addition, some reported difficulties accessing sufficient products through health or social care, with several stating they often had to purchase supplies out of their own pockets to meet daily needs.

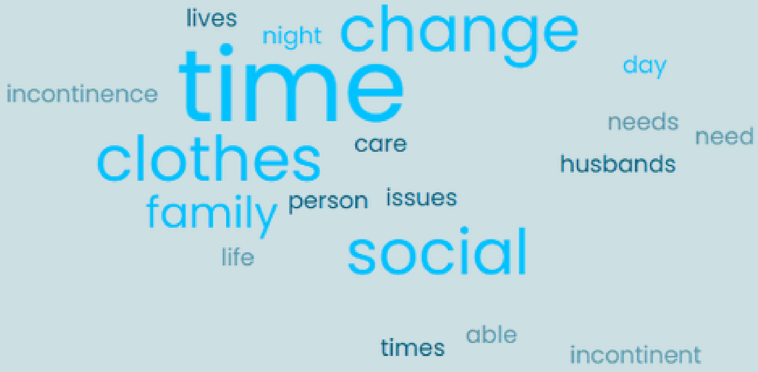
*“**The time and effort required to care for and advocate for an incontinent relative take away from other important parts of my life, including work, running my home, my marriage, and my wellbeing. The stress has even worsened my own incontinence, which I now have to manage.**”*

Daily life outside the home is also affected. Carers spoke about the need to carefully plan every outing around access to toilets, hygiene facilities and the risk of accidents, which can severely limit their ability to socialise, work or travel freely.

"I’m stressed because it’s very hard to help my parent, who is angry about her incontinence and takes it out on me. I’m experiencing palpitations and heartburn, and there seems to be no end in sight since she won’t let anyone else help."

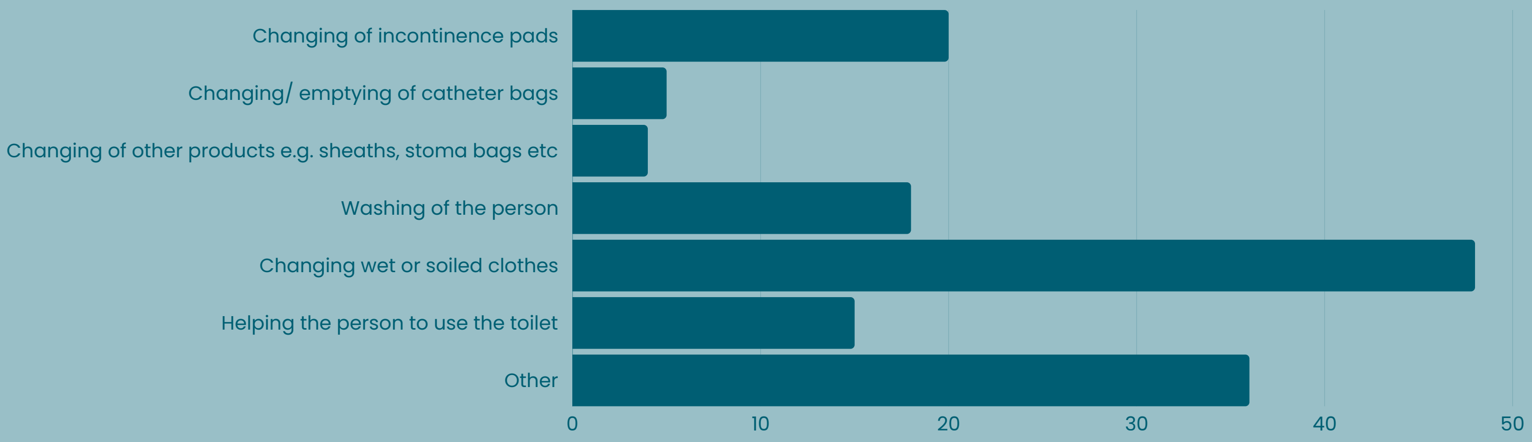
Q21

Impact on daily life
What have been the biggest changes in your own life as a result of the incontinence issue?



