



Bedwetting in children and young people

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This standard is based on CG111.

This standard should be read in conjunction with QS62, QS15, QS31 and QS36.

Quality statements

<u>Statement 1</u> Children and young people who are bedwetting have a comprehensive initial assessment.

<u>Statement 2</u> Children and young people have an agreed review date if they, or their parents or carers, are given advice about changing their daily routine to help with bedwetting.

<u>Statement 3</u> Children and young people, and their parents or carers if appropriate, have a discussion about initial treatment if bedwetting has not improved after changing their daily routine.

<u>Statement 4</u> Children and young people who are bedwetting receive the treatment agreed in their initial treatment plan.

<u>Statement 5</u> Children and young people whose bedwetting has not responded to courses of initial treatments are referred for specialist review.

Quality statement 1: Assessment

Quality statement

Children and young people who are bedwetting have a comprehensive initial assessment.

Rationale

A number of factors can cause or contribute to bedwetting in children and young people that may affect their treatment and support needs. A comprehensive initial assessment will ensure the plan for managing bedwetting meets the child's or young person's needs and helps parents or carers to cope with bedwetting.

Quality measures

The following measures can be used to assess the quality of care or service provision specified in the statement. They are examples of how the statement can be measured, and can be adapted and used flexibly.

Structure

Evidence of local arrangements to ensure that children and young people who are bedwetting have a comprehensive initial assessment.

Data source: Local data collection.

Process

Proportion of children and young people who are bedwetting who have a comprehensive initial assessment.

Numerator – the number in the denominator who have a comprehensive initial assessment.

Denominator – the number of children and young people presenting with a new episode of

bedwetting.

Data source: Local data collection.

What the quality statement means for different audiences

Service providers (such as GPs and NHS trusts) ensure that they have clear policies to train and support healthcare professionals to carry out comprehensive initial assessments for children and young people who are bedwetting.

Healthcare professionals (such as GPs, school nurses and community nurses) undertake a comprehensive initial assessment of children and young people who are bedwetting.

Commissioners ensure that the services they commission have sufficient healthcare professionals competent in carrying out comprehensive initial assessments for bedwetting.

Children and young people who are bedwetting have an assessment in which they (and their parents or carers if appropriate) are asked questions to help work out what is happening, what might be causing it, and to find out more about any other relevant problems they might have.

Source guidance

Bedwetting in under 19s. NICE guideline CG111 (2010), recommendations 1.3.1 to 1.3.19

Definitions of terms used in this quality statement

Comprehensive initial assessment

A comprehensive initial assessment of bedwetting includes the pattern of bedwetting and related factors such as fluid intake, toileting pattern and daytime symptoms, together with possible medical, emotional or physical triggers and individual needs that may have an impact on treatment and support. Physical factors such as constipation, urinary tract infection and diabetes should be identified and treated, and the impact of current medication considered. Other wider social, family, emotional and developmental issues

should also be explored to ensure the plan for managing bedwetting meets individual needs and enables the family to cope with bedwetting. Healthcare professionals should consider possible maltreatment if parents or carers are thought to regard the bedwetting as deliberate, there is evidence of punitive treatment or if bedwetting does not resolve in a child or young person who was previously dry, unless a physical or emotional trigger can be identified. [Adapted from NICE's guideline on bedwetting in under 19s, recommendations 1.3.1 to 1.3.19]

Equality and diversity considerations

Healthcare professionals should take into consideration the cultural and communication needs of children and young people (and their parents or carers if appropriate) when assessing children and young people with bedwetting.

Healthcare professionals should fully assess bedwetting in children and young people with developmental or learning difficulties or physical disabilities because symptoms can be improved with the correct support and treatment.

Quality statement 2: Review after initial advice is given

Quality statement

Children and young people have an agreed review date if they, or their parents or carers, are given advice about changing their daily routine to help with bedwetting.

Rationale

It may be appropriate to offer initial advice to children and young people, and their parents or carers, about making changes to their daily routine based on the comprehensive initial assessment of bedwetting. This could include advice on fluid intake, diet and toileting patterns, as well as approaches to lifting and waking, and reward systems. It is important to agree a date to review progress to avoid children and young people continuing with the agreed plan indefinitely with no real improvement in their bedwetting.

Quality measures

The following measures can be used to assess the quality of care or service provision specified in the statement. They are examples of how the statement can be measured, and can be adapted and used flexibly.

Structure

Evidence of local arrangements to ensure that a review date is agreed for children and young people if they, or their parents or carers, are given advice about changing their daily routine to help with bedwetting.

