OAB answers

*Helping you make decisions about treatment for **overactive bladder***

Created by:

Patiëntenorganisatie Bekkenbodem4All

SINUG Sociedad Iberoamericana de Neurourología y Uro Ginecología

Fondazione IRCCS San Gerardo dei Tintori

Sistema Socio Sanitario Regione Lombardia

Sociedad afiliada ICS

WFIPP World Federation of Incontinence and Pelvic Problems

Endorsed by:

eau Patient Office

The Overactive Bladder

Patient Decision Aid Statement of Ownership and Pledge

We, the Steering Committee, declare our independent ownership of the Patient Decision Aid (PDA), a comprehensive educational tool for people living with overactive bladder (OAB). This Patient Decision Aid aims to help patients make informed decisions about their treatment options and engage in shared decision making with their healthcare providers (HCPs).

To ensure the OAB Patient Decision Aid can continue to benefit as many people with OAB as possible, we agree to the free access, use and sharing of the tool by the organisations that we represent and the wider medical community.

This document cannot be used for commercial purposes.

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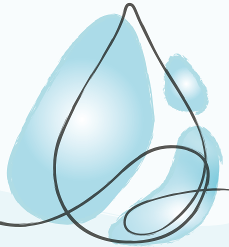
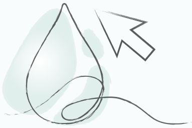


Contents

We've created this patient decision aid to support you as you make decisions about your treatment for overactive bladder (OAB).

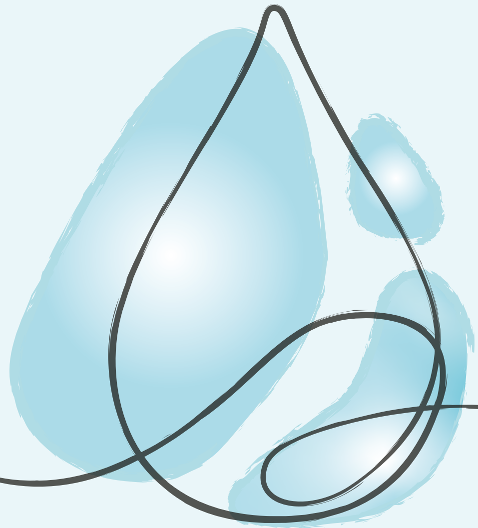
In **Section 1, page 8**, we'll help you learn more about overactive bladder and how it may affect you.



In **Section 2, page 12**, we'll guide you on your treatment journey as you learn more about your treatment options and navigate through the topics that are most appropriate for you.

You can use this Decision Aid at your own pace. Click these icons to move around the document or return to this contents page.

In **Section 3, page 20**, we'll provide tips on choosing the best option for you personally.



And in **Section 4 page 31**, we'll show you where you can find further support to manage and get treatment for your OAB.

Introduction
to the OAB Decision Aid

Life with overactive bladder (OAB) is challenging. Aside from the physical discomfort of OAB, the constant disruptions to your daily routine can seriously impact your emotional wellbeing.

There are options for treating OAB and some people may find the choice overwhelming. You may want to leave decisions up to the experts in your healthcare team. But participating in your treatment choices will help you find the treatment that best suits your needs and fits into your daily life.

This **OAB Decision Aid** has been created to help you learn more about your treatment options, how to talk to your healthcare team and how to feel empowered to make the right decisions.

Who is this OAB Decision Aid for?

This **OAB Decision Aid** was made for people whose pelvic floor rehabilitation or drug treatment no longer keeps their OAB under control and are considering what to try next.

At this stage, there are a few options that may meet your needs before thinking about invasive surgery:

- Percutaneous tibial nerve stimulation (PTNS)
- Botulinum toxin injection
- Sacral neuromodulation (SNM)

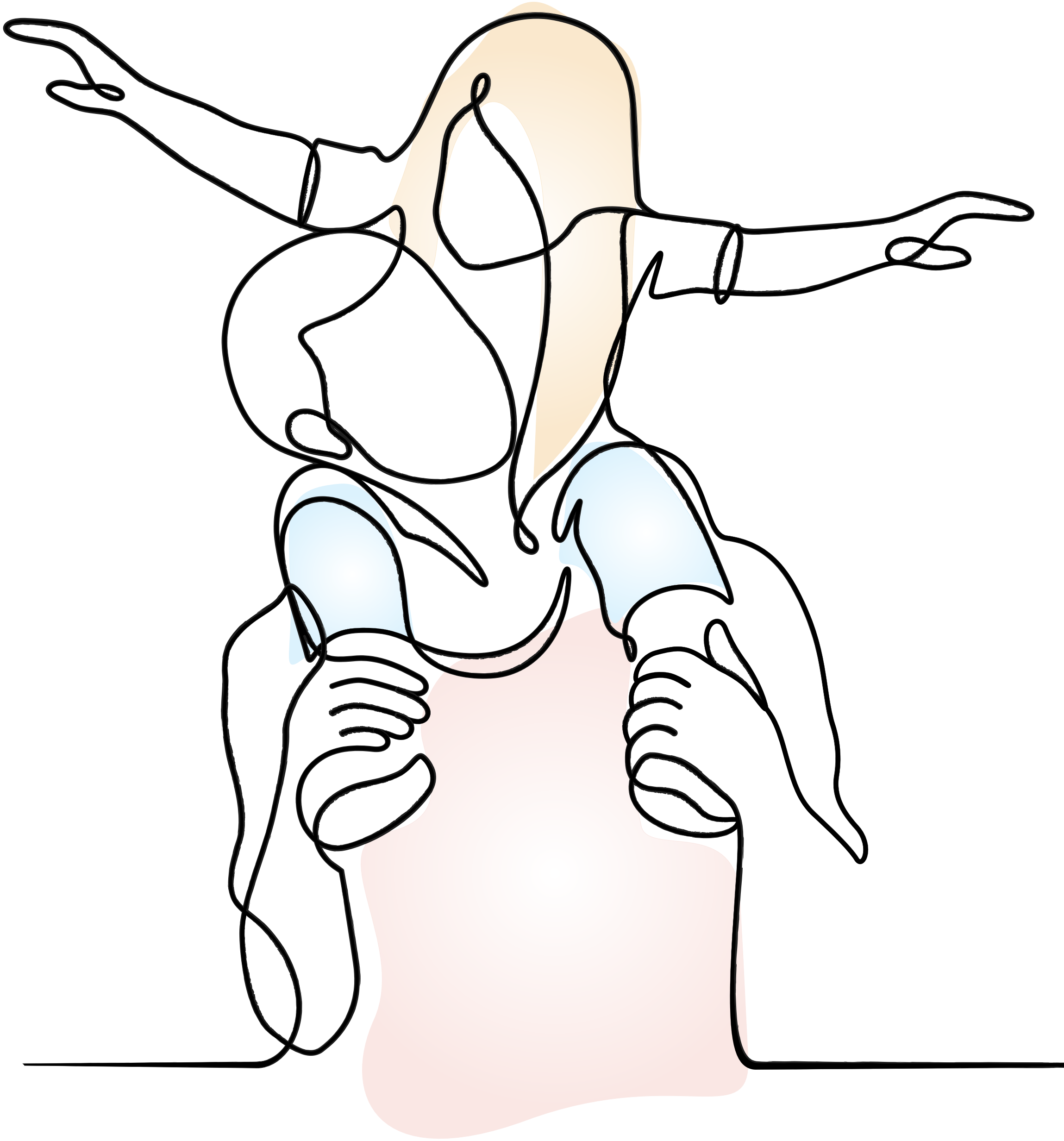
Each of these options will be explored in detail to help you understand the difference so you can make a more informed decision.

