

Understanding bedwetting in children with Down syndrome

This booklet has been produced to help parents and carers understand bedwetting, why it happens and how it can be made better.

It is important to remember that bedwetting is not the child's fault; it is not caused by anything you or your child has done or not done. Having Down syndrome is not the reason for the bedwetting. It is a problem that happens to large numbers of children and treatment can help to make it better. Any child aged 5 years and older (including children with Down syndrome), who has been toilet trained during the day for at least 3 months, and who is still wet at night should always be offered help.

Treatments for bedwetting are available, and it is important to understand that children are not able to learn to be dry when they are asleep, in the same way that they learn to use the toilet during the day.

This booklet will explain why some children wet the bed, will look at things you can do that may help and will talk about some of the treatments used and where you may be able to find help for your child.

Do not accept that the bedwetting is because of your child having Down syndrome. Most areas have nurse-led bedwetting clinics so if the bedwetting doesn't get better or is causing a problem then do ask your GP to refer you to your local clinic.

Enuresis

Enuresis is the medical name for bedwetting during sleep. To be called enuresis the wetting must happen at least twice a week, in children who are toilet trained in the day and at least five years old. To have 'enuresis' children should not have any specific medical reasons for producing extra urine (wee) at night or taking any medicines that affect the amount of urine (wee) produced or needing extra fluid /feeds during the night.

Why and how is urine (wee) made?

Urine (wee) is made to help the body get rid of waste. It is made in the kidneys and is then sent through two tubes (ureters) to the bladder. The bladder stores the urine (wee). When the bladder is nearly full it sends a message to the brain to say it is time to use the toilet.

Why does bedwetting happen?

Bedwetting happens because the child sleeps through the messages from the bladder to the brain. The bladder then empties, with the child staying asleep and the bed gets wet. Most children sleep through the night without waking to wee because their bladder is big enough to hold all the wee they make at night. Some children who do need to wee during the night are able to wake up and go to the toilet, so do not wet the bed.

Some children are wet every night, some have some dry nights, and some children wet the bed more than once a night.

Why do some children need to wee at night?

Reasons why your child may not be able to hold all the urine (wee) that they make at night are:

- The bladder is not big enough to hold all the wee they make while they are asleep.
- The bladder is big enough to hold all the wee, but it gets 'twitchy' and empties before it is full.
- The child is not making enough of a special chemical messenger called vasopressin. Vasopressin is sent to the kidneys from the brain and tells them to make less wee at night. If your child is not making enough of this chemical messenger, the kidneys make more wee at night than the bladder can hold and, if they do not wake up when the bladder is full, they will get a wet bed.

Other causes of bedwetting:



Constipation

If your child is not opening their bowels (pooping) often enough, or if they are not completely emptying their rectum (bottom) when they poo, then the poo can collect in their rectum. This then takes up space that the bladder needs and makes it harder for the bladder to work properly, which can cause bedwetting. Children should poo at least 3-4 times a week.



Drinks

Fizzy drinks and drinks with caffeine in them (tea, coffee, hot chocolate and some energy drinks) can increase the chances of wetting. Not drinking enough during the day may mean that the bladder gets used to the kidneys making small amounts of wee. When this happens, the bladder does not stretch and grow bigger, so is less able to hold all the wee made at night. Drinking too much before bed can also make wetting worse.



Family History

Bedwetting runs in families. If a parent or a close relative wet the bed, then it is more likely that your child will. This is not related to their disability.



Other factors

Not going to the toilet before going to sleep means that the child's bladder already has some wee in it when they go to sleep. This makes them less able to hold onto all the wee they make at night.

Drinking or eating in the hour before bed can make the kidneys produce more wee at night and therefore cause bedwetting.

Some children wake at night but are too frightened to get up to wee when it is dark. Some children, who wear pull-ups or nappies for bed, may think it is alright to wee in them, even when they are awake.



Other causes

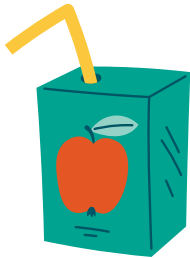
Very occasionally, children who have found it hard to get dry during the day may have problems with their bladder or kidneys (urinary system). Children with Down syndrome are more likely to have problems with their urinary system than other children, but the problems are still rare.

Sometimes it is felt that being wet in the day, or overnight is part of having a learning disability. If children are struggling to toilet train during the day, or if they are often wet during the day, or if they have constipation, they should be offered an assessment. Their doctor or school nurse should be able to give advice about this, and refer them to a specialist, if needed.

What can parents/carers do to help?



Speak to your child's school nurse, specialist nurse, doctor or consultant. They should be able to offer help in working out why your child is wetting the bed, or refer them to a specialist service for support. Knowing what is causing the bedwetting will help with the decision about what to do to try to make it better.



Try to make sure that your child is having between six and eight water-based drinks every day. Water or sugar-free squash is the best. Three of these should be had during the school day. Your child should drink more than this if it is very hot, or they are doing lots of exercise.

Do not stop your child drinking during the day, but do not encourage them to drink in the hour before they go to bed. Try to avoid giving them food in the last hour before bed as well.



Encourage your child to use the toilet every two to three hours during the day. After they have had a drink can be a good time.