Data source: Local data collection.

Process

Proportion of children and young people who have an agreed review date if they, or their

parents or carers, are given advice about changing their daily routine to help with bedwetting.

Numerator – the number in the denominator who have an agreed review date.

Denominator – the number of children or young people who are given advice about changing their daily routine to help with bedwetting.

Data source: Local data collection.

Outcome

Detection of unresolved bedwetting in children and young people who are given initial advice.

Data source: Local data collection.

What the quality statement means for different audiences

Service providers (such as GPs and NHS trusts) ensure that systems are in place for a review date to be agreed for children and young people if they, or their parents or carers, are given advice about changing their daily routine to help with bedwetting.

Healthcare professionals (such as GPs, school nurses and community nurses) agree a review date for children and young people if they, or their parents or carers, are given advice about changing their daily routine to help with bedwetting.

Commissioners ensure that they commission services from providers who agree a review date for children and young people if they, or their parents or carers, are given advice about changing their daily routine to help with bedwetting.

Children and young people who are bedwetting who are given advice about changing their daily routine to help with bedwetting (or whose parents or carers are given advice) have an agreed date to review how they are getting on and if any other treatment is needed.

Source guidance

Bedwetting in under 19s. NICE guideline CG111 (2010), recommendations 1.5.1 to 1.5.7, 1.6.1, and 1.7.1 to 1.7.3

Definitions of terms used in this quality statement

Advice about changing their daily routine

This involves providing information and advice on fluid intake, toileting, lifting and waking and the use of reward systems. [Adapted from <u>NICE's guideline on bedwetting in under 19s</u>, recommendations 1.5 to 1.7]

Equality and diversity considerations

Healthcare professionals should take into consideration the cultural and communication needs of children and young people (and their parents or carers if appropriate) when carrying out a review.

Healthcare professionals should fully assess bedwetting in children and young people with developmental or learning difficulties or physical disabilities because symptoms can be improved with the correct support and treatment.

Quality statement 3: Initial treatment

Quality statement

Children and young people, and their parents or carers if appropriate, have a discussion about initial treatment if bedwetting has not improved after changing their daily routine.

Rationale

The choice of initial treatment should be informed by the comprehensive initial assessment, and should take into account the preference of the child or young person and, if appropriate, their parents or carers. Factors such as age, associated functional difficulties and disabilities, financial burdens and living situations may affect their preferences. Discussing the initial treatment options with their healthcare professional will ensure that children and young people, and their parents or carers if appropriate, are able to make an informed decision about which treatment will meet their specific needs.

Quality measures

Structure

Evidence of local arrangements to ensure that children and young people, and their parents or carers if appropriate, have a discussion about initial treatment if bedwetting has not improved after changing their daily routine.

Data source: Local data collection.

Process

Proportion of children and young people whose bedwetting has not improved after changing their daily routine who have a recorded discussion (including their parents or carers if appropriate) about initial treatment.

Numerator – the number in the denominator who have a recorded discussion (including

their parents or carers if appropriate) about initial treatment.

Denominator – the number of children and young people whose bedwetting has not improved after changing their daily routine.

Data source: Local data collection.

Outcome

Children, young people and their parents or carers are actively involved in decisions about their care.

Data source: Local data collection. The <u>NHS England GP Patient Survey</u> asks how good the GP was in involving people in decisions about their care (this is not specific to bedwetting in children and young people).

What the quality statement means for different audiences

Service providers (such as GPs and NHS trusts) ensure that systems and policies are in place for healthcare professionals to discuss initial treatment with children and young people, and their parents or carers if appropriate, if bedwetting has not improved after changing their daily routine.

Healthcare professionals (such as GPs, school nurses and community nurses) discuss initial treatment with children and young people, and their parents or carers if appropriate, if bedwetting has not improved after changing their daily routine.

Commissioners ensure that the services they commission have policies that include discussion of initial treatment with children and young people, and their parents or carers if appropriate, if bedwetting has not improved after changing their daily routine.

Children and young people with bedwetting that hasn't improved after changing their daily routine (and their parents or carers if appropriate) discuss possible treatment (such as a bedwetting alarm or medication) with their healthcare professional.

