**Spasticity DRAFT algorithm** - please note this is an overview of the guidance. See the Full version of the guideline for a comprehensive summary of the guidance, footnotes relating to licensing etc

## Overarching principles

Offer immediate referral to a local multidisciplinary child development team that can be accessed when needed and is linked to regional specialist centres.

The local multidisciplinary child development team should be experienced in the management of spasticity in children and young people and include a paediatrician, a paediatric physiotherapist and have access to a paediatric occupational therapist.

Access to a paediatric occupational therapist is needed for children and young people with spasticity that affects the upper limb.

Offer a management programme that is:

- individualised
- goal focused
- developed and implemented in partnership with the child or young person and their family or carers.

Local multidisciplinary child development teams and regional specialist centres should enable children, young people and parents or carers, to be partners in the development and implementation of management programmes by offering:

- relevant information and educational materials
- regular opportunities for discussion and
- advice on developmental potential and how different treatment options may affect this.

When formulating a management programme take into account the impact of treatment schedules on family circumstances.

Identify and agree with children,young people and parents or carers, goals and assessments that:

- are appropriate for their age and development
- will aim to improve their body function, structure,activity and participation in line with the domains of the World Health Organization's International Classification of Functioning, Disability and Health

Record and communicate the child or young person's individualised goals within the local multidisciplinary child development team and with all healthcare professionals who care for them.

Monitor the child or young person for:

- progression of spasticity
- development of secondary consequences of spasticity
- response to treatments
- the need for changes to individualised goals and
- the need for timely referral to regional specialist centres.

Healthcare professionals in regional specialist centres who assess children and young people's suitability for oral drugs, botulinum toxin type A, continuous pump-administered intrathecal baclofen, or orthopaedic surgery or selective dorsal rhizotomy should communicate with the child or young person's local multidisciplinary child development team to ensure compatibility and continuity of local and specialist services.

Before starting treatment, regional specialist centres should ensure that local multidisciplinary child development teams have allocated resources for locally provided post-treatment services.

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### Physical therapy

Do not offer botulinum toxin type A, continuous pump-administered intrathecal baclofen, or orthopaedic surgery or selective dorsal rhizotomy to children and young people unless they are participating actively in a programme of care and physical therapy.

Offer adjunctive physical therapy following treatments involving botulinum toxin type A, continuous pump-administered intrathecal baclofen, or orthopaedic surgery or selective dorsal rhizotomy to ensure effectiveness of these treatments.

## Physical therapy (physiotherapy and occupational therapy)

### General Principles

Offer verbal and written information about physical therapy interventions needed to achieve intended goals. This information should emphasise possible advantages, difficulties, adverse effects (for example time commitment and discomfort) to enable participation in choosing a suitable physical therapy programme.

Offer to refer children and young people to a physiotherapist who is a member of the local multidisciplinary child development team.

When considering who should deliver physical therapy, take into account:

- whether the child or young person and their parents or carers are able to deliver the specific therapy
- training the child or young person or their parents or carers might need
- the wishes of the child or young person and their parents or carers.

Offer children and young people a physical therapy programme tailored to their individual needs and aimed at specific goals, such as:

- enhancing skill development and improving function
- enhancing the ability to participate in everyday activities
- preventing or delaying the onset of complications such as contractures.

When formulating physical therapy programmes take account of:

- the views of the child or young person and their parents or carers
- the likelihood of achieving the intended goals of treatment
- the implications for the child or young person and their family in implementing the plan, including the time and effort involved and potential barriers (for example, barriers associated with particular cultural practices).

Physical therapists should have a central role in preparing young people (and their parents or carers) for transition and transfer to adult physical therapy services (for example, helping them to take responsibility for their own physical therapy).

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## Which therapy to use

Consider task-focused active-use therapies such as constraint-induced movement therapy followed by bimanual therapy to enhance manual skills.

Consider structuring task-focused active-use therapy as an intensive programme over a short time period (for example, 4–8 weeks).

Consider muscle-strengthening therapy where assessment suggests that muscle weakness is contributing to loss of function or joint deformity.

Direct muscle-strengthening therapies towards specific goals and incorporate progressive repetitive exercises performed against resistance.

Consider postural management strategies to:

- prevent or slow the development of contractures in children and young people at risk of developing these
- enable the child or young person to take part in activities appropriate to the child or young person's stage of development.

As part of postural management consider an individualised physical therapy programme that includes:

- resting positions and
- low-load active or passive stretching over 24 hours.

