NICE National Institute for
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public

Spasticity in children and young people

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About this information

NICE clinical guidelines advise the NHS on caring for people with specific conditions or diseases and the treatments they should receive. The information applies to people using the NHS in England and Wales.

This information explains the advice about the care and treatment of children and young people with spasticity that is set out in NICE clinical guideline 145.

Does this information apply to me?

Yes, if you are:

- a young person with spasticity as a result of a non-progressive brain disorder, including those with spasticity resulting from cerebral palsy.

- a parent or carer of a child or young person with spasticity as a result of a non-progressive brain disorder, including those with spasticity resulting from cerebral palsy.

Non-progressive means that the problems in the brain have already happened and will not worsen. However, the effects of the brain disorder may change as the child grows and develops.

No, if you are a young person, or the parent or carer of a child or young person:

- with spasticity resulting from a progressive brain disorder
- who does not have spasticity but has a condition called dystonia or other motor disorders.

Care for children and young people with spasticity

In the NHS, patients and healthcare professionals have rights and responsibilities as set out in the NHS Constitution (www.dh.gov.uk/en/DH_132961). All NICE guidance is written to reflect these. Children and young people with spasticity and their parents and carers (if appropriate) have the right to be involved in discussions and make informed decisions about treatment and care with the healthcare team. Their choices are important and healthcare professionals should support these wherever possible. All children, young people and their parents and carers should be treated with dignity and respect.

To help children and young people, and their parents and carers, to make decisions, healthcare professionals should explain spasticity and the possible treatments for it. They should cover possible benefits and risks related to the circumstances of the child or young person. Children and young people, and their parents and carers, should be given relevant information that is suitable for them and reflects any religious, ethnic, or cultural needs they have. It should also take into account whether they have any learning disability, sight or hearing problem or language difficulties. Children and young people, and their parents and carers, should have access to an interpreter or advocate (someone who helps you put your views across) if needed.

When parents and carers are involved they should be able to discuss or review the child's care. As treatment progresses, or circumstances change, it is possible for children and young people and their parents and carers to change their mind about assessments, investigations and treatments.

Healthcare professionals should follow the Department of Health's advice on consent (www.dh.gov.uk/en/DH_103643) and the code of practice for the Mental Capacity Act. Information about the Act and consent issues is available from www.nhs.uk/CarersDirect/moneyandlegal/legal. In Wales healthcare professionals should follow advice on consent from the Welsh Government (www.wales.nhs.uk/consent).

If the child or young person is under 16, their parents or carers will need to agree to their treatment, unless it is clear that the child fully understands the treatment and can give their own consent.

Care of young people who are moving from services for children to adult services should be planned according to guidance from the Department of Health ('Transition: getting it right for young people' available from www.dh.gov.uk).

Spasticity

Spasticity is a condition that affects the muscles, making them more stiff and rigid than usual, and it may be accompanied by other problems such as uncontrolled movements. It is caused by problems with the part of the brain that controls movement.

Spasticity most commonly affects the legs and arms, but it can also affect any part of the body – for example, the trunk, neck and face. It can cause problems with posture, sitting, walking, hand and arm movements, speech and swallowing. It can also cause discomfort, pain, cramps and spasms.

Cerebral palsy is the most common cause of spasticity in children and young people. Cerebral palsy includes various conditions that affect muscle control and movement. In children who are born with a brain injury causing cerebral palsy, spasticity may not be present at birth and may only become evident over time. In other cases, spasticity may occur later in childhood or adolescence – for example, as a result of a serious head injury.

This information is about the care and treatment your child should receive for spasticity caused by non-progressive brain disorders, such as cerebral palsy. It does not cover other aspects of cerebral palsy such as speech difficulties or visual impairment.

This information contains two sections – one for parents and carers of children with spasticity and one for young people with spasticity. The first part of this information is written mainly for parents and carers, although it makes clear that children and young people should be included in the discussions and decision-making wherever possible.