Source guidance

Bedwetting in under 19s. NICE guideline CG111 (2010), recommendations 1.4.1 to 1.4.5, 1.8.1, 1.10.1 and 1.10.2

Definitions of terms used in this quality statement

Changing their daily routine

This involves making changes to the child or young person's routine based on information and advice provided on fluid intake, toileting, lifting and waking and the use of reward systems. [Adapted from NICE's guideline on bedwetting in under 19s, recommendations 1.5 to 1.7]

Initial treatment for bedwetting

An alarm should be offered as first-line treatment unless it is considered undesirable or inappropriate (for example, if bedwetting is very infrequent, that is, less than 1 or 2 wet beds per week, or the parents or carers are having emotional difficulty coping with the burden of bedwetting or are expressing anger, negativity or blame towards the child or young person).

Desmopressin may be offered as initial treatment to children and young people older than 7 years if an alarm is undesirable or inappropriate, or if the priority for the child is to achieve a rapid short-term improvement in bedwetting.

Consideration of which initial treatment is most appropriate will depend on the child or young person's age, the frequency of bedwetting and the motivation and needs of the child or young person and their parents or carers.

An alarm or desmopressin may be considered for children aged 5 to 7 years. The decision about suitable treatment for 5- to 7-year-olds should take into account the pattern of bedwetting as well as the child's ability, maturity, motivation and understanding of an alarm, their wider living circumstances and the views of their parents or carers. [Adapted from NICE's guideline on bedwetting in under 19s, recommendations 1.4.5, 1.8.1, 1.8.8, 1.10.1 and 1.10.2]

Equality and diversity considerations

When discussing initial treatment of bedwetting in children and young people with developmental or learning difficulties or physical disabilities, healthcare professionals should be aware that symptoms can be improved with the correct support and treatment.

Initial treatment may be considered for children and young people with developmental or learning difficulties or physical disabilities, tailored to their individual needs and abilities.

Quality statement 4: Access to treatment

Quality statement

Children and young people who are bedwetting receive the treatment agreed in their initial treatment plan.

Rationale

Once a child or young person and, if appropriate, their parents or carers, have made an informed choice about using an alarm or desmopressin as the treatment for bedwetting, this should be agreed in their initial treatment plan. They should then receive the treatment in their plan. Bedwetting can put families under considerable pressure and once they have asked for help they need to receive treatment so they can resolve the problem. Any delay in their agreed treatment being available, for example as a result of local waiting lists or treatment policy, may put families under unnecessary pressure and have a negative impact on the outcomes for the child or young person.

Quality measures

Structure

Evidence of local arrangements to ensure that children and young people who are bedwetting receive the treatment agreed in their initial treatment plan.

Data source: Local data collection.

Process

a) Proportion of children and young people who are bedwetting who receive the treatment agreed in their initial treatment plan.

Numerator – the number in the denominator who receive the treatment agreed in their initial treatment plan.

Denominator – the number of children and young people who are bedwetting who have an initial treatment plan.

Data source: Local data collection.

b) Waiting times to receive initial treatment for bedwetting.

Data source: Local data collection.

Outcome

Patient satisfaction with the availability of initial treatment for bedwetting.

Data source: Local data collection.

What the quality statement means for different audiences

Service providers (such as GPs and NHS trusts) ensure that they have appropriate policies and resources to support healthcare professionals to agree initial treatment plans for bedwetting and to provide the treatment agreed in those plans.

Healthcare professionals (such as GPs, school nurses and community nurses) ensure that children and young people who are bedwetting have an initial treatment plan and receive the treatment agreed in their plan.

Commissioners ensure that they commission services with policies and resources to enable children and young people who are bedwetting to have an initial treatment plan and to receive the treatment agreed in their plan. This includes ensuring that services provide enough suitable alarms for bedwetting to meet demand.

Children and young people who are bedwetting have an agreed plan for their treatment (such as using a bedwetting alarm or taking medication) and are able to get the treatment in their plan.

Source guidance

Bedwetting in under 19s. NICE guideline CG111 (2010), recommendations 1.4.5, 1.8.1, 1.10.1 and 1.10.2

Definitions of terms used in this quality statement

Initial treatment for bedwetting

An alarm should be offered as first-line treatment unless it is considered undesirable or inappropriate (for example, if bedwetting is very infrequent, that is, less than 1 or 2 wet beds per week, or the parents or carers are having emotional difficulty coping with the burden of bedwetting or are expressing anger, negativity or blame towards the child or young person).

Desmopressin may be offered to children and young people older than 7 years if an alarm is undesirable or inappropriate, or if the priority for the child is to achieve a quick short-term improvement in bedwetting.

Consideration of which initial treatment is most appropriate will depend on the child or young person's age, the frequency of bedwetting and the motivation and needs of the child or young person and their parents or carers.