Offer training to parents and carers involved in delivering postural management programmes.

Assess whether any equipment or techniques used in the physical therapy plan is safe and appropriate, for example in children or young people with any of the following:

- poorly controlled co-existing epilepsy
- respiratory compromise
- risk of aspiration
- risk of bone fracture due to osteoporosis (for example, children and young people who are non-ambulatory, malnourished or taking anticonvulsant therapy).

Where there is risk of bone fractures due to osteoporosis (for example, children and young people who are non-ambulatory, malnourished or taking anticonvulsant therapy), consider sustained low-load stretching to prevent or limit contractures and joint deformity. Depending on the individual circumstances (for example recent history of fractures, bone pain, broken skin), consider low-load stretching and weight bearing including use of orthoses or serial casting.

## Monitor and reassess

Monitor children and young people at risk of developing functional difficulties related to their condition. Consider a programme of daily maintenance activities for children and young people with or at risk of developing functional difficulties.

Reassess at regular intervals all children and young people receiving a programme of physical therapy to ensure that:

- the intended goals are being achieved
- the therapy programme remains appropriate to the child or young person's individual needs.

## Botulinum toxin type A

Consider the use of serial casting after botulinum toxin type A treatment to improve passive range of movement if muscle tightness is identified alongside dynamic spasticity. To improve the cast's tolerability and allow better stretch of muscle, do not apply serial casts for 2-4 weeks after botulinum toxin type A treatment.

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# Orthoses

## General principles

Consider orthoses for children and young people with spasticity to:

- improve posture
- facilitate upper limb function
- improve walking efficiency
- prevent or slow development of contractures
- prevent or slow hip migration.

Determine realistic goals for treatment with orthoses based on a careful individual assessment, and discuss the options, risks and benefits of wearing them with children and young people and their parents or carers.

Ensure that orthoses have been designed, sized and fitted correctly.

Inform children and young people with orthoses and their parents and carers:

- how to apply them
- when to wear them and for how long
- when and where to seek further advice.

Ensure that an orthotist is involved when a custom-made orthosis is being used.

Minimise delays in the supply of orthoses after measurement and in the repair of orthoses.

Review orthotic use at every contact with the local multidisciplinary child development team to ensure that orthoses:

- are still acceptable to the child or young person and their parents or carers
- remain in good repair
- remain appropriate to intended treatment goals
- remain well fitting
- are being used as advised
- are not causing discomfort or pain
- are not causing injury
- are not causing sleep disturbance.

## Cautions in the use of orthoses

Assess whether orthoses might:

- cause difficulties with self-care or care by others
- cause difficulties in relation to hygiene
- be unacceptable to the child or young person because of their appearance.

Advise about the risk of pressure sores with orthoses.

Inform children and young people and their parents or carers to remove orthoses that are causing pain that cannot be relieved immediately through repositioning of the limb in the orthosis or adjustment of the strapping.

When deciding whether to offer an orthosis, balance the benefits, risks and potential consequences of muscle wasting through lack of use. Discuss these with the child or young person and their parents or carers.

Be cautious in offering rigid orthoses to children and young people with severe spasticity or dyskinesis because rigid orthoses are often poorly tolerated in this group.

## Botulinum toxin type A injection and orthoses

Consider an orthosis after treatment with botulinum toxin type A.

Consider treatment with botulinum toxin type A if this is likely to improve the tolerability of an orthosis.

## Overnight use of orthoses

Consider overnight use of orthoses. If an orthosis is used overnight:

- check that overnight use does not disturb sleep
- use night resting splints for muscles that control two joints (for example, the ankle and knee, in the case of the gastrocnemius muscle).

## Upper limb and trunk orthoses

Consider the following for children and young people with upper limb spasticity:

- elbow gaiters to maintain extension and improve function
- rigid wrist orthoses to prevent contractures and limit wrist and hand flexion deformity
- dynamic orthoses to improve hand function (for example, a thumb abduction splint if the child or young person has a ‘thumb in palm’ deformity).

Consider offering body trunk orthoses to children and young people for the management of spasticity with co-existing scoliosis or kyphosis if this will help with sitting.

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### Lower limb orthoses

When deciding whether to offer an ankle–foot orthosis, discuss with the child or young person and their parents and carers the balance of benefits, and risk of worsened gait in children and young people with:

- hip or knee contractures
- femoral or tibial anteversion.