On **page 13** you can find a table that outlines the treatment options to help you choose the right treatment for you.

How was the OAB Decision Aid made?

The contents of this Decision Aid were co-created, reviewed and approved by medical experts and patient advocates to ensure the information is accurate and unbiased.

This patient decision aid was developed with funding from *Medtronic*. All content was co-created and validated by an independent steering committee of expert healthcare professionals and representatives from patient advocacy groups. For more information, see page 38.



What is OAB?

Overactive bladder (OAB) is a condition that changes the way you urinate.

This can affect different people in different ways, but generally people with OAB may find themselves needing to urinate urgently more often than usual throughout the day, having to wake up repeatedly at night to go to the bathroom, or even leaking urine in severe cases.

Around two in 10 people experiences OAB at some point in their lives. It is mostly seen in women, but also affects men and children.[1] Some people who have OAB ignore it because they think it is part of getting older or a result of childbirth.

Around *two in 10 people* experience OAB at some point in their lives.

Sometimes, OAB can be a sign of more serious health issues like diabetes or nerve problems.

Your healthcare team can help you understand more about OAB, but you may find some of the explanations here useful.

How does it feel to live with OAB?

People with OAB report feeling psychological distress,[2] which is a state of emotional suffering characterised by symptoms of unhappiness, restlessness and feeling tense.[3] People living with OAB may experience anxiety because of their symptoms and one in three show signs of depression.[4] Unfortunately, anxiety and depression also increase the likelihood and severity of urinary incontinence in people with OAB.[5]

Living with overactive bladder can make you feel afraid, insecure, embarrassed, helpless or ashamed because of sudden bladder leaks or frequent trips to the bathroom.

It's important to get over the hurdle of being embarrassed so that you can have honest, open discussions with your doctor and wider healthcare team about your symptoms and get the appropriate help you need.

OAB can only be properly diagnosed and managed with the help of a healthcare team. They may perform several tests to try to find the cause of your OAB:[6]

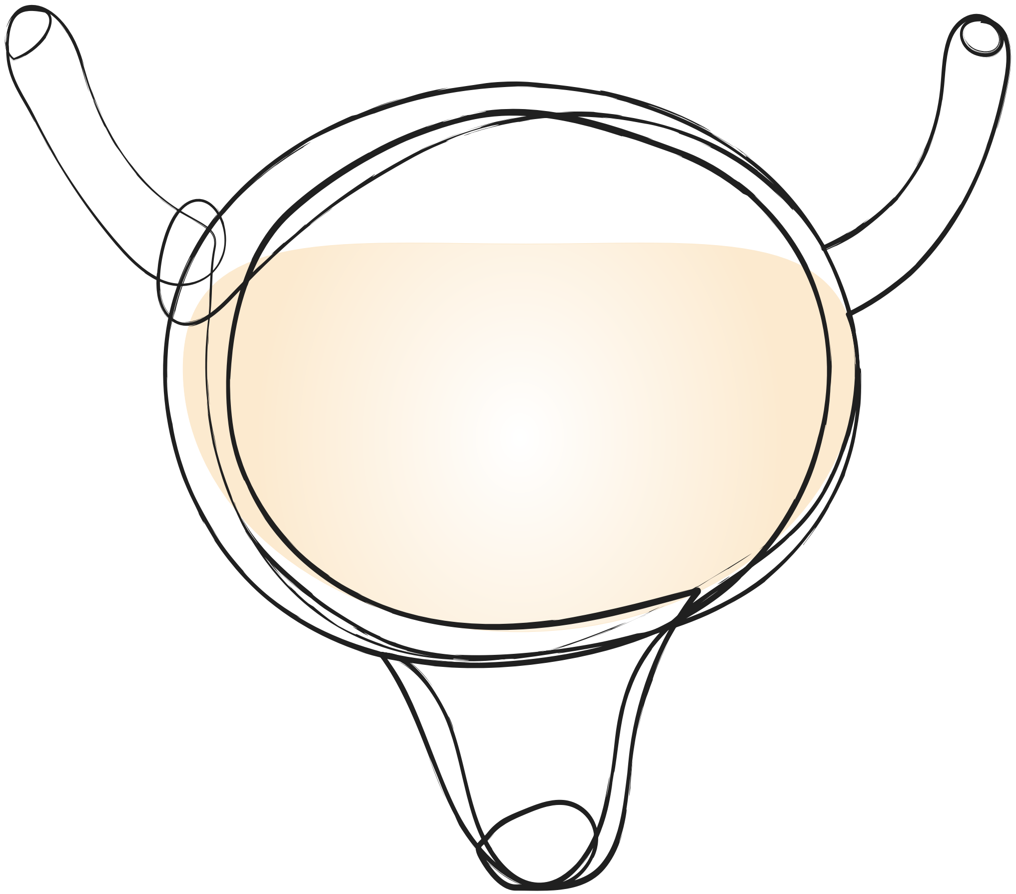
- Measuring how much you urinate over a given time with a bladder diary
- Taking a urine sample to look for blood or signs of infection
- Using an ultrasound to see if your bladder isn't emptying fully when you urinate
- They might also use a catheter (a small tube inserted through the urethra) to drain and measure any leftover urine
- Using a catheter with special pressure sensors to find out if your bladder muscles are squeezing before your bladder is full (also called a "urodynamics study").

Living with overactive bladder can make you feel *afraid, insecure, embarrassed, helpless or ashamed* because of sudden bladder leaks or frequent trips to the bathroom.

What causes OAB?[7]

The normal function of your bladder depends on a few of your body's internal systems working together properly:

- Your kidneys filter waste and excess water out of your blood, creating 1–2 litres of urine every day
- Urine travels down to your bladder through the ureters
- Your bladder slowly fills up and expands
- Your bladder can hold around 500 millilitres of urine before it needs to be emptied
- When your bladder is full, it sends signals through nerves to your brain
- Then your bladder muscles contract to squeeze urine out through your urethra
- Once you have emptied your bladder the cycle starts again



Who is in my OAB healthcare team?[8]

Your healthcare team will have several core members. You may have more contact with one than the others, but they are all working to support you to manage your OAB and have the best possible quality of life.