An alarm or desmopressin may be considered for children aged 5 to 7 years. The decision about suitable treatment for 5- to 7-year-olds should take into account the pattern of bedwetting as well as the child's ability, maturity, motivation and understanding of an alarm, their wider living circumstances and the views of their parents or carers. [Adapted from NICE's guideline on bedwetting in under 19s, recommendations 1.4.5, 1.8.1, 1.8.8, 1.10.1 and 1.10.2]

Equality and diversity considerations

Although some parents and carers may be willing and able to buy an alarm for their child, this should not be assumed. Children and young people whose parents or carers cannot afford to buy an alarm should not be disadvantaged by having to wait before they can get access to this treatment.

The type of alarm should be selected to meet the specific needs of children and young people with developmental or learning difficulties or physical disabilities.

Quality statement 5: Access to specialist review

Quality statement

Children and young people whose bedwetting has not responded to courses of initial treatments are referred for a specialist review.

Rationale

If bedwetting in children and young people does not respond to courses of initial treatments, referral should be made for a specialist review so that the factors associated with a poor response (for example, overactive bladder, underlying disease, or social and/or emotional issues) can be assessed. Services that provide specialist reviews after courses of initial treatments have been tried for bedwetting may help to reduce the number of inappropriate hospital referrals, which will benefit the child or young person and may reduce costs.

Quality measures

Structure

Evidence of local arrangements to ensure that children and young people whose bedwetting has not responded to courses of initial treatments can access a specialist review.

Data source: Local data collection.

Process

Proportion of children and young people whose bedwetting has not responded to courses of initial treatments who are referred for a specialist review.

Numerator – the number in the denominator referred for a specialist review.

Denominator – the number of children and young people whose bedwetting has not responded to courses of initial treatments.

Data source: Local data collection.

Outcome

Reduction in inappropriate hospital referrals.

Data source: Local data collection.

What the quality statement means for different audiences

Service providers (such as GPs and NHS trusts) ensure that healthcare professionals are aware of agreed referral pathways to access a specialist review for bedwetting.

Healthcare professionals (such as GPs, school nurses and community nurses) refer children and young people who are bedwetting for specialist review if their bedwetting does not respond to courses of initial treatments.

Commissioners ensure that they commission services to provide specialist reviews for bedwetting with agreed referral pathways from primary care.

Children and young people with bedwetting that hasn't improved after trying initial treatments (such as a bedwetting alarm and/or medication) are referred to a specialist who can provide extra support.

Source guidance

Bedwetting in under 19s. NICE guideline CG111 (2010), recommendation 1.12.1

Definitions of terms used in this quality statement

Bedwetting that has not responded

Bedwetting has not responded to treatment if the child has not achieved 14 consecutive dry nights or a 90% improvement in the number of wet nights per week. The response to treatment should be assessed as follows:

- The response to an alarm or desmopressin should be assessed at 4 weeks. If there are
 no early signs of response (smaller wet patches, fewer wetting episodes per night or
 fewer wet nights), treatment should be reviewed.
- Children and young people should continue treatment for 3 months if there are early signs of a response at 4 weeks. If complete dryness is not achieved after 3 months, treatment should be reviewed.
- Treatment with an alarm should only continue after 3 months if the bedwetting is still
 improving and the child or young person, and their parents or carers if appropriate, are
 motivated to continue. Bedwetting may continue to improve for up to 6 months with
 desmopressin but treatment should be withdrawn for 1 week after 3 months to check
 if dryness has been achieved.

[Adapted from NICE's guideline on bedwetting in under 19s, recommendations 1.8.2, 1.8.4, 1.10.6, 1.10.11 and 1.11.3]

Courses of initial treatments

An alarm should be offered as first-line treatment unless it is considered undesirable or inappropriate (for example, if bedwetting is very infrequent, that is, less than 1 or 2 wet beds per week, or the parents or carers are having emotional difficulty coping with the burden of bedwetting or are expressing anger, negativity or blame towards the child or young person).

Desmopressin may be offered to children and young people older than 7 years if an alarm is undesirable or inappropriate, or if the priority for the child is to achieve a quick short-term improvement in bedwetting.

Consideration of which initial treatment is most appropriate will depend on the child or

young person's age, the frequency of bedwetting and the motivation and needs of the child or young person and their parents or carers.