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Consider ground reaction ankle–foot orthoses to assist with walking if the child or young person has a crouch gait and good passive range of movement at the hip and knee.

For children and young people with equinus deformities that impair their gait consider:

- a solid ankle–foot orthosis if they have good control of knee or hip extension
- a hinged ankle–foot orthosis if they have poor control of knee or hip extension.

In children whose motor development is between 8 months and 2 years consider offering supramalleolar orthoses or supportive orthotic footwear instead of ankle–foot orthoses.

Consider ankle–foot orthoses for children and young people with serious functional limitations (GMFCS levels 4 and 5) to improve foot position for sitting, transfers between sitting and standing, and assisted standing.

Inform children and young people and their parents and carers that ankle–foot orthoses intended to stretch muscles (for example, rigid, hinged or ground-reaction force ankle–foot orthoses) should usually be worn for at least 6 hours each day.

Consider knee gaiters for children and young people with knee flexion deformities.

Consider hip orthoses:

- to improve function if scissoring is causing difficulties with sitting, standing or walking
- to limit hip adduction and reduce the risk of hip migration.

## Oral Drugs

Consider oral diazepam if spasticity is contributing to:

- discomfort or pain
- muscle spasms (for example night-time muscle spasms)
- functional disability and
- a rapid effect is desirable (for example, in pain crisis).

Consider oral baclofen if spasticity is contributing to:

- discomfort or pain
- muscle spasms
- functional disability and
- a sustained long-term effect is desired (for example, to relieve continuous discomfort or to improve motor function).

Start oral diazepam treatment with a single dose at bedtime. If the clinical response is unsatisfactory consider:

- increasing the dose or
- adding a daytime dose.

Start oral baclofen treatment with a low dose and increase the dose stepwise over about 4 weeks to achieve the optimum therapeutic effect.

If oral diazepam is used because of its rapid onset of action, consider changing to oral baclofen if long-term treatment is indicated.

Continue using oral diazepam or oral baclofen if they have a clinical benefit and are well tolerated, but consider whether to stop treatment every time the child or young person's management programme is reviewed and at least every 6 months.

If adverse effects (such as drowsiness) occur with oral diazepam or oral baclofen consider reducing the dose or stopping treatment.

If the clinical response to oral diazepam or oral baclofen used alone is unsatisfactory within 4–6 weeks, stop using the drug or consider a trial of combination treatment with both oral diazepam and oral baclofen.

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# Botulinum toxin type A

## When to use botulinum toxin type A

Consider botulinum toxin type A where focal spasticity of the upper limb is:

- impeding fine motor function
- compromising care and hygiene
- causing pain
- impeding tolerance of other treatments, such as orthoses
- causing concerns about appearance to the child or young person.

Consider botulinum toxin type A where focal spasticity of the lower limb is:

- impeding gross motor function
- compromising care and hygiene
- causing pain
- disturbing sleeping patterns
- impeding tolerance of other treatments, such as orthoses and use of equipment to support posture
- causing cosmetic concerns to the child or young person.

Do not offer botulinum toxin type A in children and young people:

- with severe muscle weakness
- with a previous adverse reaction or allergy
- who are currently taking aminoglycosides.

Consider botulinum toxin type A with caution if:

- the child or young person has any of the following
  - a bleeding disorder or is receiving anti-coagulation therapy
  - generalised spasticity
  - fixed muscle contractures
  - marked bony deformity or
- where there are concerns about the child or young person engaging with post-treatment adjunctive therapy.

Consider using botulinum toxin type A to treat rapid-onset spasticity causing abnormal postures and soft-tissue shortening after acquired brain injury.

## Assessment

Local multidisciplinary child development teams and regional specialist centres involved in the assessment and administration of botulinum toxin type A should have expertise in child neurology, child development and musculoskeletal assessment in order to decide on:

- the need for botulinum toxin type A
- administration of botulinum toxin type A
- offering repeat injections.

Include movement and motor function in assessments for treatment with botulinum toxin type A and involve a paediatric physiotherapist or paediatric occupational therapist.

## Access to orthotic services

Ensure that children and young people who receive treatment with botulinum toxin type A are offered timely access to orthotic services

## Treatment

Consider using ultrasound-guided injection or electrical muscular stimulation when injecting botulinum toxin type A into muscles.

Minimise distress to the child or young person undergoing treatment with botulinum toxin type A by considering the need for the:

- topical or systemic analgesia or anaesthesia
- sedation.

