

Overactive Bladder (OAB) UK Patient Insights

April 2024

Survey report prepared, created & funded by Astellas Pharma Ltd. in partnership with Bladder Health UK

Job code: MAT-GB-BET-2024-00103 | Date of preparation: May 2024







Contents

Foreword –	3
Executive summary –	4
Overactive bladder (OAB): The facts –	5
OAB patient insights snapshot –	6
An exploration of the key survey findings –	7
Country breakdown of results –	11
Conclusion –	12

Foreword

We all know how it feels when we're bursting for the loo.

It's frustrating and panic-inducing if a toilet isn't nearby. People living with an overactive bladder (OAB) experience this unpleasant sensation all too often.



Suzanne Evans, Business Director Bladder Health UK

OAB is a common condition in both men and women, affecting around 12% of the population in the UK.¹ The prevalence rises with age.² Given the population is getting older, the number of people living with OAB is increasing.³ Around 4.5 million people in England have OAB and by 2035, this number is estimated to reach over 7 million.^{4,5}

The symptoms of OAB can differ from person to person and they might change over time.⁶ Patients may experience a sudden desire to urinate, going to the toilet every couple of hours, waking up multiple times during the night to urinate and even involuntary leakage.⁶

Quality of life can be severely impacted by OAB.² Travelling may be difficult due to concerns around locating the nearest toilet. At home, there can be an increased amount of washing and ironing due to urine leakage. Cinema visits, sports games and flights might affect patients who feel on edge if they are unable to sit in an aisle seat for easy escape should they feel the urge. Individuals with OAB may feel distress, inconvenience, loss of self-esteem and self-control. Personal relationships may be affected too.

Patients are at the heart of everything we do at *Bladder Health UK* and raising awareness backed by evidence helps to facilitate change and to bring benefits to the sufferers.

This report aims to address the lack of quantifiable patient data in an area of growing importance. We hope to stimulate discussion and encourage people to understand the disruption OAB can cause. The more openly we talk about the condition, the more patients will be able to get their lives back on track.

Executive summary

OAB can significantly impact a person's quality of life.²

Whilst people may notice the symptoms and actively make adaptions to try and relieve them, delaying booking a doctor's appointment and opening up to them is all too common.⁷

The key challenges include:



Low patient recognition of OAB

Awareness of OAB is limited. This means a high number of patients are living with OAB without knowing what it is.8

While many people experience symptoms, few make a connection to the condition being something that is manageable with medical help.8



Shame associated with a bladder condition

OAB can have a significant impact on patients, but the desire to conceal the condition means they

are not always willing to speak to their doctor.9 Feelings of embarrassment are common among people living with bladder problems, resulting in poorer outcomes.9



Defaulting to 'coping' mechanisms

People with undiagnosed OAB are likely to try and self-manage their symptoms with techniques such as using incontinence pads and

pelvic floor exercises.^{9,10} In addition, they make lifestyle modifications like drinking less, which can hinder them from getting the correct medical interventions and care that they need.9,10



A slow diagnosis pathway

Once a person has decided to see a doctor, it can still take time to receive an OAB diagnosis as this can often take several visits. Our

research suggests it might take women longer than men to be diagnosed. 7,8

With OAB cases on the rise, we are at a tipping point in the UK.5 Unless urgent action is taken, these challenges will become more difficult to address.⁵ To improve outcomes in OAB, we are calling for people to:

Understand the symptoms of OAB rather than putting it down to ageing or for women, childbirth

Speak more openly about **OAB** to remove stigma associated with bladder problems, including with their families and friends

Recognise any adaptions they're making

to manage their OAB, putting their quality of life at risk, rather than seeking medical guidance and treatment



situations

See a doctor right away if **OAB** symptoms are suspected and have the confidence to talk about how the condition is affecting everyday

Overactive bladder (OAB): The facts

What is OAB?

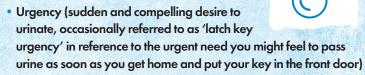
OAB is a common problem that affects how the bladder behaves. It is characterised by a spontaneous and sudden squeezing of the muscle in the wall of the bladder, even when there isn't much urine in the bladder. The bladder muscles seem to give wrong messages to the brain causing the bladder to feel fuller than it actually is. As a result, the bladder contracts too early when it is not very full, and unexpectedly. This involuntary contraction creates the urgent need to urinate, often at inappropriate times.