Q5

Physical care
Which aspect of physical care is/was the most challenging for you?



Loss of freedom and social isolation

The research also revealed how incontinence can lead to a significant loss of freedom and deep social isolation for families. Many carers shared that their social lives had all but disappeared. Travel, holidays and family events were often avoided altogether, with some refusing invitations out of fear that an accident might occur. Even simple activities involving things like leaving the house for more than an hour became difficult or impossible, leading to further feelings of disconnection and loneliness.

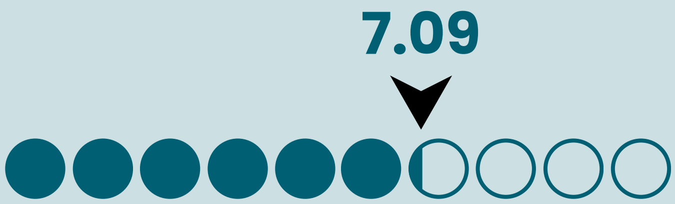
"I no longer feel like a wife, only a caregiver, and our retirement plans are on hold. I even joke about moving into the bathroom since that's where we spend most of our time."

“I can't leave my husband alone for more than 30 minutes, and it leaves me feeling isolated. Taking him to appointments or even for a walk is challenging because he often needs last-minute changes of clothes. He is not the man I married 52 years ago.“

"”No holidays or day trips, and constant stress trying to find suitable public facilities when out. Long journeys are particularly stressful, knowing my wife may need to go despite wearing pads."

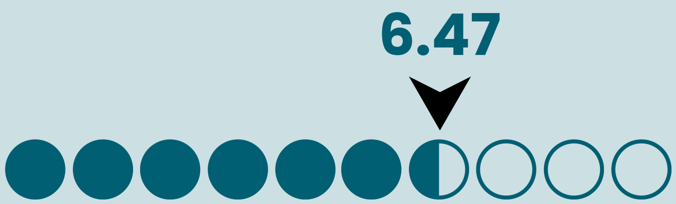
Q13

Quality of life & support access
On a scale of 1-10, how significantly has your quality of life been negatively affected by supporting someone with incontinence?



Q14

Isolation
On a scale of 1-10, how isolated do you feel as a result of the issue?



But for many carers, the impact goes beyond their own isolation. They spoke about the guilt and emotional burden of feeling responsible for the isolation experienced by the person they care for. Turning down invitations, avoiding day trips or holidays, or saying “no” to spontaneous outings wasn't just about managing practical challenges – it often came with an overwhelming sense of letting their loved one down.

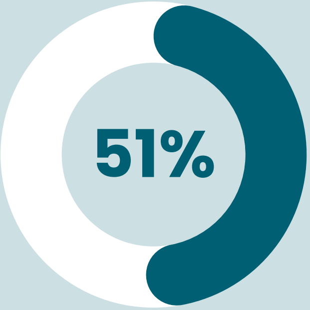
“I do everything I can to get the help and support he needs. I feel like I hit a wall at every turn. He's now being bullied at school. I feel guilt that he can't take part in social activities. I just feel useless.”

“I worry about social issues and potential bullying when she goes to friends' houses, as well as the physical impact on her. I also feel guilty that I caused it.”