Questions you might like to ask your healthcare team

- What can I/we do to help and support my child?
- Who will be involved in my child's care?
- What assessments and treatments will my child need?
- Are there any support organisations in my local area?
- Is there any additional support that I/we as carer(s) might benefit from or be entitled to?

Care that your child should receive

If you think that your child's care does not match what is described in this information, please talk to a member of your child's healthcare team in the first instance.

Once your child has been diagnosed with spasticity they should be referred straight away for specialist help. A team of healthcare professionals will provide and coordinate the care that your child needs. This team will work in partnership with you and your child to develop and carry out a management programme that includes specific treatment goals and takes into account the possible impact of any treatment on your child and the rest of your family. To help you to be partners in this, you and your child should be offered information that is appropriate for your child's age and development. You should be offered regular opportunities for discussion with your child's healthcare professionals, and also be given contact details of patient organisations that can provide more information, help and support.

You should be given advice about what it might be possible for your child to achieve and which would be the best treatments to help them get to that stage. Once you and your child and the healthcare team have agreed the goals for your child's treatment and how your child will be assessed, this information should be recorded and shared with the other healthcare professionals involved in caring for your child. Goals for treatment might include:

- improving your child's motor function (for example, grasping an object or walking) and posture
- enhancing your child's ability to take part in everyday activities
- easing pain and discomfort, including muscle spasms
- preventing or delaying the possible complications of spasticity, such as contractures (abnormal shortening of the muscle).

The healthcare team should make sure your child is given any equipment they need as part of their treatment. If your child has additional difficulties – for example, difficulties with speech, learning or understanding others – the healthcare team should ensure that they have access to all the relevant services.

Monitoring your child's condition

Your child should be offered regular check-ups to see:

- how they are responding to treatment
- whether the spasticity is getting worse
- whether they have problems such as pain or contractures caused by spasticity
- whether their goals are still valid or need to be changed.

Some children may be at risk of hip displacement. Hip displacement means that one or both hip joints become partially or completely dislocated. This tends to occur gradually, so the healthcare team will check for signs of hip displacement. If they have concerns, your child should be offered a hip X-ray. If your child has cerebral palsy on both sides of the body (known as bilateral cerebral palsy) they should have a hip X-ray when they are 2 years old. Depending on the results of the X-ray your child may be offered a repeat X-ray after 6 months, annually or every 6 months to monitor their hips.

When the time comes, the healthcare team will help you and your child prepare for your child's transfer to adult services.

Physiotherapy and occupational therapy

Once your child has been referred for specialist treatment, they should be assessed by a physiotherapist. They may also be seen by an occupational therapist. This is someone who helps your child's health and wellbeing by finding out what aspects of their condition and surroundings cause them difficulties, and focusing on practical activities that help them with these things.

Your child should be offered physical therapy (physiotherapy, occupational therapy, or both) as part of their treatment programme, which should aim to meet your child's specific treatment goals. For example, the physical therapy could include enhancing skill development, function and ability to take part in everyday activities; preventing pain or contractures; muscle strengthening or stretching exercises (or both); and activities to help with posture.

The therapist should discuss the physical therapy with you and your child and take your views into consideration when suggesting a suitable type of therapy. They should give you verbal and written (or appropriate formats) information about the type of physical therapy needed and its benefits and difficulties. They will consider any difficulties of carrying out the programme, and whether you or your child would need training if the therapy was to be carried out at home outside the therapy sessions.

The therapist will need to make sure that any equipment or techniques needed for the therapy programme are safe for your child, especially if your child has additional conditions such as epilepsy or osteoporosis. They should also encourage your child to incorporate the physical therapy into daily activities – for example, standing at the sink while brushing teeth in order to stretch leg muscles.

The therapist should check at regular intervals to make sure that the therapy is still helping your child to reach the goals that you have agreed, and modify the treatment plan if necessary.

Physical therapy following other treatments

Your child will need to have a special programme of physical therapy after having any of the following treatments:

- botulinum toxin
- intrathecal baclofen
- orthopaedic surgery
- selective dorsal rhizotomy.