An alarm or desmopressin may be considered for children aged 5 to 7 years. The decision about suitable treatment for 5- to 7-year-olds should take into account the pattern of bedwetting as well as the child's ability, maturity, motivation and understanding of an alarm, their wider living circumstances and the views of their parents or carers.

If bedwetting does not respond to initial alarm treatment, courses of treatment with a combination of alarm and desmopressin and/or desmopressin alone may be offered depending on the response achieved and whether an alarm remains acceptable. [Adapted from NICE's guideline on bedwetting in under 19s, recommendations 1.4.5, 1.8.1, 1.8.8, 1.10.1, 1.10.2, 1.9.1 and 1.9.2]

Specialist review

Children and young people whose bedwetting has not responded to courses of initial treatments should be referred to the next step up in service that provides comprehensive continence assessment and treatment for children and young people (for example, from a level 1 service such as in primary care which provides general advice and may also provide initial treatment, to a level 2 specialist service that undertakes comprehensive assessment, or level 3 secondary or tertiary services for children and young people with symptoms that require medical assessment). The characteristics and settings for these services would depend on local arrangements.

An example of a level 2 service is a children's community continence service that treats bladder and bowel problems and delayed toilet training, and is delivered by an experienced and competent multidisciplinary team led by a paediatric continence nurse specialist. [Adapted from the <u>Paediatric Continence Forum's Paediatric continence</u> commissioning guide, section 1.5]

Equality and diversity considerations

When referring children and young people for a specialist review, any potential difficulties in accessing services, which may include distance, disability and financial barriers, should be taken into account.

When discussing treatment for bedwetting in children and young people with

developmental or learning difficulties or physical disabilities, the healthcare professional should be aware that symptoms can be improved with the correct support and treatment.

Update information

Minor changes since publication

April 2020: Changes have been made to statement 5 to update the source guidance and the definition of specialist review. Links and references have also been updated throughout.

About this quality standard

NICE quality standards describe high-priority areas for quality improvement in a defined care or service area. Each standard consists of a prioritised set of specific, concise and measurable statements. NICE quality standards draw on existing NICE or NICE-accredited guidance that provides an underpinning, comprehensive set of recommendations, and are designed to support the measurement of improvement.

Expected levels of achievement for quality measures are not specified. Quality standards are intended to drive up the quality of care, and so achievement levels of 100% should be aspired to (or 0% if the quality statement states that something should not be done). However, this may not always be appropriate in practice. Taking account of safety, shared decision-making, choice and professional judgement, desired levels of achievement should be defined locally.

Information about <u>how NICE quality standards are developed</u> is available from the NICE website.

See our <u>webpage on quality standards advisory committees</u> for details about our standing committees. Information about the topic experts invited to join the standing members is available from the webpage for this quality standard.

NICE has produced a <u>quality standard service improvement template</u> to help providers make an initial assessment of their service compared with a selection of quality statements. This tool is updated monthly to include new quality standards.

NICE guidance and quality standards apply in England and Wales. Decisions on how they apply in Scotland and Northern Ireland are made by the Scottish government and Northern Ireland Executive. NICE quality standards may include references to organisations or people responsible for commissioning or providing care that may be relevant only to England.

Diversity, equality and language

Equality issues were considered during development and <u>equality assessments for this</u> quality standard are available. Good communication between health and social care

practitioners and children and young people who are bedwetting, and their parents or carers (if appropriate), is essential. Treatment, care and support, and the information given about it, should be both age-appropriate and culturally appropriate. It should also be accessible to people with additional needs such as physical, sensory or learning disabilities, and to people who do not speak or read English. Children and young people who are bedwetting and their parents or carers (if appropriate) should have access to an interpreter or advocate if needed.

Commissioners and providers should aim to achieve the quality standard in their local context, in light of their duties to have due regard to the need to eliminate unlawful discrimination, advance equality of opportunity and foster good relations. Nothing in this quality standard should be interpreted in a way that would be inconsistent with compliance with those duties.

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Endorsing organisation

This quality standard has been endorsed by NHS England, as required by the Health and Social Care Act (2012)

Supporting organisations

Many organisations share NICE's commitment to quality improvement using evidence-based guidance. The following supporting organisations have recognised the benefit of the quality standard in improving care for patients, carers, service users and members of the public. They have agreed to work with NICE to ensure that those commissioning or providing services are made aware of and encouraged to use the quality standard.

- ERIC (Education and Resources for Improving Childhood Continence)
- Paediatric Continence Forum
- PromoCon
- Royal College of Paediatrics and Child Health
- Royal College of Nursing (RCN)