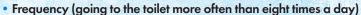
Prevalence

- OAB affects men and women of all ages¹
- It is estimated that 12%
 of the population in
 the UK is impacted by OAB, with
 prevalence increasing with age
- Around 4.5 million people have OAB in the UK⁴

Symptoms

OAB is characterised by a group of 4 main symptoms:





- Nocturia (waking up more than once a night to urinate)
- Urge incontinence (small or large quantities of involuntary loss of urine)⁶



Primary care

Around 317,000 doctor appointments are made for OAB per month, translating to approximately 3.8 million appointments each year⁵



Secondary care

An estimated 390,000 additional falls are reported each year for those over 65 related to OAB, resulting in around 22,600 hospital admissions⁵

Costs

 The cost of OAB in England is approximately £3.7 billion per year⁵



 OAB-related falls leading to hospitalisation for over 65s is forecast to cost £246.7 million each year in England⁵



Looking ahead

- A 43% increase in the number of people with OAB in England is predicted by 2035, linked to the ageing population⁵
- Numbers of people living with OAB in the UK are forecast to rise from around 5 million today to over 7 million by 2035⁵
- Costs from OAB are set to rise to more than £5 billion in England by 20355
- If no action is taken, direct costs from OAB covering medical consultations, clinical depression and the use of incontinence pads are set to rise by £2 billion in England by 2035⁵
- The costs from falls related to OAB resulting in hospitalisation in England are estimated to increase over three fold to £830 million by 2035⁵



OAB patient insights snapshot

In December 2023, Astellas conducted a survey* of OAB patients in the UK to understand their perspectives on living with the condition, including pre- and post-diagnosis and management.⁷

The UK-wide results of the survey found:7



65% stated that, on average, they needed to urinate more than 7 times a day prior to a diagnosis with OAB⁷



28% of respondents had to wake up more than 5 times a night to go to the toilet, on average, prior to diagnosis⁷



63% of people felt OAB negatively impacted their sleep, 44% their social life, 42% their mental health, and 38% their work⁷



32% avoid social situations due to their OAB, with a similar percentage avoiding unfamiliar places (30%) and avoiding certain foods and drinks (28%)⁷



47% of people with OAB have wet themselves because they couldn't find a public toilet?



45% waited more than 6 months before making an appointment to see their doctor about their OAB symptoms, and 24% waited for more than a year⁷



Over a quarter (28%) of patients have never confided in family or friends about their OAB journey



85% of people with OAB believe working with their doctor or continence service has improved their lifestyle⁷

^{*500} people living with OAB responded to the online questionnaire.

Country breakdown of respondents: England (426), Scotland (41), Wales (25), Northern Ireland (8)

An exploration of the key survey findings

The urge to urinate is frequent and unpleasant

On average, prior to diagnosis, 65% stated that they needed to urinate more than 7 times a day, while 28% of respondents had to wake up more than 5 times a night to go to the toilet. Men are more than twice as likely to wake up more than 5 times a night from their OAB than women.

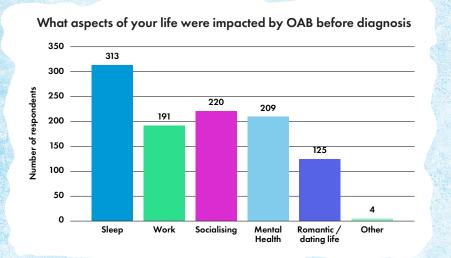
How would you describe the sudden and strong urge to urinate?

- Painful
- Annoying and inconvenient
- Uncontrollable
- Uncomfortable
- **Desperation**
- Embarrassing

OAB negatively impacts many aspects of life

Shockingly, nearly half of people with OAB (47%) have wet themselves because they couldn't find a toilet in public.⁷ People report many aspects of their life being negatively impacted including their sleep, work, romantic and social life and their mental health.⁷

- Men are more than likely to experience issues at work resulting from OAB compared to women
- Women's mental health is more likely to suffer than men's



Lifestyle modifications are common

Prior to an OAB diagnosis, 60% of respondents tried to drink less, and 28% chose to avoid certain foods and drinks.⁷ While the decision to drink less seems logical to reduce the need to go to the toilet, cutting down on fluids is not an effective way to manage the symptoms of OAB.⁷ A reduced fluid intake makes urine more concentrated and is likely to make symptoms worse or lead to more serious complaints.⁶

In fact, avoidance behaviours are frequent – not only with what is consumed but avoiding unfamiliar places (30%) and social situations (32%). Giving up on visiting new places and seeing people is not the answer when managing OAB.

Men are more likely to avoid social situations and certain foods and drinks than women.