General practitioner (GP)
Your GP is probably the first person you went to about your symptoms. The GP may have referred you to a specialist who then confirmed your diagnosis and prescribed you treatment. Your GP may be responsible for monitoring your health between follow-up appointments with a specialist.

Gynaecologist
A doctor who specialises in the female reproductive system.

Urologist
A surgeon trained to diagnose and treat health issues around the bladder and urinary tract.

Nurse practitioner
A highly trained nurse/practitioner who has specialised in managing specific conditions such as OAB.

Physiotherapist
An allied health professional who can teach you exercises to strengthen your pelvic floor muscles and gain better control over relaxing those muscles when you urinate.

If your OAB is a result of another condition, your healthcare team may also include a range of specialists who will help to treat the underlying cause of your OAB:

- **Endocrinologist** – a doctor specialising in hormones
- **Nephrologist** – a doctor specialising in the kidneys
- **Neurologist** – a doctor specialising in nerves and the brain

Understanding your treatment options

This section of the OAB Decision Aid contains a detailed description of treatment options. These may be suitable if you feel your pelvic floor rehabilitation or drug treatment are not managing your symptoms effectively.

Trying one treatment doesn't necessarily mean you have to stay with that treatment. You can try different options or may even decide you don't want treatment at all.

All the information here reflects current practice guidelines and has been reviewed by medical experts and patient advocates to ensure you have all the information you need to make an informed choice about your care.

As a first step, why not talk to your doctors about these options at your next appointment?

Table 1: Summary of three treatment options for OAB management

	PERCUTANEOUS TIBIAL NERVE STIMULATION (PTNS)	**BOTULINUM TOXIN A INJECTIONS**	**SACRAL NEUROMODULATION (SNM)**
What is it?	A small electrical current is sent through the tibial nerve in your leg, which is connected to the nerves of your bladder and pelvic floor.	Botulinum toxin A is injected into the bladder muscle through the urethra with the aim to reduce bladder contractions/sensations.	A small electrical current is sent through the sacral nerve, from the base of your spine into the bladder.
How often is it done?	1 session per week for 12 weeks, then once a month	Every 6–12 months (mid/yearly)	The implant can stay up to 15 years depending on the make and model.
How is it done?	A healthcare professional inserts a small needle above your ankle and an electrode near the arch of the foot.	A doctor inserts a tube with a camera (a cystoscope) through your urethra and injects the botulinum toxin with a small needle into your bladder muscle.	A doctor implants a pacemaker-like device inside your buttock to change the electrical signals in the pelvic floor nerves.
Where is it done?	Hospital or clinic	Hospital	Hospital
How long does the procedure last?	30 minutes per session	May require overnight hospital stay	May require overnight hospital stay
Potential side effects	During the treatment, your toes might stretch or curl on their own, or you may feel tingling in your foot. Following treatment, you may have bruising, pain or bleeding around the ankle or a tingling sensation in your leg.	After the injection, you may feel sore once the anaesthesia wears off or find some blood in your urine for up to two days. Some people have to use a catheter for a short period, which is a flexible tube inserted into the bladder to help the urine drain freely, if the bladder muscle has a stronger reaction than expected. Botulinum toxin injection into the bladder can also increase risk of urinary tract infections.	Some people feel pain at the nerve site, through the skin or the entrance point. The implant may shift position, causing pain, or the area around the implant may get infected.

Percutaneous tibial nerve stimulation (PTNS)[9]

What is PTNS?

One of the possible causes of OAB is a problem with the nerves of the bladder and pelvic floor. In some cases, the brain sends the wrong signals from the bladder to the brain, tricking you into feeling the urge to urinate when your bladder is not full.

PTNS uses electrical signals to fix nerve problems that may cause OAB. This is called "neuromodulation". In this case, the current goes through your tibial nerve of your leg, which is connected to the nerves of your bladder and pelvic floor. This current is produced only during treatment and will not continue after the treatment session is over.

Clinical trials have shown that PTNS can reduce the urge to urinate, how often someone needs to urinate and how often someone might wet themselves compared with no treatment.[9]

How is PTNS done?

Your tibial nerve runs from your knee to your ankle, which makes it easily accessible from the outside. No surgery is required. The healthcare professional inserts a small needle above your ankle and places a sticky patch containing an electrode near the arch of your foot.

A harmless electrical current travels between the needle and the electrode, passing through the tibial nerve. You might see your toes stretch or curl on their own during treatment, or you might feel a tingling sensation in your foot. If you find the treatment is not reducing your OAB symptoms, your doctor can increase the electrical current. You may need to finish the course before seeing results.

A normal course of PTNS is 12 weekly sessions of treatment lasting 30 minutes each. The sessions are carried out in a hospital or clinic, supervised by a member of your healthcare team. You should be able to resume your normal activities as soon as the session is over. After the 12-week course, most people still need monthly treatments to keep their OAB symptoms under control.[10]

Side effects of PTNS are rare, but a few people treated with PTNS have reported bruising, pain or bleeding around the ankle where the needle was inserted or experience a tingling sensation in the rest of their leg.[9] If you experience these or any other side effects, you should talk to your healthcare team.

Botulinum toxin A injections

What is Botulinum toxin A?[11,12]

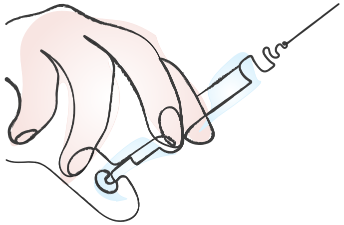
Botulinum toxin A is injected into a muscle, so that muscle can no longer move (also called "paralysis"). You may have heard of "Botox", which is one brand of Botulinum toxin A.

Botulinum toxin A is injected into the bladder wall to reduce or stop the bladder from contracting abnormally and pushing urine out involuntarily. Many clinical trials have used Botulinum toxin A to treat different conditions, including OAB.[11] These studies found benefits in reducing the urge to urinate, how often someone needs to urinate and how often someone might wet themselves compared with no treatment.

Some people have to use a catheter (a flexible tube inserted into the bladder to help the urine drain freely) for a short period if the bladder muscle has a stronger reaction than expected.[13]

If you choose to get Botulinum toxin A injections, your healthcare team may recommend learning how to catheterise safely before the injections. Other potential side effects include an increased risk of urinary tract infections.[12]

Botulinum toxin A wears off after around six months, so injections are repeated every six to 12 months.



How are Botulinum toxin A injections done?

Botulinum toxin A injections require hospital visits for the day and having surgery. To inject directly into the bladder wall, the surgeon needs to insert a tube with a camera inside (a cystoscope) through your urethra and into the inside of your bladder. The cystoscope also contains a small needle, through which the Botox is injected once the surgeon has found the right place.