Local multidisciplinary child development teams and regional specialist centres involved in the assessment and administration of botulinum toxin type A should:

- monitor effectiveness of the first botulinum toxin type A injection by repeating pre-injection assessment 6-12 weeks after the injection (both assessments should preferably be performed by the same healthcare professionals)
- monitor effectiveness of subsequent botulinum toxin type A injections and the need for further injections at 3–6 months.

If the clinical response to treatment is satisfactory review the child or young person's goals and consider repeat injections if:

- the problem that prompted initial treatment returns after treatment wears off
- new goals are identified.

Inform children and young people and their parents and carers:

- how to recognise serious but rare complications associated with botulinum toxin type A (swallowing difficulties and breathing difficulties)
- that these complications may arise during the first week after botulinum toxin type A treatment, and
- that the child or young person should return to hospital immediately if they occur.

Consider injecting botulinum toxin type A into more than one muscle, but ensure that:

- maximum doses are not exceeded
- a clear functional goal is identified
- the child or young person and their parents or carers understand the possible side effects.

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# Intrathecal baclofen

## When to consider continuous pump-administered intrathecal baclofen (CITB)

Consider treatment with CITB if, despite the use of non-invasive treatments, spasticity, with or without dystonia, is causing difficulties with any of the following:

- pain or muscle spasms
- posture or function
- self-care (or ease of care in the case of parents or carers).

Be aware that children and young people who benefit from CITB typically have:

- moderate to severe motor function problems (GMFCS level 3-5)
- bilateral spasticity affecting upper and lower limbs.

Consider the balance of benefits and risks of reducing spasticity with CITB, if that spasticity supports function (for example, by compensating for muscle weakness. Discuss this with the child or young person and their parents and carers.

## Intrathecal baclofen testing

Perform a pre-test assessment, including where necessary, an assessment of joint range of movement under general anaesthesia.

Perform intrathecal baclofen testing to assess therapeutic effect and to check for adverse effects in children and young people being considered for treatment

Inform verbally and in writing, before starting intrathecal baclofen testing :

- what the test will entail
- how the test might predict successful treatment with CITB and achievement of individualised goals
- adverse effects of CITB that might be predicted by testing
- adverse effects that might be associated with intrathecal baclofen testing.

Inform verbally and in writing all of the following about CITB :

- the surgical procedure used for implantation of the infusion pump
- the need for regular hospital follow-up visits
- requirements for pump maintenance
- risks associated with implantation of the pump, pump-related complications, and adverse effects associated with CITB infusion.

Intrathecal baclofen testing should be:

- performed by a regional specialist centre that is carries out the necessary assessments
- undertaken in an inpatient setting to ensure safety, allows assessment of outcomes.

Administer the test dose/s of intrathecal baclofen using a catheter inserted under general anaesthesia

Assess the response to intrathecal baclofen testing using standardised outcome measures within 3-5 hours of administration or later if the effects of the general anaesthetic have not worn off. Take account of individualised goals and the following criteria for a satisfactory response:

- reduction in spasticity or dystonia
- reduction in pain or muscle spasms
- improved posture and function, including head control
- improved self-care (or ease of care in the case of parents or carers).

Discuss with the child or young person and their parents or carers their subjective assessments of the response to intrathecal baclofen testing. Subjective assessments should include reports on self-care (or ease of care in the case of parents or carers). Consider using a standardised questionnaire to document their assessments.

Pre- and post-test assessments should be performed by the same healthcare professionals in the regional specialist centre.

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## Continuous pump-administered intrathecal baclofen (CITB)

Perform implantation of the infusion pump and start treatment within 3 months of a satisfactory response to intrathecal baclofen testing (see recommendation.

Be aware of the following potential contraindications to treatment with CITB:

- the child or young person is too small to accommodate an infusion pump
- co-existing medical conditions (for example, uncontrolled epilepsy and coagulation disorders)
- intercurrent infections (systemic or around operative sites) which can increase the risks associated with CITB temporarily
- spinal fusion
- malnutrition which increases the risk of post-surgical complications (including infection and delayed healing)
- some respiratory conditions

Offer regular follow-up and a consistent contact with the regional specialist centre to support children, young people, their parents or carers

Monitor the response to CITB. Take account of individualised goals and the criteria for a satisfactory response.