Questions you might like to ask about physiotherapy or occupational therapy

- How much time and effort will the therapy take?
- Will I or my child need any training?
- How likely is my child to reach their goals?
- What are the benefits of this treatment?
- Is the treatment likely to cause any problems?

Orthoses

Your child may be offered an orthosis to help with their spasticity. Orthoses are devices that fit onto the body and can help improve posture; walking; position of the limbs when lying, sitting, or standing; and using the arms, wrists and hands.

When the healthcare professionals looking after your child are considering whether your child would benefit from an orthosis they should discuss the benefits and risks with you. They will also take other things into account, such as whether it would cause problems with hygiene, or be unacceptable to your child because of its appearance.

If you (and/or your child) agree that your child should use an orthosis, the healthcare team should discuss possible treatment goals with you. The orthosis should be designed specially for your child, and advice will be given on how to fit and wear it, for how long, and when to wear it. For example, sometimes orthoses can be worn at night. Your child's healthcare team should advise you that if the orthosis causes pain, and this is not helped even after making adjustments or repositioning it, you (or your child) should remove it. You should also be informed about when and where to ask for further help.

Every time the healthcare team sees your child they should check that the orthosis is still acceptable to your child and not causing any problems, such as discomfort or pain. They should also check whether the orthosis still fits properly, is in good condition, is still helping, and is being used correctly. If your child wears an orthosis at night their healthcare team should check whether it's disturbing their sleep.

Questions you might like to ask about orthoses

- How long will my child need to wear the orthosis for?
- Does the orthosis have to be worn all the time?
- When can the orthosis be taken off?
- Will my child be able to do normal everyday activities?
- What are the benefits of wearing an orthosis?
- Will wearing an orthosis cause any problems?

Treatment with drugs

Some treatments may not be suitable for your child, depending on their exact circumstances. If you have questions about specific treatments and options covered in this information, please talk to a member of your child's healthcare team.

Oral drugs

Diazepam and baclofen

If your child has spasticity and it's causing them discomfort, pain or muscle spasms, or it's stopping them from doing normal everyday tasks, there are drugs that may help them. If they need help with pain in the short term, the healthcare professionals looking after your child may recommend a drug to take by mouth (known as an oral drug) called diazepam. If they need help over a longer time, they may be recommended baclofen.

If your child is being treated with diazepam, the drug should normally be taken at bedtime. If it doesn't seem to be working, the healthcare team may try increasing the dose or adding a dose to take during the day. Treatment with baclofen starts off with a low dose which is then gradually increased over around 4 weeks to produce the best effect.

If the treatment with diazepam and baclofen isn't helping when these drugs are used on their own for 4 to 6 weeks, your child's healthcare team may suggest trying both drugs at the same time.

Your child's healthcare team should check at least every 6 months to make sure the treatment is still working, and whether your child is having any problems with it. If the drugs make your child drowsy or cause other problems, the healthcare team may suggest reducing the dose, or stopping the treatment altogether. If, for some reason, a decision is made to stop the treatment, and your child has been taking the drugs for several weeks or longer, it will be important to reduce the dose gradually to help their body adjust.

Dystonia is involuntary muscle contraction that causes certain parts of the body to go into abnormal or painful positions. If your child has dystonia that is causing a lot of problems with posture, pain and everyday activities, their healthcare team may recommend trying various oral drugs.

Botulinum toxin type A

Botulinum toxin is a drug that is injected into muscles to relieve spasticity. Your child's healthcare team might consider botulinum toxin injections for your child if their spasticity is causing them difficulty with looking after themselves, or restricting their ability to move normally or to use an orthosis. Botulinum toxin might also be recommended if your child's spasticity is causing pain, disturbing their sleep or causing them concern about their appearance by its effect on the posture of the arms, hands or feet.