You can choose to be awake or asleep during the injection. If you decide to stay awake, you will be given a local anaesthetic to numb the area. If you would rather be asleep, you will be given a general anaesthetic. Anaesthetics have their own side effects, such as feeling dizzy and sick, but these tend to wear off quite quickly.[14]

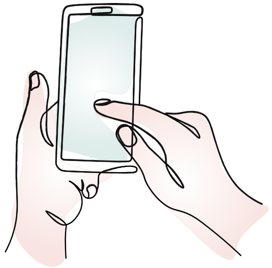
After the injection, you should be able to go home the same day. You may be given some pain medication in case you feel sore once the anaesthesia wears off. You might also find you have some blood in your urine for up to two days. This is normal, but if it continues for longer you should talk to your healthcare team.

Sacral neuromodulation (SNM)[15,16]

What is SNM?

Similar to PTNS, SNM treatment works through neuromodulation. In this case, acting on the sacral nerve, which travels from the sacrum at the base of your spine straight into the bladder. This isn't easily accessible from outside the body, so it requires surgery to insert an electrical implant under your skin.

This implant can be controlled wirelessly through an app on your phone. The implant can be turned off if needed, for example when going through airport security or entering some banks.



How are SNM implants inserted?

Before the permanent implant, your doctor will insert a temporary implant to see if it improves your symptoms. This involves a minor surgery, performed under local or general anaesthetic. This wire is attached to an electrical device outside the body that sends signals to the sacral nerve. The goal of these electrical signals is to restore normal bladder emptying without causing any discomfort.

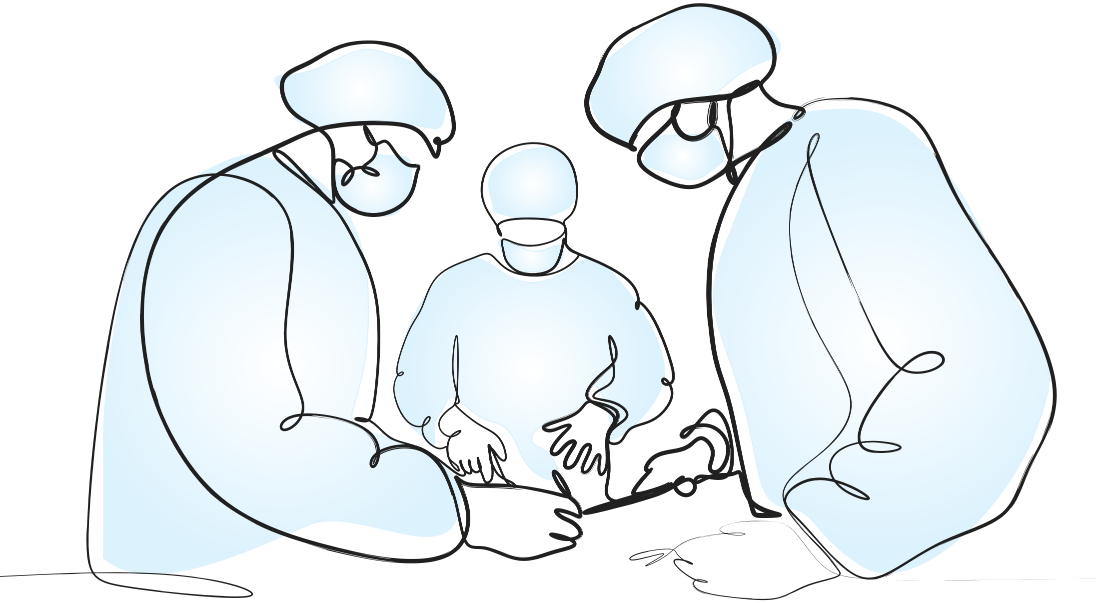
Over the course of 1–4 weeks, you will see whether there is any improvement in your OAB symptoms. If there is, you may choose to have a second, more invasive surgery under general anaesthetic to insert a permanent implant. The implant sits in a pocket under the skin of your buttock and can stay there for up to 10-15 years, depending on the make and model.[17]

Your body may gradually get used to the extra electrical signals over time, so your OAB symptoms can start to come back even with the implant switched on. If this happens, you should set an appointment with your healthcare team so they can easily adjust the strength and the direction of the signal with a remote controller. You should have follow-up appointments once a year as well to make sure the implant is working properly.

If you experience any discomfort at any time during your SNM treatment, you should speak to your healthcare team as soon as possible. Some people feel pain at the point the wires touch the nerves, or if the wires move through the skin. Others feel pain around the site of the surgery. It's possible also that the implant might shift position and cause pain, or that the area around the implant might get infected. Your healthcare team can help you manage these issues if they appear.

Other surgical options

For people who find that none of these other treatments bring their symptoms under control, there are more invasive surgeries that might work better. These include bladder reconstruction (such as augmentation cystoplasty) and urinary diversion (such as urostomy). You can ask your healthcare team for more information if needed.



Some suggested questions:	Yes/Maybe/No
Do I have enough information about each treatment or do I need my doctor to explain them to me in more depth?	
Is there anything that concerns me about any of the treatment options?	
Do I think any of the treatments meet my treatment goals?	
Is having no treatment an option for me?	
Is anyone else involved in your treatment decision-making? • I prefer the doctor to decide for me • I prefer my family member(s) to decide for me • I prefer to decide myself, once I have all the information • I prefer to share the decision with my doctor	

