

Bedwetting (enuresis) in children with sickle cell disease

This leaflet offers more information about bedwetting in children with sickle cell disease (SCD), including why it is more common amongst children with SCD and what you can do to help. If you have any further questions or concerns, please contact us using the details given 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 not an uncommon 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 years, bedwetting is common in children and young people.

The medical name for bedwetting at night is **nocturnal enuresis**. 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 sickle cell disease?

Children and young people with sickle cell disease (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. Also, when children or young people with SCD are asleep, they may not notice that the bladder is full, and this can cause them to wet the bed.

In addition, some 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 who are able to stay dry at night. Bedwetting may also interfere with your child's social development and he/she may not want to attend sleepovers, overnight school trips or visit relatives.

Having a child that wets the bed can interfere with family life, since parents have to get up during the night to change the sheets. Parents may feel frustrated due to lack of sleep, increased laundry and 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 I do to help my child?

Although you cannot stop your child's bedwetting, there are a number of things that 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. You should also avoid energy drinks. It is recommended that they drink healthy drinks i.e. milk and/or water. Children should be encouraged to drink six to eight cups of fluid equally spaced out through the day.
- Ensure 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 on the cusp of sleepiness.
- 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 for each time they get up and use the toilet, consider using a sticker chart to reward him/her.
- When an agreed number of stickers have been given, a special treat may be awarded, such as watching a video or having an extra story.

Do not make a fuss if your child has wet the bed. Help him/her to change the sheets and then go 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 you and your child to a special clinic for a full evaluation. Following the evaluation, your child may be offered a number of treatment options such as:

- **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 him/her 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 actually passing urine 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**

Desmopressin can be used for the treatment of bedwetting. It 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 discontinued; the bedwetting may start up again. Desmopressin should not be used if your child is vomiting or has diarrhoea or if your child needs to drink through the night e.g. during a sickling crisis.

- **Imipramine**

If desmopressin does not work, another medication called 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**

This medication 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 support

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.

Tel: 020 8961 7795 **Web:** www.sicklecellsociety.org

UK Thalassaemia Society

Raises awareness in health education and provides counselling services to children with thalassaemia and their parents/families.

Web: www.ukts.org

ERIC

Education and resources for improving Childhood continence. This charity provides support and help through their website and helpline.

Web: www.eric.org.uk

Contact us

If you have any questions or concerns about bed wetting, please contact the sickle cell team:

Consultant paediatrician and haematologist **t:** 020 7188 7774

Paediatric Haematology CNS **t:** 020 7188 4486, Bleep 2733. Call the hospital switchboard on 0207 188 7188 and ask for bleep desk. Ask for bleep 2733 and wait for a response.

Deputy Paediatric Haematology CNS **t:** 020 7188 9432

For more information leaflets on conditions, procedures, treatments and services offered at our hospitals, please visit www.guysandstthomas.nhs.uk/leaflets

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.

T: 020 7188 3003 10am to 5pm, Monday to Friday

E: letstalkmedicines@gstt.nhs.uk

Your comments and concerns

For advice, support or to raise a concern, contact our Patient Advice and Liaison Service (PALS). To make a complaint, contact the complaints department.

T: 020 7188 8801 (PALS) **e:** pals@gstt.nhs.uk

T: 020 7188 3514 (complaints) **e:** complaints2@gstt.nhs.uk

Language Support Services

If you need an interpreter or information about your care in a different language or format, please get in touch:

t: 020 7188 8815 **e:** languagesupport@gstt.nhs.uk

NHS 111

Offers medical help and advice from fully trained advisers supported by experienced nurses and paramedics. Available over the phone 24 hours a day.

T: 111

NHS Choices

Provides online information and guidance on all aspects of health and healthcare, to help you make choices about your health.

W: www.nhs.uk

Get involved and have your say: become a member of the Trust

Members of Guy's and St Thomas' NHS Foundation Trust contribute to the organisation on a voluntary basis. We count on them for feedback, local knowledge and support. Membership is free and it is up to you how much you get involved. To find out more, and to become a member:

T: 0800 731 0319 **e:** members@gstt.nhs.uk **w:** www.guysandstthomas.nhs.uk/membership

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