Avoid fizzy drinks, or ones with caffeine (tea, coffee, hot chocolate and some energy drinks), as they can make wetting worse.

Encourage your child to wee just before they go to sleep.



Try to make sure your child is not worried about getting up to use the toilet if they wake up during the night. If the toilet is a long way from their room, or if they are frightened to go to the toilet at night, you could try leaving a potty or bucket in their room.



Try to make sure they do not get constipated, by encouraging them to have plenty of water-based drinks and plenty of fruit and vegetables every day (about six to eight drinks and five portions of fruit and vegetables). If they are struggling to poo, if poos are always or often hard, or painful to pass, or if they are pooing less than once every three days, they may be constipated. If you think they may be constipated, you could talk to their doctor or nurse.

What can parents/carers do to help?



Small rewards might help your child stay motivated to do things like drinking well and going to the toilet when they are asked. Rewards should not be used for dry nights, as your child will not be able to control what their body does while they are asleep.



If your child uses nappies or pull-ups in bed, you could try without them for three or four nights to see if that helps. You will need to use a washable or disposable bed pad or plastic cover to protect the mattress if your child is wetting.

Helping the bladder to work better: bladder training

If the bedwetting is caused by the bladder not holding enough wee, or by the bladder getting 'twitchy' as it fills, then you may be asked to help your child with 'bladder training'. This involves:

- Making sure your child has a water-based drink every two hours.
- Trying different types of drinks to see if this has any effect on the wetting.
- Making sure your child tries to wee after each drink.
- Making sure your child is sitting on the toilet properly (for girls, and for boys who cannot or do not want to stand to wee). They may need a toilet insert seat to be comfortable. They may need a stool or box to support their feet as well. If your child has problems with balance, they may need the help of an occupational therapist, to make sure they can sit safely and comfortably on the toilet.
- Making sure your child spends enough time on the toilet to completely finish weeing before they leave.

You may be asked to keep a chart of when your child has a drink and when they wee. If possible, you may be asked to measure their wees to see how much their bladder is holding.

The doctor or nurse may suggest some medicine or tablets to help the bladder relax while it is filling.

Helping the kidneys to make less wee at night - Desmopressin

Sometimes medicine is prescribed to help with the bedwetting. If your child's doctor or nurse thinks that the wetting is caused by your child making too much wee at night (because they are not making enough of their own vasopressin), they may suggest that your child tries a medicine called Desmopressin. This can be taken by most children who are five years or older. Your doctor or nurse will talk to you about whether it would be suitable for your child.



Desmopressin works by giving the same message to the kidneys as the vasopressin that the body produces naturally. It tells the kidneys to make less urine (wee) at night than they do during the day. Most children normally only produce enough urine at night to fill the bladder once. However, children with bedwetting, due to a lack of vasopressin, can produce up to two or more bladder-size volumes of urine.

Desmopressin comes as a melt that dissolves very quickly under your child's tongue, as a tablet or more recently as a liquid. Desmopressin starts to work very quickly and can be taken for as long as it is needed. It should be taken at bedtime and only works on nights when it is taken. It is normally suggested that children have a break from Desmopressin every three months, to see if they still need it, or if their body has learnt to keep them dry without the medicine.

Desmopressin does not work for everyone, and it may not be suitable for everyone. The amount of Desmopressin needed is also different for different children. Your nurse or doctor will tell you what the right dose is for your child.

If your child is prescribed Desmopressin, it is important that they do not drink for one hour before taking it and for eight hours afterwards (they should be asleep then). If they normally drink just before going to bed, or if they take a drink to bed with them, let your doctor or nurse know.

It is important that you do not give Desmopressin to your child if they are unwell with diarrhoea, vomiting (are being sick), or if they have a raised temperature. They may start taking it again when they are better.

Helping the bladder hold more wee at night – the enuresis alarm

The enuresis alarm helps your child's brain to wake them when the bladder is full. It works by making a noise as soon as your child starts to wet. It often takes a few nights (or even longer) for children to learn to wake up to the alarm sounds, so they usually need you to help, by going to wake them as soon as the alarm starts to make a noise.

There are two types of alarm. One has a sound box that sits near the bed and a mat that goes under the bottom sheet. It is called a bed-mat alarm. The other type of alarm, a body-worn alarm, clips onto your child's pyjamas and underwear. The doctor or nurse will talk to you about which type of alarm is best for your child.

When your child starts to wet during the night, the alarm will make a noise. You need to make sure that your child has woken, or you will need to wake them up, with the alarm still making a noise. You may need to help them turn the alarm off, if they cannot manage on their own. Then they need to go to the toilet and try to wee. They should change any wet clothes or bedding, before going back to sleep. They may need your help with this.

It can take a few weeks for alarms to start to work and a few months for children to become dry at night. Alarms are not suitable for all children and families, but your doctor or nurse will talk to you about this. Alarms are suitable for some children with learning disabilities.

Further information

NICE

The National Institute for Health and Care Excellence (NICE) have produced a guidance document and a quality standard about assessment and treatment for children with bedwetting, called 'The management of bedwetting in children and young people'. Families may find this helpful. It is available online at the NICE website:

www.nice.org.uk/guidance/cg111

DSUK

The Down Syndrome UK website has further information about bedwetting and other bladder and bowel issues.

www.downsyndromeuk.co.uk/parents/toilettraining/