Preparation becomes more important for people living with OAB, with 32% of respondents mapping out toilet locations on travel routes, for example.⁷

Women are almost twice as likely to try pelvic floor exercises, more than twice as likely to use incontinence pads, and tend to map out toilets on travel routes and go to the toilet pre-emptively than men.⁷

An exploration of the key survey findings

It can take years for OAB patients to seek help

Approximately a quarter (24%) of people with OAB waited more than a year to make an appointment to see their doctor.⁷ This corresponds to over one million people who may be living with symptoms of OAB but are delaying asking for medical help.⁴⁷

Men are more likely than women to book a doctor's appointment immediately – perhaps because men have concerns around the changes in their body being a sign of prostate cancer, or women viewing symptoms as a natural consequence of ageing or childbirth.⁷

This lack of proactivity in speaking to a doctor could be connected to embarrassment. Only 15% of people discussed their OAB symptoms with a close family member or friend before diagnosis, and 28% have never told a family member or friend about their condition – even after diagnosis.

People not talking about their OAB with those closest to them, paired with avoidance behaviours such as missing out on social occasions, highlights the potentially isolating nature of OAB.⁷

Men and women are equally as likely to tell their family and friends about their OAB symptoms pre- and post-diagnosis.⁷

With women's mental health more likely to suffer with OAB than men, this further underlines the importance of addressing the potentially isolating impact OAB can have on women specifically.⁷

Frequent need for urination Daily life affected Impacted sleep Embarrassment Worry Incontinence Frustration Uncomfortable Friends/family advice Social life affected

Case study

Emily, 24
Cardiff, Wales

Emily first started experiencing OAB symptoms whilst she was still in school, noticing a heightened urgency than her peers and occasional leakage. After a few months of her symptoms persisting, Emily decided enough was enough and went to see her doctor. Given her age, it took a little while for Emily to be referred; however, her OAB diagnosis was confirmed following several tests that took place over a couple of months.

Like many, Emily had little awareness of OAB when she started to experience symptoms, assuming it was a condition that only people in their 60s had. Emily's symptoms significantly impacted her life prior to receiving her diagnosis, feeling like she was unable to participate in certain activities and constantly "feeling stressed and worried that I'd be in school and have an accident."

At this time Emily felt like she needed to keep her condition a secret from her friends, considering it embarrassing.

Thankfully, her diagnosis and subsequent work with her doctor has meant that Emily is much better able to control her symptoms and manage her condition. Whilst Emily still has to plan around her OAB, including having a radar key (which allows access to staff toilets and locked public toilets), it no longer dictates her day or prevents her from living her life to the fullest. In Emily's case, her diagnosis made her feel much more comfortable in opening up to her friends, family and work, who have supported her to better manage her condition.

An exploration of the key survey findings

An OAB diagnosis is not straightforward and can take time



It took 47% of people with OAB more than 3 months to receive

a diagnosis, and 26% of patients required more than 3 doctor visits before they were diagnosed with OAB.⁷



Men are more likely to receive a diagnosis in the first 3 months compared to women, and women are almost twice as likely to

wait over a year for a diagnosis than men.⁷ Furthermore, men are more likely to receive an OAB diagnosis in the first 3 doctor visits compared to women, and women are five times more likely than men to have over 10 visits before receiving a diagnosis.⁷



These findings support previous evidence suggesting health inequalities exist for women

when managing their bladder health, facing more challenges than men as they navigate the health system.⁷¹¹

Remember...

A doctor may conduct numerous tests to help diagnose OAB, including physical examinations and testing a person's pee – in addition to the patient being asked to create a bladder diary over time or being referred to a team of specialists (and the assessments recommended may vary depending on the patient).^{6,12}

This can mean that multiple appointments may be needed to reach a diagnosis, and people with symptoms of OAB should not be disheartened or deterred from returning to their next appointment if they do not receive a diagnosis in their first appointment.¹²

An OAB diagnosis can bring relief and an improved quality of life



85% of people with OAB believe working with their doctor or continence service has improved their lifestyle⁷

Men are more likely than women to notice a 'major' improvement in their symptoms and almost twice as likely to report an improvement in their quality of life?



48% of patients have more peace of mind after a formal diagnosis of OAB, with relief (43%), reduced concerns about leakages (25%) and decreased worry about where the toilet is (19%)

frequently mentioned as reasons for feeling like they have returned to a normal lifestyle⁷

Did you know...?