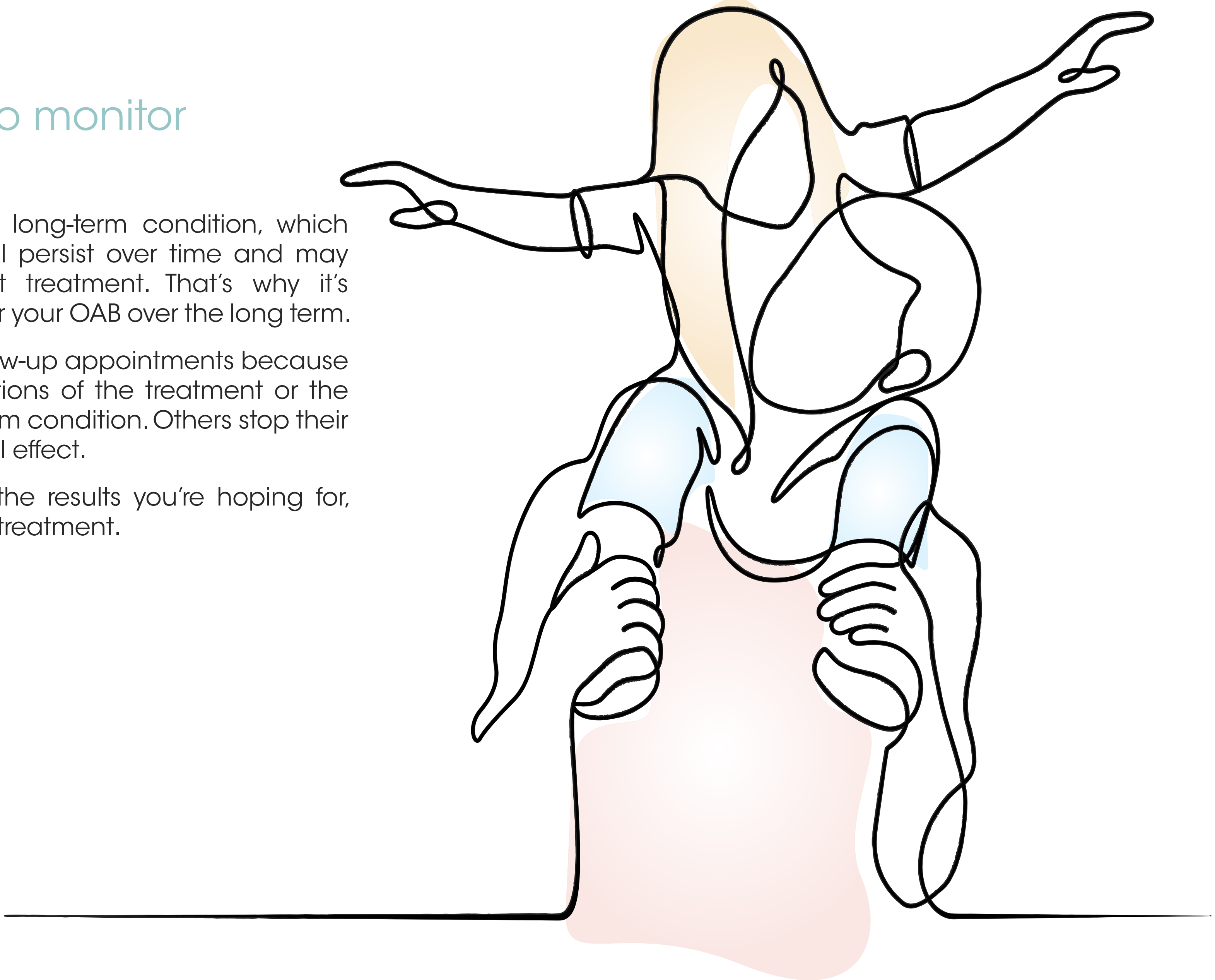
If you have responded with mostly "no" or "maybe" please speak to your doctor. You can take this table with you to support your conversation.

Why it's important to monitor your OAB[18]

Overactive bladder is often a long-term condition, which means that your symptoms will persist over time and may become more severe without treatment. That's why it's important to continue to monitor your OAB over the long term.

Some people stop going to follow-up appointments because of side effects, unmet expectations of the treatment or the realisation that OAB is a long-term condition. Others stop their treatment before it has taken full effect.

If one treatment doesn't give the results you're hoping for, consider trying another type of treatment.



Choosing what's right for you

Now that you know what your options are, you need to choose the right treatment plan for you.

It can be a little overwhelming, so we've provided some tools to help you. Whether you choose a treatment on your own, with your family or in partnership with your healthcare team, it's important that you feel comfortable with your decision.

Talking to your healthcare team about your OAB treatment options[19]

Your healthcare provider deals with issues like this every day and they want to help. They also want to listen to you because you are the expert on your symptoms, feelings, needs and concerns. Talking openly with your healthcare team will give you an opportunity to get the treatment you need.

Before your appointment, think about how your OAB and the symptoms you are experiencing impact you on a daily basis:

- Is your OAB impacting your day-to-day life? (e.g. interfering with your work, relationships, and/or social life)
- If **yes**: We recommend you use the checklist below to identify which area of your day-to-day life is impacted the most. Take this list to your doctor so you can discuss possible next steps.
- If **no**: We recommend you carry on monitoring your symptoms and if they become distressing or start to impact on your day-to-day life, then reach out to your doctor and discuss possible next steps.

Record how much your OAB negatively impacts your…

	Not at all	*Slightly*	*Somewhat*	*Moderately*	*Extremely*
Ability to do my job well					
Ability to pursue your hobbies and past times					
Ability to enjoy your sex life					
Ability to spend quality time with your family and friends					
Quality of sleep					
Ability to carry out day-to-day tasks (e.g. shopping)					
Ability to travel					
Emotional wellbeing (e.g. Do you feel embarrassed, judged by others etc.) Does that bother you?					
Mental health (e.g. experiencing depression/anxiety in response to OAB)					

What matters most to you when considering a treatment choice?

	Completely	*Moderately*	*Somewhat*	*Slightly*	*Not at all*
How long the treatment lasts					
How often the treatment needs to be repeated					
How quickly I will get relief from OAB symptoms					
How invasive the treatment is					
Risk of complications from treatment					
Potential side effects of the treatment					
The treatment procedure					
Access to the treatment centre					
The waiting list for the treatment					
Cost of the treatment					
Other: please specify					

Now that you've thought about what matters most to you, what treatment would you prefer?
Circle your answer below and discuss it with your doctor.

My current choice is:

- Percutaneous tibial nerve stimulation (PTNS)
- Botulinum toxin A injections
- Sacral neuromodulation (SNM)
- Other surgical options
- No surgery
- Not sure

This is because:

You can also bring a list of questions you have about your treatment. Remember, you have a right to be informed. Here are some examples of questions you may want to ask:

- Will it get worse if left untreated?
- What treatments are available?
- How long will the treatment last?
- What do you recommend?
- Are there any side effects?
- Are there other treatments that I should consider?
- Are there any incontinence products you recommend?
- Should I limit my fluid intake?
- Should I stop drinking after a certain time?
- Should I alter my diet or exercise?
- Can you recommend any websites where I can learn more?

Your healthcare provider will also ask you questions about your symptoms. They may feel personal, but don't be shy about your answers as they can help provide better treatment options.

Common barriers to personal empowerment

It's normal to feel self-conscious when you're speaking to your doctor, but sharing your concerns and asking questions will help to find the right solution for you. It will also empower you with the information you need to make decisions that work for you.

There are a few reasons why you may struggle to feel in control of your treatment:

1

Communication difficulties with your healthcare team

Clear communication with your doctor is important to most people, but you may feel that your doctor doesn't understand or listen to your experiences and perspectives about your bladder symptoms. For women, speaking with a male doctor can also make you feel that he doesn't understand your situation. Disconnect in communication can also result from you and your doctor using different words and explanations for your condition and treatment. For example, some people use the expression 'overactive bladder' or 'OAB' while others refer to 'incontinence' which isn't the same thing.