Treatment with botulinum toxin

To make sure that botulinum toxin is suitable, your child will have an assessment to test their muscle tone, range of movement and ability to carry out voluntary movements. This will also provide information to help measure their response to treatment.

When considering whether or not your child should have botulinum toxin, you should be given information about what the treatment involves, the possible benefits of the treatment and how likely it is that the treatment goals will be reached. Your child may need to wear a cast or orthosis after the treatment – for example, to stretch the muscles. They will also need a special programme of physical therapy.

Before starting the treatment, your child's healthcare team should tell you that in very rare cases botulinum toxin can cause swallowing and breathing difficulties. They will explain how to recognise that this may be happening and that you should return to the hospital immediately if these complications occur.

During the treatment, your child may be able to have a painkiller, anaesthetic or sedative to make the injection less uncomfortable and to help with accuracy of injection.

Your child's healthcare team should check after 6 to 12 weeks that the botulinum toxin is working, and then again after 3 to 6 months to check whether more injections are needed.

Intrathecal baclofen pump

If, despite other treatments, your child has persistent pain or muscle spasms, or problems with posture, everyday activities or personal care, the healthcare professionals looking after your child may recommend treatment with a baclofen pump (also known as intrathecal baclofen). This involves implanting a small pump in the tissues under the skin close to the waist. The pump then slowly injects baclofen through a tube into the fluid surrounding the spinal cord. Because the baclofen is given directly into the spinal fluid in a low dose, it has fewer side effects than oral baclofen and is much more effective at reducing spasticity and the problems it causes.

Your child's healthcare team will look at the benefits and risks of having a pump and discuss these with you. They should also give you information about the treatment (see box below).

There might be reasons why your child can't have this treatment. For example, they might be too small for a pump, or they might have a condition that would make it unsafe for them (for example, a serious infection).

Baclofen testing

Before your child can have the baclofen pump, they should be assessed and then offered a test to check the effects of the baclofen on their spasticity. This involves giving your child a general anaesthetic, and then injecting a small amount of baclofen into the fluid around the spinal cord.

Around 3 to 5 hours after the injection (or later if the anaesthetic hasn't worn off), your child should be checked to see how well the baclofen has worked. The healthcare team will also discuss the response to the treatment with you.

Information about using a baclofen pump

Testing

Before your child has the baclofen test, you should be given verbal and written (or appropriate formats) information about:

- what the test will involve and possible side effects
- how the test might show whether treatment with baclofen is likely to work and whether it is likely to cause problems.

Treatment

Before your child has the treatment, you should be given verbal and written (or appropriate formats) information about:

- how the pump is implanted
- risks and problems related to the pump or treatment, or both

- looking after the pump and using it safely
- the fact that it is dangerous to stop the baclofen pump suddenly
- the need for regular hospital appointments after the pump has been implanted (for example, to refill or reprogram the pump).

Treatment with the baclofen pump

If your child's spasticity responds well to baclofen testing, your child should be offered pump implantation within 3 months of having the test. Your child should be able to have regular appointments with the healthcare team for pump refills, and so that they can check how well the treatment is working and if there are any unwanted effects. They may increase the dose to make the baclofen more effective by reprogramming the pump.

If the treatment isn't working and this is not caused by problems with the equipment, the healthcare team may discuss removing the pump and discuss other treatment options with you – for example, surgery.

A baclofen pump usually continues to work for several years. After this, you will need to decide with the healthcare professionals looking after your child whether it should be replaced. To help with this, the dose of baclofen may be reduced gradually to check whether the treatment is still helping.

Questions you might like to ask about treatment with the baclofen pump

- Please tell me why you have decided to offer my child this particular type of treatment.
- How long will my child need to use the pump for?
- Are there any side effects?
- Will my child be able to do normal everyday activities?

- Please tell me what the treatment will involve.
- How long will it take to have an effect?
- How does the pump work?
- Are there any risks associated with this treatment?
- Are there treatment options other than a baclofen pump?
- Is there some written material (like a leaflet) about the treatment that I can have?