Inform children and young people and their parents or carers verbally and in writing:

- about safe and effective management
- about the effects of intrathecal baclofen, possible adverse effects, and symptoms and signs suggesting the dose is too low or too high
- about safe and effective management of the infusion pump, including correct pump settings and the potential for pump-related complications
- that it is dangerous to stop the CITB infusion suddenly and should not be stopped before seeking advice from a healthcare professional
- that the child or young person will need to attend hospital for follow-up appointments, for example, to refill and reprogram the infusion pump

If the response is unsatisfactory offer continued support from the local multidisciplinary care team and consider referral for specialist support.

Exercise caution with spasticity and co-existing scoliosis if the child or young person:

- has not yet undergone spinal fusion, implant the infusion pump before performing spinal fusion
- has undergone spinal fusion, be aware that the operative procedure for implanting the pump will be more difficult technically and may not be possible.

Titrate the dose of intrathecal baclofen after pump implantation to optimise effectiveness and reassess achievement of individualised goals.

Repeat assessments after titration to determine the response to the new dose. The post-titration assessment should be performed by the same healthcare professionals in the regional specialist centre that performed the pre- and post-implantation assessments.

If treatment is judged to be unsatisfactory and the infusion pump system has been confirmed to be working, consider reducing the dose gradually to determine whether spasticity and associated symptoms increase.

When the infusion pump is coming to the end of its lifespan, consider reducing the dose gradually to enable the child or young person to decide whether or not to have a new pump.

## Selective dorsal rhizotomy

Offer selective dorsal rhizotomy to improve walking ability only in the context of clinical research [see priority research recommendation]

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# Orthopaedic surgery

## Referral

Offer referral to an orthopaedic surgeon if there is clinical or radiological evidence of hip displacement or spinal deformity.(xxxx)

Consider referring for an orthopaedic opinion if any of the following indications is present:

- the posture of an upper limb is causing difficulties with putting on or taking off clothing
- hand or upper limb function is limited by functionally short muscles (where spasticity prevents muscles stretching to their full length during functional tasks), pain or an unfavourable limb posture
- a contracture of the shoulder, elbow, wrist or hand causes difficulty with skin crease hygiene
- lower limb function is limited by functionally short muscles or an unfavourable limb posture
- walking is limited by functionally short lower limb muscles, joint contracture, abnormal torsion of the femur or tibia, foot deformity, or lower limb pain
- the cosmetic appearance of the upper limb causes significant concern for the child or young person.(xx)

Consider orthopaedic surgery as an adjunct to other interventions because timely surgery can prevent deterioration and ameliorate function.(XX)

## Monitoring

Monitor children and young people to identify displacement of the hip and spinal deformity.

Clinically monitor all children and young people for signs of hip migration and recognise the following as evidence of hip displacement:

- abnormal hip migration percentage (more than 30%)
- increasing hip migration percentage
- deterioration in hip abduction
- pain arising from the hip
- reduced range of hip movement
- increased hip muscle tone
- decreased ability or tolerance for sitting or standing because of worsening hip joint contracture or bony deformity
- clinically important leg length difference
- increasing difficulty of perineal care or hygiene.

Perform a hip X-ray to monitor hip migration:

- by the age of 18 months in children with bilateral cerebral palsy
- in children with poor prognosis for walking (total body involved), delayed walking or who are using an external support for spastic diplegia
- in children or young people with signs of hip displacement.

Repeat the hip X-ray every 6 months in children and young people with hip migration percentage greater than 15% or in whom hip migration percentage is increasing by more than 10% per year.

## Before undertaking orthopaedic surgery

Before undertaking orthopaedic surgery discuss and agree with the child or young person and their parents or carers a rehabilitation programme and how and where it will be delivered. The programme may include:

- inpatient care and subsequent follow-up
- physical therapy
- orthoses
- other adjunctive treatments, such as oral drugs and botulinum toxin type A.

## Performing orthopaedic surgery

Orthopaedic surgery should:

- be undertaken by surgeons experienced in the concepts and techniques of performing such surgery in this group of patients and
- take place in a paediatric setting.

Aim to perform single-event multilevel orthopaedic surgery to improve gait (rather than as staged surgical episodes) informed by a thorough preoperative functional assessment, preferably including a pre-operative gait analysis and interpretation of the results by a surgical team with experience in such analyses

## Assessment

Assess outcomes of gait-improvement orthopaedic surgery 1–2 years after performing the surgery. Use the same criteria for pre- and post-operative assessments.