2

Stigma of living with OAB

People with OAB often feel stigmatised by the frequency and urgency to urinate, as well as having to deal with incontinence. This stigma can stem from having to leave social situations to find a bathroom, losing control of your bodily functions and other people's speculation that you have a 'problem' and you're unable to control your condition. Men may be concerned about how often they are seen going to the bathroom and fear being seen as impotent. Women may fear the perception that they're unclean or worry that OAB may cause problems during sex.[20]

3

Self-reliance and coping techniques

Empowering yourself to discuss your condition with your doctor and share in the decision-making of your treatment can be difficult when you feel dissatisfied with your healthcare management. Some people abandon medical care and develop their own ways of coping without treatment. These techniques may include finding escape routes and bathroom access in new environments and avoiding activities and places where access to bathrooms is unknown. But sometimes, these coping strategies make the symptoms worse and increase your levels of anxiety and psychological stress.[21]

4

Reluctance to ask questions

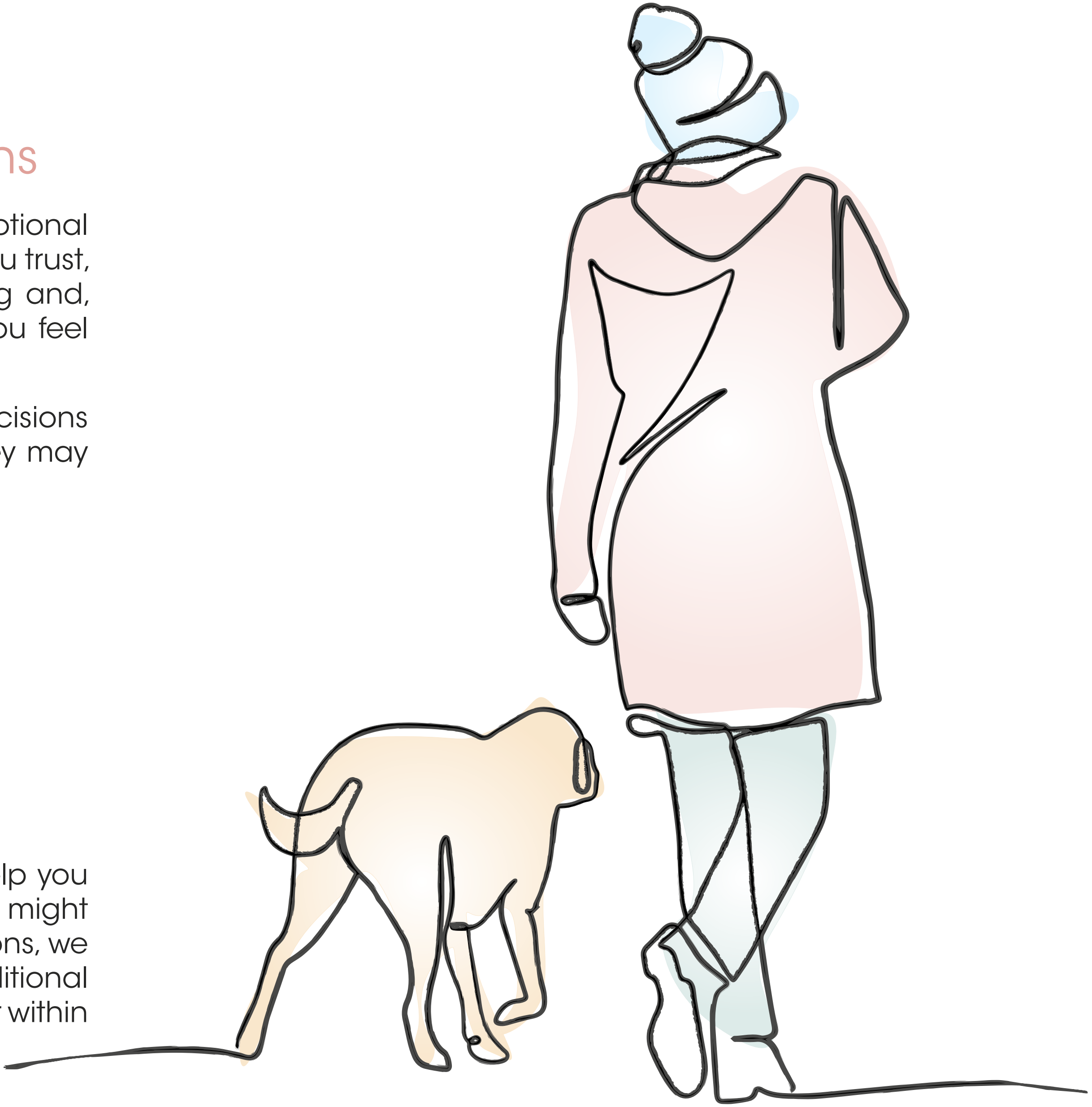
Talking to your doctor about your symptoms and your emotional wellbeing can help, but sharing details of your OAB can feel embarrassing.[22] You may also feel uncomfortable asking questions about your condition or even guilty for taking up the doctor's time.[23] Some people feel their symptoms aren't severe enough to bother a doctor with or they believe their symptoms are simply part of aging. The average person with OAB waits 3.5 years before they seek help from a physician,[22] which results in untreated symptoms and additional stress.

Talking to your family and friends about your OAB treatment options

Your friends and family can be a reliable source of emotional and practical support for you. If you talk with people you trust, you may find they are going through the same thing and, together, you can build a support network to help you feel more in control of your treatment choices.

Family and friends can also help you to make decisions about your treatment. They may want to help, but they may not know how. Ask them if they will help you with:

- booking appointments
- coming with you to appointments
- choosing the right incontinence product
- finding resources and information online
- making time to talk about your options



Identifying your support needs

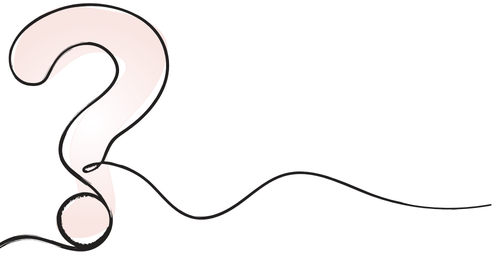
Opposite are some reflective questions which may help you to identify any potential barriers or support needs you might have. If you answer 'yes' to any of the following questions, we have made some suggestions of ways you can get additional support or where you can find further information, either within this decision aid or beyond.

Questions about travel	**Yes/ No**	**If yes...**
Do you have other responsibilities or time constraints (e.g. work, childcare) that might make it difficult to attend regular treatments or follow-ups?		It is common for people to feel overwhelmed with daily commitments and responsibilities, making it difficult to find the time to attend appointments. It's ok to ask others for help. We all need a little help and support at times. Think about possible ways other people in your life could help you, for example, asking a friend or colleague to take on some of your responsibilities while you attend your treatment appointments.
Do you have difficulties accessing or travelling to/from treatment facilities? (e.g. transport issues/ mobility issues)		You may find it difficult to access certain treatment facilities if you do not have a car, money for transport or have mobility issues. These barriers might make it hard for you to consider long-term treatment options or your preferred choice of treatment. Consider asking a family member or close friend if they can commit to helping you to access treatment appointments either by driving you to and from appointments or coming with you.
Questions about communicating with your doctor	**Yes/ No**	**If yes...**
Do you feel you lack the social support you need to make a decision about a treatment plan?		It can be hard to make an important decision on your own. People often worry they will make the wrong choice. It can help to talk through your options with others and get different perspectives. You could consider asking for support from: • Your doctor • Other members of your healthcare team • A trusted friend • A patient group or other members of an online support group [see **page 34**] If your feel your treatment choice will impact family members/a caregiver, then it would be good idea to discuss your options with them and find a solution that works for everyone. This way you can be confident that they know how and when they may need to offer you practical support.