Surgery

Orthopaedic surgery

Orthopaedic surgery can sometimes be important in treating spasticity and its complications. Some children and young people may be offered an assessment by an orthopaedic surgeon (who specialises in problems affecting bones and joints) to see if surgery could help them. Surgery might help some children and young people with:

- a displaced hip
- curvature of the spine
- difficulties with arm or leg function due to muscle shortening, contractures or bony deformities
- difficulties with hygiene in skin creases at the wrist, elbow or hip (for example, if the child's elbow is too bent to allow easy washing)
- concerns about their appearance because of how their arm or hand looks.

Before surgery the healthcare team should discuss with you and your child the aims of the surgery and how likely your child is to achieve them, what the surgery will involve, and any specific risks. They should also discuss the care your child will receive afterwards. This is called a rehabilitation programme. It will involve physiotherapy, and possibly other treatments such as orthoses or drug treatment.

If your child needs several surgical procedures the surgeon will aim to do these at the same time if possible. If your child has had surgery to improve their walking, it may take 1 to 2 years for the full effects of the treatment to be achieved, so they should have an assessment of their walking 1 to 2 years after the operation.

Selective dorsal rhizotomy

Selective dorsal rhizotomy is a major surgical procedure that aims to improve walking in those children and young people who are already walking with aids or likely to walk with aids (such as a walking frame). It involves cutting selected nerves in the lower spine to reduce spasticity. Your child's doctor should discuss this procedure with you and your child, including the problems it might cause, that the treatment is irreversible, and that the effects of the treatment in the long term are unclear.

Information for young people with spasticity

If you have spasticity you will be looked after by a team of expert healthcare professionals. They should involve you and your parents or carers in planning your programme of care and ask you about your views. You and the healthcare professionals will agree on your treatment goals – for example, to improve your posture, or your skills and activities. You should be given information that is relevant for a person of your age.

Throughout your treatment you should have checks to make sure that your treatments are working as well as possible, and have changes to your treatment plan if needed.

Physical therapy

You should be offered physiotherapy, occupational therapy, or both, to help you reach your goals (see Physiotherapy and occupational therapy for more information). This could involve muscle exercises, or activities to help you with your posture or everyday activities. You may need help with your physical therapy, or you may be able to do it yourself. You and your parents and carers should be given training if you need it.

You will need to have a special physiotherapy and/or occupational therapy programme if you have certain other treatments such as botulinum toxin, a baclofen pump or surgery (see below).

Orthoses

As part of your care plan you may be offered an orthosis to wear. Orthoses are devices that fit onto the body that can help improve your posture and movement. Your healthcare team should take into account your feelings about how an orthosis might look and affect your appearance. If you decide to use one, it should be designed specially for you, and you should be given any advice you need. If you need to wear it at night, your healthcare team should check that it's not disturbing your sleep.

Drug treatment

You may be offered drug treatment to help with your spasticity. If it is causing you discomfort or pain, you may be offered an oral drug (taken by mouth) called baclofen or diazepam.

You may be offered treatment with another drug called botulinum toxin, which is injected into the muscles. If necessary, you can have treatment to help with any discomfort during the injections.

Some people are offered a treatment known as a baclofen pump. This involves having surgery to place a small pump under your skin near your waist, which releases baclofen into your system to relax your muscles. You should have an assessment and a test to check the effects of the baclofen before you have the pump, which can continue to work for several years.

Surgery

Sometimes surgery can help people with spasticity – for example, if there are difficulties due to contractures affecting your posture and movement.

More information

The organisations below can provide more information and support for people with spasticity. NICE is not responsible for the quality or accuracy of any information or advice provided by these organisations.

- Cerebra, 0800 328 1159 www.cerebra.org.uk
- Go Kids Go, 01482 887163 www.go-kids-go.org.uk
- Hemi Help, 0845 123 2372 www.hemihelp.org.uk
- Scope, 0808 800 3333 www.scope.org.uk

You can also go to NHS Choices (www.nhs.uk) for more information.

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