

Bedwetting (nocturnal enuresis) in children with sickle cell disease (SCD)

This leaflet gives more information about bedwetting in children with SCD, including why it is more common among children with SCD, and what you can do to help your child. If you have any more questions or concerns, please contact us using (details at the end of this leaflet).

What is bedwetting?

Bedwetting is a common term for accidentally wetting the bed (urinating) during the night.

Bedwetting is a common problem. There are an estimated 500,000 children and young people in the UK with bedwetting issues at night. Although most children are able to stay dry throughout the night by the age of four, bedwetting is common. It is considered to be a problem when children over five years of age wet the bed three or more times a week.

Does my child's bedwetting have anything to do with their SCD?

Children and young people with SCD are more likely to have problems with bedwetting. This is mainly because the kidneys of people with SCD are less able to produce concentrated urine and instead make large amounts of dilute urine. This dilute urine fills up the bladder quickly, resulting in the child needing to urinate during the night.

In addition, some sickle cell children have a smaller bladder than normal which also means that their bladders fill quickly and they are unable to get through the night without urinating. If the child or young person with SCD is not able to wake from sleep in response to their bladder being full, this can result in them wetting the bed.

How can bedwetting affect my child?

Bedwetting can have a negative effect on a child's self-esteem and can make them feel anxious and sad. They may feel like babies compared to friends and siblings (brothers and sisters) who are able to stay dry at night. Bedwetting may also interfere with your child's social development and they may not want to go on sleepovers, overnight school trips or visit relatives.

Having a child that wets the bed can interfere with family life, as parents have to get up to change the sheets. Parents may feel frustrated due to lack of sleep, increased laundry, and the inability to help the child. It is important to remember that the child has no control over their bedwetting and should not be punished or told off for it.

What can you do to help your child?

Although you cannot stop your child's bedwetting, there are some things you can do to help the situation and make bedwetting less likely/frequent:

- Make sure your child uses the toilet regularly during the day.
- Avoid giving your child drinks such as tea, hot chocolate or cola (caffeine is a diuretic so you wee more). You should also avoid energy drinks. It is recommended that they drink healthy drinks, for example, milk and/or water. Children should be encouraged to drink 6-8 cups of fluid equally spaced out through the day.
- Make sure your child uses the toilet just before going to sleep. If your child is awake in bed, reading or watching TV, encourage them to use the toilet every half an hour until they are feeling very sleepy.
- If your child wakes up in the night for any other reason, ask them to get up and use the toilet, even if they don't feel that they need to.
- Ask your child to use the toilet as soon as they wake up in the morning.
- Use an alarm clock to wake your child every four hours and ask them to go to the toilet.
- Praise your child each time they get up and use the toilet - consider using a sticker chart to reward them. When an agreed number of stickers have been given, a special treat may be awarded, such as watching a film or having an extra story.

Do not make a fuss if your child has wet the bed. Help them change the sheets and get them back to bed. Remember, it may take a couple of weeks for the child to get into a routine of waking up.

What help can we get if the bedwetting continues?

If the bedwetting continues, we will refer your child to a special clinic for a full evaluation. After the evaluation, your child may be offered a number of treatment options, outlined below.

Bedwetting alarm

This is an alarm attached to a sensor pad that is placed in your child's underwear or under the sheet of the bed. When the child starts to urinate, the alarm will sound and wake up the child, alerting them to get up and go to the toilet. With time and training your child will get quicker and quicker at waking, until they learn to wake before urinating, in response to the feeling of a full bladder.

Medication

Medication for the treatment of bedwetting may be used when other methods haven't worked. These are only used when the child is older than six years. These medications include:

- **Desmopressin (tablets)**
This is considered as a first line of treatment along with the use of an alarm. It works by helping to make the urine more concentrated, so that there is less of it. However, it is likely that once desmopressin is stopped, the bedwetting may start up again. Desmopressin should not be used if your child is vomiting, has diarrhoea, or if they need to drink through the night, for example, during a sickling crisis.
- **Imipramine (tablets)**
If desmopressin does not work, imipramine may be used. Side effects are common and can include loss of appetite, headaches, diarrhoea, constipation, dry mouth and anxiety. Using this drug may mean drier nights, but children often resume bedwetting once they stop taking it.
- **Oxybutynin (tablets)**
This can be used to improve bladder capacity if it is found to be small, and can be used in combination with desmopressin.

What will happen in the future?

Most children will stop wetting the bed eventually. However, a small number may continue to wet the bed even when they grow up. Further support is available from your child's doctors and nurses, if you have concerns.

Further sources of information

The Sickle Cell Society, provides advice, information and support to people with SCD and their families, and raises funds for the education of carers and health professionals, **t:** 020 8961 7795 **w:** www.sicklecellsociety.org

ERIC, education and resources for improving Childhood continence. This charity provides support and help through their website and helpline, **w:** www.eric.org.uk

Contact us

Lead consultant for haemoglobin disorders, and consultant in haematology, phone: 020 7188 6203 (secretary), **email:** Dudhma.Banu@gstt.nhs.uk

Lead nurse, phone: 020 7188 9432 or 07918 338730 **email:** HaemoglobinopathyCNS@gstt.nhs.uk

Nurse specialist, phone: 07771 345847 or 07517 592436 **email:** HaemoglobinopathyCNS@gstt.nhs.uk

Research nurse, phone: 020 7188 6637 or 07517 592436

Specialist nurse – community, phone: 020 3049 5993 or 07880 781545

Therapy and psychology team, phone: 020 7188 9125 or 07817 905844

Evelina London Medicines Helpline

If you have any questions or concerns about your child's medicines, please speak to the staff caring for them or contact our helpline.

phone: 020 7188 3003, Monday to Friday, 10am to 5pm **email:** letstalkmedicines@gstt.nhs.uk

Your comments and concerns

For advice, support or to raise a concern, contact our Patient Advice and Liaison Service (PALS), **phone** 020 7188 8801 **email** pals@gstt.nhs.uk. To make a complaint contact the resolution department **phone** 020 7188 3514 **email** complaints2@gstt.nhs.uk

Language and accessible support services

If you need an interpreter or information about your care in a different language or format, please contact the department your appointment is with.

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