83% of respondents said their one piece of advice for people who think they might have OAB is to see a doctor as soon as possible.⁷

Country breakdown of results

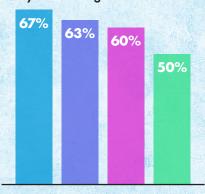




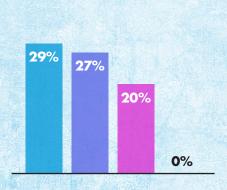


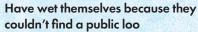


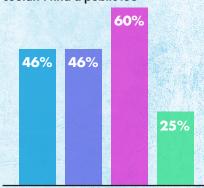
Needed to urinate more than 7 times a day before diagnosis



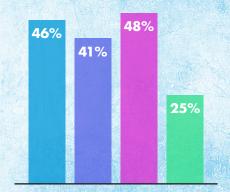
Had to wake up more than 5 times a night prior to diagnosis



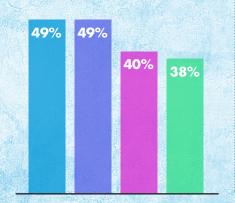




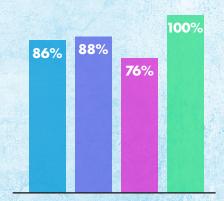
Waited more than 6 months before making a doctor appointment



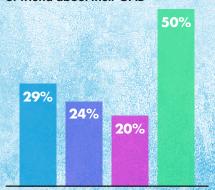
Waited over 2 months for an OAB diagnosis after contacting their doctor



OAB patients believe working with their doctor has improved their life



Have never told a family member or friend about their OAB⁷



Conclusion

Millions of people are living with the symptoms of OAB, without knowing what it is or that it is a manageable condition – sacrificing their quality of life rather than seeking medical help. If people don't know what OAB is and that they don't need to simply accept their symptoms – in a society where there is a stigma associated with bladder conditions – what action can we take to ensure that the impact of OAB does not continue to rise? It is time to take back control of our nation's bladder health.

This report paints a picture of the unmet patient needs in OAB and provides a snapshot of the current state of the nation for people living with this condition. Ultimately, this report should inspire action to be taken across the UK. The scale of the problem means we must act now.

As the survey shows, OAB can severely impact people's sleep, work, romantic life, willingness to socialise and mental health. It can make people feel worried, frustrated and embarrassed. With a shocking number of people wetting themselves in public because they couldn't find a toilet in time, the desperate situation many people are facing across the UK is brought into sobering focus.

While there are challenges around the recognition of OAB, societal stigma and delays in patients coming forward to speak to their doctor, areas of opportunity do exist to improve the patient experience and outcomes:



Facilitating more open conversations with the general public to shake the entrenched embarrassment associated with OAB and help people talk openly about the impact OAB has on their quality of life.



Empowering people with symptoms of OAB to both recognise them and to not simply accept them.



Helping people realise the sacrifices they are making to accommodate symptoms of OAB and drawing on this energy to seek medical help.



Encouraging people to seek medical help quicker, and to return to follow-up appointments even if they do not get answers in their first appointment.

We must harness these opportunities now to drive more positive outcomes for people with OAB in the future. The first step is for people who suspect they might have a bladder problem to speak to their doctor as soon as possible.







References

- 1. Irwin D, et al. Symptom bother and health care-seeking behavior among individuals with overactive bladder. Eur Urol. 2008;53(5):1029–39.
- 2. Irwin D, et al. Population-based survey of urinary incontinence, overactive bladder, and other lower urinary tract symptoms in five countries: Results of the EPIC study. Eur Urol. 2006;50(6):1306–14.
- 3. Government Office for Science. Future of an ageing population. Available at: https://assets.publishing.service.gov.uk/media/5d273adce5274a5862768ff9/future-of-an-ageing-population.pdf. Last accessed March 2024.
- **4.** UK Parliament. Overactive bladder syndrome. Available at: https://edm.parliament.uk/early-day-motion/59326/overactive-bladder-syndrome. Last accessed March 2024.
- 5. Future Health. Who's counting? The case for urgent action to improve NHS continence care. MAT-GB-NON-2023-00179.
- 6. Patient Info. Overactive bladder syndrome. Available at: https://patient.info/womens-health/lower-urinary-tract-symptoms-in-women-luts/overactive-bladder-syndrome-oab. Last accessed March 2024.
- **7.** Astellas OAB Patient Survey Results Data on File
- **8.** Malde S, et al. Case-finding tools for the diagnosis of OAB in women: A narrative review. Neurourol Urodyn. 2020;39(1):13–24.
- Abrams P, et al. Overactive bladder significantly affects quality of life. Am J Manag Care. 2000;6(Suppl. 11):S580–90.
- **10.** Turell W, et al. Taking OAB seriously: A qualitative evaluation of primary care education on OAB. Int J Clin Pract. 2020;74(11)e13604.
- 11. Eapen R and Radomski S. Gender differences in overactive bladder. Can J Urol. 2016;23(Suppl. 1):2–9.
- 12. Kirby M, et al. Overactive bladder: the importance of new guidance. Int J Clin Practic. 2006;60(10):1263-71.