Barriers to support and services

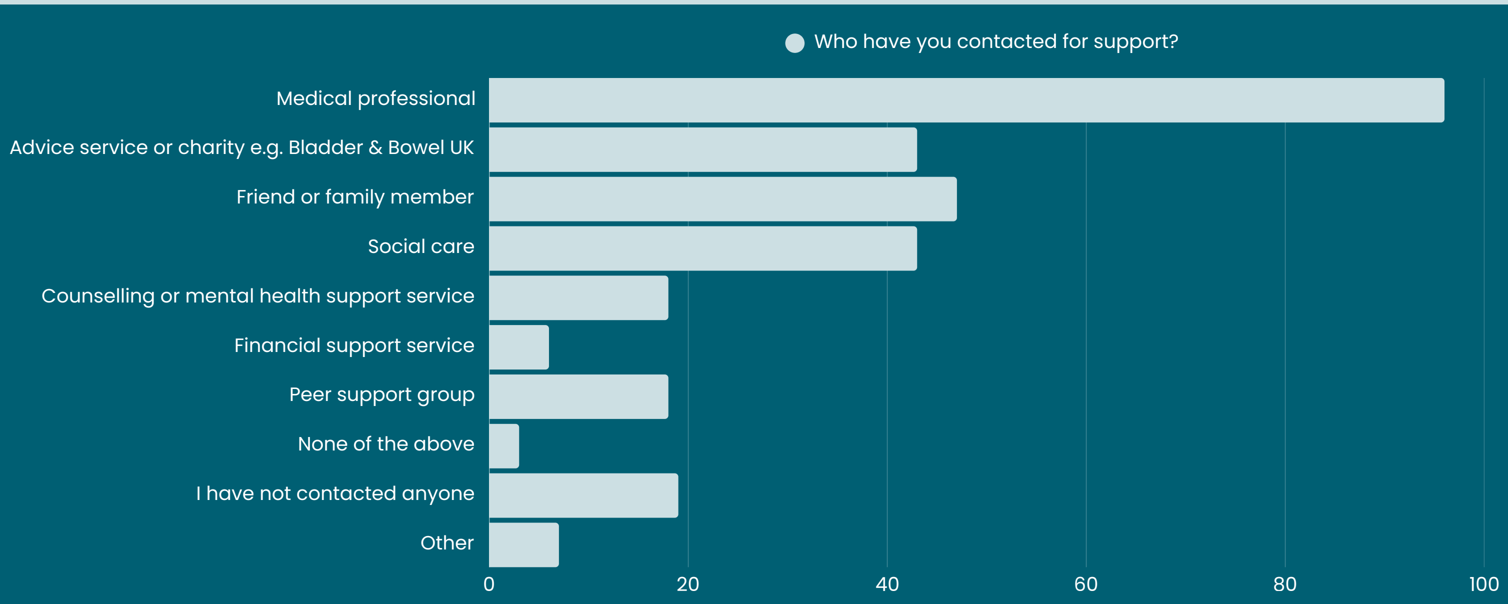
Many respondents spoke about the struggle to access appropriate support, often feeling they were navigating the challenges of incontinence entirely on their own. Long waiting times were a common concern, with some reporting waits of over six months to be seen by bladder and bowel services. Others described inconsistent or dismissive care from GPs, making it harder to get the help they needed.