Questions about your perceptions and emotions	**Yes/ No**	**If yes...**
Are you unsure about whether treatment for your overactive bladder is necessary for you personally because your symptoms are manageable?		Some people with overactive bladder may feel that they do not need treatment to help with their symptoms as they have developed strategies to get by. This is totally fine, everyone is different and has different priorities. However, if self-management or prior treatments are no longer working for you and you are struggling in your day-to-day life, there is no shame in exploring your treatment options. It may be helpful for you to write a list to compare your reasons for wanting (pros) and not wanting (cons) to start treatment or try a new treatment for overactive bladder. This might help you to clarify your thoughts. You could also discuss your list with your doctor so that they understand how you think and feel.
Do you think standard medical treatments will not work for you because they haven't worked in the past?		People may feel that trying a treatment or another treatment for their overactive bladder is pointless if nothing has worked for them in the past. This is a common response, however, there are treatments for overactive bladder that work very differently from the ones that you may have tried already. Everyone is different and respond to treatments in their own way. The treatment that works best for you may be one you have yet to try. You do not have to continue to cope on your own. There are potential alternatives.
Do you have concerns about experiencing side effects of starting a new treatment plan?		When starting a new treatment, many people worry about experiencing side effects. The good news is that many of the potential side effects of treatments are mild and/or temporary. If you have any concerns about side effects of any overactive bladder treatments, speak to your doctor so you can discuss any potential side effects that might be concerning you. [See also **page 13** for potential side effects of each treatment]

Questions about your perceptions and emotions	**Yes/ No**	**If yes...**
Do you experience any emotional/ psychological distress living with the symptoms of overactive bladder syndrome?		It is normal to experience a range of emotions if you are living with a chronic condition such as overactive bladder. You may feel frustrated, anxious or embarrassed. These are all normal reactions. You may find it helpful to talk to talk to a professional therapist or counsellor about how you are feeling. Ask your doctor if they can refer you to a professional or help you find one yourself.
Do you feel you lack the social support you need to make a decision about a treatment plan?		It can be hard to make an important decision on your own. People often worry they will make the wrong choice. It can help to talk through your options with others and get different perspectives. You could consider asking for support from: • Your doctor • Other members of your healthcare team • A trusted friend • A patient group or other members of an online support group [see **Section 4**] If your feel your treatment choice will impact family members/a caregiver, then it would be good idea to discuss your options with them and find a solution that works for everyone. This way you can be confident that they know how and when they may need to offer you practical support.

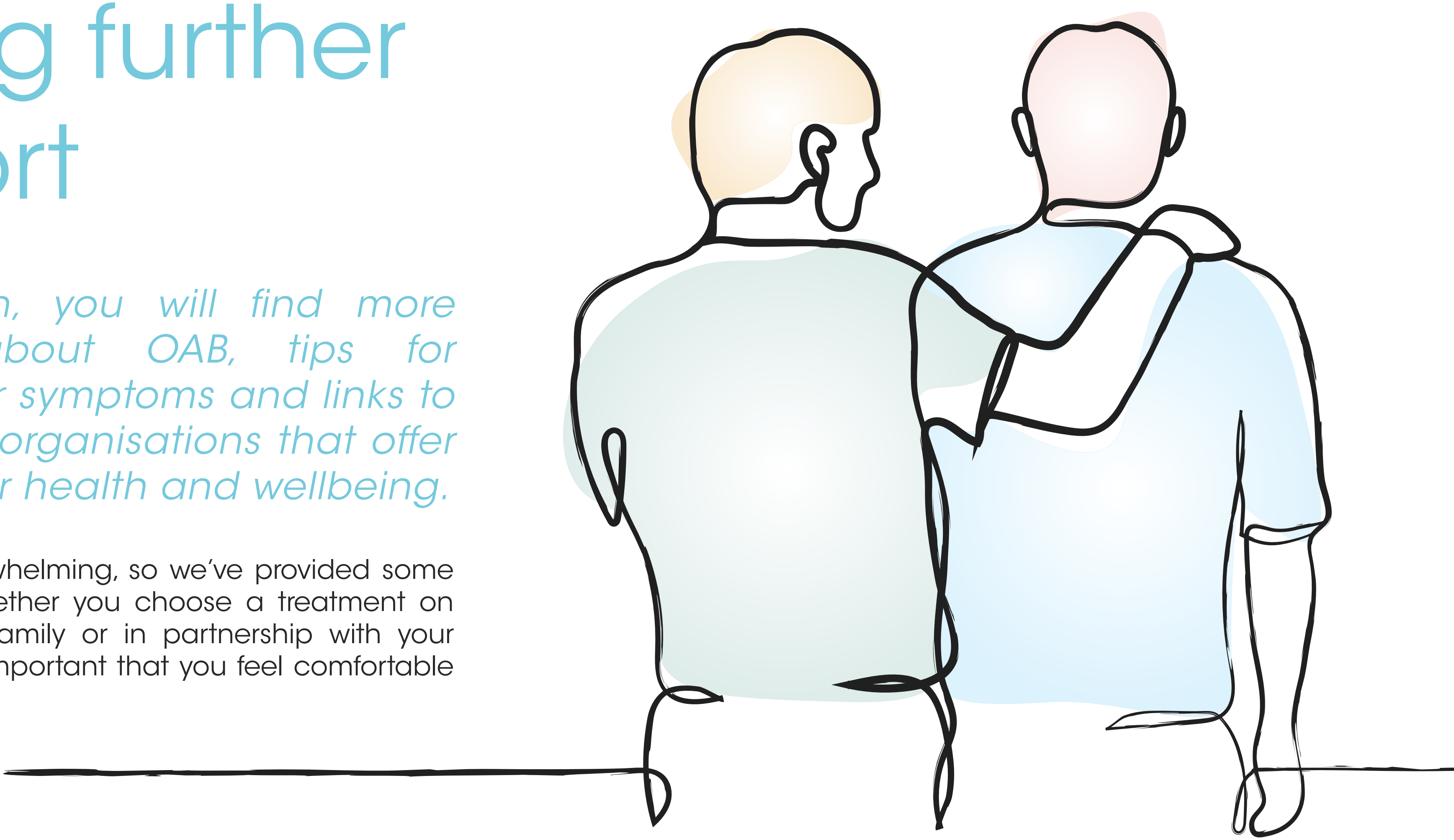
What treatments would you like to learn more about?
What would you like to ask your doctor?



