

The strain of caring for someone with incontinence is real and can be overwhelming. Behind closed doors, thousands of family members and support networks quietly shoulder the physical and emotional demands of continence care every day. Their work is often hidden, unrecognised and unrelenting – yet it underpins the wellbeing of the person they support and often determines whether care can continue at home.

# Recent research with 146 carers highlights the scale of this burden:

- **Emotional impact** over six in ten reported symptoms of anxiety or depression as a direct result of their caring role. Many described feelings of exhaustion, loss of identity and isolation.
- **Practical disruption** daily life is defined by continence routines, from multiple night-time pad changes to constant laundry, leaving little time for rest, relationships or paid work.
- **Social and financial strain** carers frequently reported the loss of freedom to leave the house, attend social events, or maintain employment. At the same time, they face rising costs for essential products, utility bills and reduced household income.
- Barriers to help many carers struggle to access bladder and bowel services, with long waiting times for assessment, limited choice and quantity of supplied products, and a lack of clear signposting on where to get help, all adding to their stress.

Together, these findings show that while incontinence is often framed as a health issue for the individual, it is equally a hidden crisis for families and support networks.

This resource is designed for healthcare professionals to help them recognise early signs of hidden carer strain, open up supportive conversations and take appropriate action – whether providing inthe-moment support, signposting relevant services or escalating concerns when urgent intervention is needed.

# Spotting early warning signs

Look for cues in language, behaviour and appearance that suggest hidden carer strain.





## What they say:

- "It's just been a lot lately."
- "I don't really get out anymore."
- "We're just managing for now."

#### What you see:

- Carer appears exhausted or detached.
- Describes little or no time for sleep, social life or self-care.
- Minimises their role: "I'm just the daughter."
- Expresses guilt, resentment, frustration or irritability.

### Opening up the conversation

Natural, open prompts can help carers reflect without needing to self-identify as "struggling":

- "How are you finding things day-to-day?"
- "Are you getting any time for yourself?"
- "What support do you have around you right now?"
- "What's been the hardest part recently?"
- "Have you noticed any changes in your own health or wellbeing?"

#### When & how to Intervene

If you suspect strain, healthcare professionals can:

### Provide immediate support

- Validate: "This sounds like a huge responsibility you're doing so much."
- Normalise: "Many carers feel this way you're not alone."

Explore needs holistically: Ask what they need – emotionally, practically, socially, or financially – and signpost or refer to services that can support the carer's overall wellbeing, not just their caring role.





### Signpost

### Carer support services

- Bladder & Bowel UK Helpline
- Local Council Carer Support Services
- Carer's Assessment (via local authority)
- Respite Care Services
- Carers UK
- Community Nursing Teams
- GP or Practice Nurse

## Mental health/wellbeing services

- NHS 111 (Mental Health Option)
- Mind
- Carers UK Listening Support Service
- Samaritans (116 123)
- Alzheimer's Society
- Carers Trust
- Hub of Hope

#### Escalate if red flags appear

- Signs of exhaustion, illness or injury
- Emotional distress (crying, panic, hopelessness)
- Carers saying they're struggling to provide safe care, for example,
  "I sometimes can't lift my parent safely on my own."
- Statements such as "I can't do this anymore"

### **Escalation pathway**

- Within your team raise concerns with your line manager, senior nurse/clinical lead or the safeguarding lead.
- Safeguarding concerns contact your local authority's Adult or Children's safeguarding team.
- **Urgent need for extra care** refer to social care teams for emergency packages or respite.
- Medical or emotional crisis involve GP, community nursing, mental health crisis teams, or emergency services if there is immediate danger.





In these cases, safeguarding, urgent referrals, or escalation within your team may be required to protect both the carer and the person they care for.

# **Key Takeaway**

Behind every person with incontinence may be a carer who is silently struggling. By recognising early signs, asking the right questions and linking carers to appropriate support, healthcare professionals can help prevent burnout. Effective continence management also supports the wellbeing of the person being cared for, helping to prevent skin problems, manage other medical conditions, maintain mobility and independence, and preserve dignity. This dual focus benefits both carers and the people they support.

Based on findings from: The Impact of Families and Support Networks Impact Report (Bladder & Bowel UK, September 2025). Scan the QR code to read the impact report in full:



# **Further information**

Find more information about bladder and bowel health in our information library at <a href="https://www.bbuk.org.uk">www.bbuk.org.uk</a>. You can also contact the <a href="mailto:Bladder & Bowel UK">Bladder & Bowel UK</a> <a href="mailto:confidential helpline">confidential helpline</a> (0161 214 4591).

For further advice on bladder and bowel problems speak to your GP or other healthcare professional.