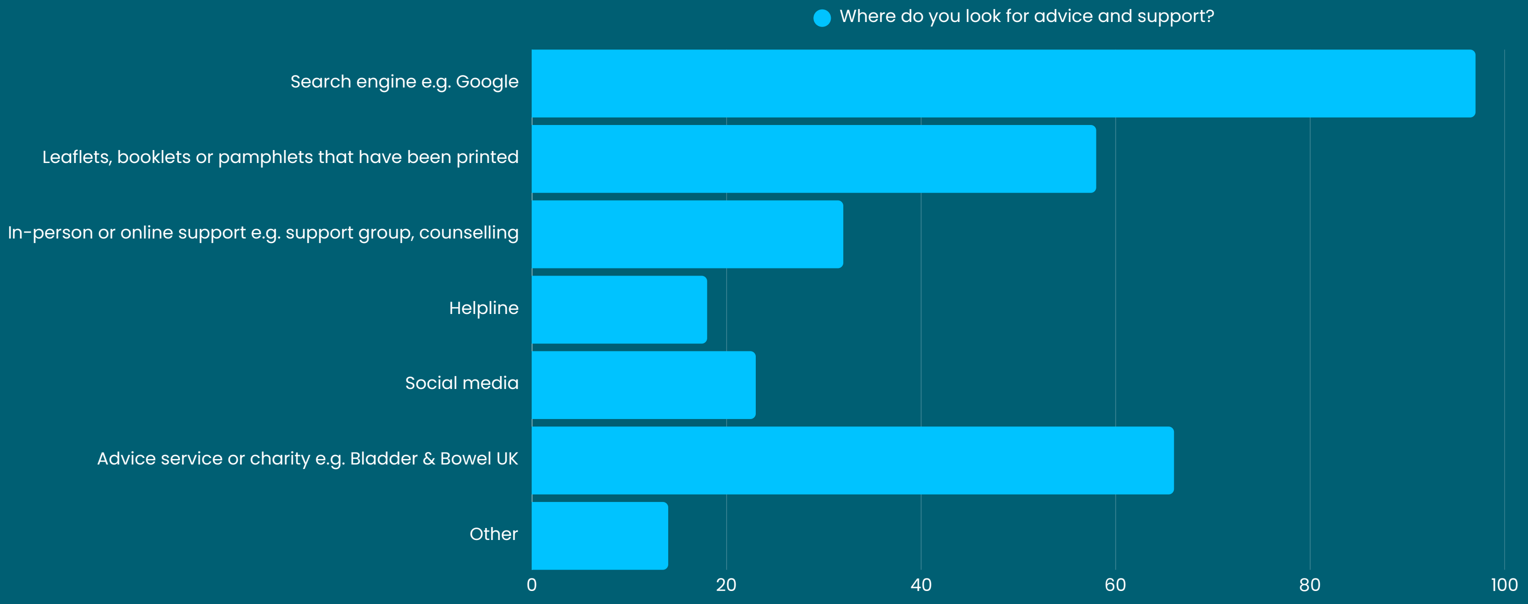
Even when support was available, it often came with strict limitations. Several carers highlighted the rationing of essential supplies, such as a maximum of four pads per day, which was simply not enough to meet their needs. The process of accessing support was also described as overwhelming, with complicated forms, unclear eligibility criteria and systems that felt inaccessible or not designed with carers in mind.



Quality of life & support access
have wanted support but felt unable to access it

Quality of life & support access
of respondents were unsure who to speak to





Financial pressures

Caring for someone with incontinence often places a significant financial strain on families. Many respondents spoke about the ongoing cost of essential supplies such as hygiene products, bedding, wipes and bin bags, much of which had to be purchased out of pocket. In addition, some carers had reduced their working hours or left employment entirely to provide full-time care, leading to a loss of income and long-term financial insecurity.

Daily washing to manage hygiene needs also caused utility bills to rise sharply, adding to the burden. Despite the time, labour and emotional toll involved, many carers felt there was little or no financial recognition for the care they were providing, leaving them feeling unsupported and undervalued by the system.

Financial impact

Respondent were asked on a scale of 1-10, how significantly they have been financially impacted by incontinence.