Finding further support

In this section, you will find more information about OAB, tips for managing your symptoms and links to resources and organisations that offer support for your health and wellbeing.

It can be a little overwhelming, so we've provided some tools to help you. Whether you choose a treatment on your own, with your family or in partnership with your healthcare team, it's important that you feel comfortable with your decision.



Myth buster

Many people think OAB is just a normal part of the aging process or it's your fault if you can't control your bladder, but these are just myths. Here's a few more myths about OAB and the truth that will help you learn to live a better life.

Myth #1:
You should empty your bladder often

If you go to the bathroom too often, you may be training your bladder to only be able to hold small amounts of urine. This means you won't be able to hold it in when you really do have to go.[24]

Myth #2:
It's better to hover over a public toilet seat when weeing

Women often hover over public toilets for fear of catching something from the toilet seat, but this effort puts a strain on your pelvic floor muscles. You can't catch an infection from a toilet seat. Sitting down to empty your bladder allows the muscles to relax.[24]

Myth #3:
You should drink 2 litres of water a day

The amount of water you need every day varies with each individual, depending on things like how much exercise you are doing, so it's best to check with your doctor. You should drink water when you feel thirsty to avoid your urine becoming too concentrated and developing kidney stones.[24]

Myth #4:
It's normal to leak a bit when you exercise, sneeze, cough or laugh

Leaking urine is a symptom of stress incontinence, which can be treated. If you leak urine, see your doctor as it can worsen over time if left untreated.[24]

Myth #5:
Only women can have an overactive bladder

Both men and women can experience an overactive bladder. For men, it often happens due to an enlarged prostate. Half of all men have an enlarged prostate by the time they turn 60, and by the age of 85, the occurrence can be as high as 90 percent.[24]

Myth #6:
Bladder problems are a natural part of aging

Bladder problems are more common as people get older, but they can occur at any age. Urinary incontinence is not a normal part of aging.[25]

Top tips to manage OAB symptoms[6]

While some coping mechanisms only increase your stress and anxiety and make your symptoms worse, other habits can help you manage your condition and live a better life.

- **Drink enough water**
  Too much fluid can make your symptoms worse, but not drinking can increase the urge to urinate, so ask your doctor how much water you should drink every day.
- **Limit foods and drinks that irritate your bladder**
  Try to avoid foods that make your condition worse, such as caffeine, alcohol, tea, carbonated drinks, citrus juice and fruit, chocolate, spicy foods, and tomatoes.
- **Maintain a healthy weight**
  People who are overweight are at a greater risk of stress urinary incontinence. Losing weight can help to ease your other symptoms too.
- **Eat more fibre**
  Constipation can make urinary incontinence worse, so adding more fibre to your diet can help to keep you regular.
- **Quit smoking**
  Smoking is not only bad for your lungs, it irritates your OAB symptoms.
- **Wear absorbent pads or underwear**
  These can help to contain liquid and control odour if you have leaks.
- **Try bladder training**
  Going to the bathroom only when you need to can help your bladder get used to being full.[26] Ask your GP for more information.
- **Exercise your pelvic floor muscles**
  These muscles support the bladder, pelvis and urethra and can become weak after surgery, pregnancy or childbirth. Pelvic floor exercises can help strengthen them and improve OAB symptoms as well as your quality of life.[27]
- **Try yoga or meditation**
  Yoga and self-reflection can also help improve your quality of life, including reducing depression and improving your sleep.[28]

- **Seek medical help**
  Medical treatment for OAB can help relieve your physical symptoms and improve your anxiety and depression.[29]
- **Try behavioural therapy**
  Adding behavioural therapy to your medical treatment provides improvements to both your symptoms and quality of life. Behavioural therapy is based on understanding how your thoughts and beliefs affect your actions and moods.[30]
- **Connect with others**
  Talking with other people who have OAB can help you to feel less embarrassed about the condition when you realise many others are experiencing the same difficulties as you.[31]

Helpful organisations based in the UK

If you would like more information about overactive bladder (OAB) or support with living with OAB, you can contact the following organisations. They provide a wealth of information and resources, including stories from other people living with OAB, forums to connect with others, telephone support services, local support groups and information about the latest research.

BladderProblems.co.uk
https://www.bladderproblem.co.uk/index.html

Bladder Health UK
https://bladderhealthuk.org/

Bladder and Bowel Community
https://www.bladderandbowel.org/

WFIPP's Support in Continence
https://supportincontinence.org

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Appendix

What is shared decision-making (SDM)?

Shared decision-making is a process in which doctors and patients work together to reach a decision about healthcare.[1] It involves talking about tests and treatments and choosing options based on both the medical information and the individual's needs and preferences. Healthcare professionals are the experts on the medical evidence and patients are the experts on what matters most to them.[2]

What are the main principles of shared decision-making?[3]

Shared decision-making with your healthcare team should make you feel comfortable, well informed and confident about your choices. When you make shared decisions with your healthcare team, you have:

1. The right to be involved and supported in your healthcare
2. A conversation focused on your specific needs, whether it is in person, by phone or video call
3. The right to be listened to
4. The right to be given high-quality sources of information, such as links to the NHS website, appropriate patient organisations, or relevant NICE guidelines and quality-assured patient decision aids, plus time and support to make decisions[1]
5. The understanding that all adults can make decisions
6. The option of making decisions with the help of family or friends
7. Confidence that everyone should be supported

What are the benefits of SDM?

Information alone is not enough to support you when you are making a decision about your health.[4] Most people want to be more involved in making decisions about their health and care.[5] Sometimes, it can be difficult to understand your medical needs and the treatments involved, or you may feel nervous about asking questions or expressing your concerns.

Shared decision-making gives you an active role in your care so you can understand the risks, benefits and possible side effects of different treatment options. People who are more involved in their own healthcare decisions are more satisfied with the care they receive.[6] Shared decision-making also benefits people by:[1]

- Giving you the opportunity to discuss and share information so you have a good understanding of different options.
- Empowering you to make decisions about the treatment and care that is right for you at that time. This includes choosing to continue with their current treatment or choosing no treatment at all.
- Giving you the choice about how much you want to participate in decision-making.

What if I don't want to make shared decisions?

Many people want to play an active role in making decisions about their treatment and ensure the options match their needs and values.[7] But others may feel overwhelmed or confused by treatment decisions and prefer to trust their GP will make the right decision for them. Some individuals may not want to take part in making decisions at a particular time, such as choosing a treatment plan.

Some decisions are not urgent, even when an illness is serious. You don't have to make decisions about your treatment right away. Some people may need more time to think about their options and discuss them with family and friends or have more time to gather information before they make their decision.[8]

Decisions about your OAB treatment should be based on what is best for you, according to your circumstances and values. [9] Part of what is best for you is how comfortable you feel making decisions about your care. You don't have to participate in shared decision-making if you don't want to. Your healthcare provider should consider your personal preferences for how much you want to be involved in making decisions about your treatment and tailor your care accordingly.

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