10%
ranked the impact as 10

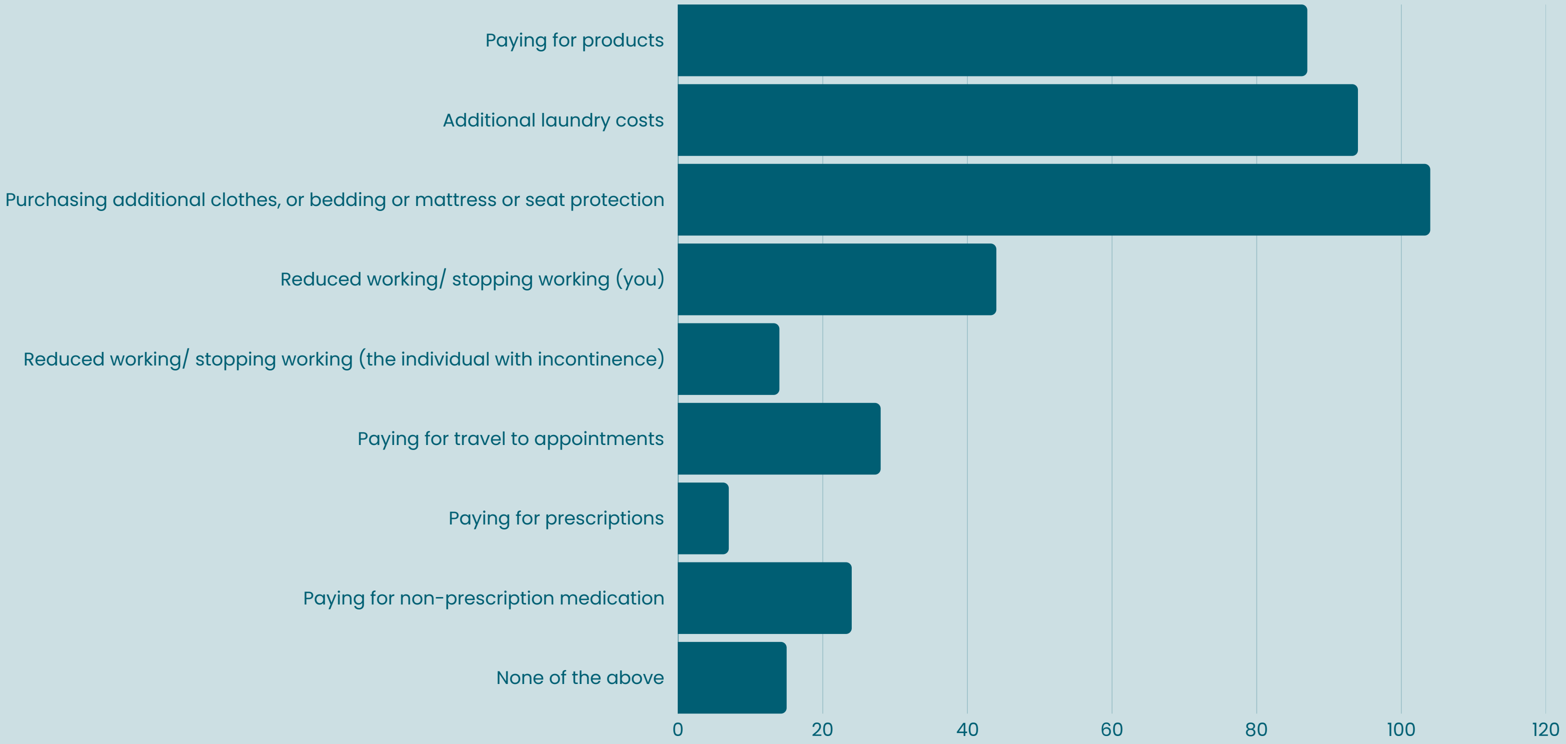
11%
ranked the impact as 9

12%
ranked the impact as 8

14%
ranked the impact as 7

If you would like to say more about the financial impact on you, please do so here.

Which of the following financial issues, related to the issue of incontinence, concern you?



Recommendations

1. Faster access to services

Timely access to continence services can make a significant difference to quality of life. Setting a maximum wait time of four weeks for an initial assessment, supported by clear referral pathways, would help people receive the right support at the right time.

2. Prevention and awareness

Bladder and bowel health can be promoted across all stages of life. Opportunities exist in settings such as health visiting, school nursing, learning disability services, memory clinics and neurodegenerative condition clinics to encourage early, open conversations and reduce the risk of problems developing or worsening.

3. Recognition and support for carers

Carers play a vital role in supporting people with incontinence. Offering emotional support, such as counselling, peer groups and helplines, alongside access to carer-specific funding or allowances, can help to acknowledge and ease the additional responsibilities they carry.

4. Practical support and equipment

Access to appropriate equipment, such as manual handling aids and protective bedding, can help people manage daily life more effectively. Public facilities with suitable toilets and hygiene provisions also make it easier for people affected by incontinence to participate in community life.

5. More inclusive systems

Clearer eligibility criteria, simplified forms and straightforward processes can make it easier for people to access support. Training for healthcare professionals on communication, dignity and inclusivity can further improve the quality of care provided.

6. Fair and needs-based product provision

Continence products should be provided in a way that reflects individual needs. A fair, consistent approach to allocation can help ensure people have the products they require to maintain dignity and independence.

Bladder & Bowel UK
Part of Disabled Living | Registered Charity No: 224742
Bladder & Bowel UK will continue to amplify the voices of carers and work alongside partners like Attends to continue to press for change.